SYMPTOM EXPERIENCES IN THE ILLNESS TRAJECTORY OF CHILDREN WITH CANCER AND THEIR FAMILIES

By

Roberta Lynn Woodgate

A thesis
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ROBERTA LYNN WOODGATE

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirement of the degree of DOCTOR OF PHILOSOPHY

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ABSTRACT

Many childhood malignancies once regarded as fatal have become curable with the initiation of multimodal therapy. However, such therapy is not without its costs. Aggressive treatment is associated with many adverse consequences for both children with cancer and their families. Uncontrolled symptoms can have a negative impact on families, leading to increased suffering and impaired quality of life. Knowledge about how the childhood cancer-symptom course is experienced by children and their families is required to improve symptom management. Guided by the philosophy of interpretive interactionism, an interpretive research design framed within the qualitative paradigm was undertaken to explore and describe the childhood cancer-symptom course experienced by children and their families. Such an approach was required to interpret and understand the personal meanings and responses that the children and families constructed around living day-to-day with symptoms throughout the childhood cancer trajectory. Tenets from the following two philosophical approaches of interpretive work shaped the research process: the grounded theory research method and illness narratives.

The research was conducted in three settings: the participants' homes, an inpatient pediatric cancer unit; and an outpatient pediatric cancer unit. Children (4 to 18 years of age) diagnosed with a variety of cancer diagnoses and their families (parents and siblings) were the primary participants for this study. A theoretical purposeful sample of 39 families participated in the study with 15 of the families being studied longitudinally over a period of one to two years. Use of multiple data collection methods included: open-ended formal and informal interviewing; observing children and their families during

various periods, at various sites, and at different points in time; maintaining field notes and a reflexive journal; rating the children's symptoms; focus group interviews; and preparing a demographic profile of all participants. The grounded theory method of constant comparative analysis was used to identify the basic psychosocial phenomenon and process related to children's and their families' experiences with childhood cancer-symptoms. As well, the development of illness narratives helped to confirm the paradigmatic relationships of the theoretical categories that emerged from this study and facilitated the discovery of meaningful interpretations of the children's and families' cancer-symptom experiences.

Data analysis led to the development of two substantive theories. The first theory, Keeping the Spirit Alive: The Spirit Within, describes a developing model that depicts the children's and families' overall experience with cancer. Although the original intent of the study was to interpret and understand the personal meanings and responses that children and families construct in relation to the childhood cancer-symptoms, children and their families were unable to focus solely on the symptoms. Instead they needed to talk about the overall cancer experience. From the telling of their stories, the first model, Keeping the Spirit Alive, evolved. In this model, the core category of "getting through all the rough spots" was identified as the basic psychosocial phenomenon or problem experienced by children and their families. All the rough spots emphasized the fact that there were many aspects to the cancer-symptom trajectory that made cancer a hard and difficult experience to live through. Not only did the children and families have to encounter the rough spots or times, they also had to experience the phenomenon of

having to actually "get through" the rough times in order to truly get a sense of what the cancer experience encompassed.

The second core category of the model, "keeping the spirit alive," emerged as the basic psychosocial process. The "keeping the spirit alive" process referred to the children's and families' ability to not let all the roughness of the cancer-symptom trajectory get the better of them, or more specifically not letting the cancer destroy their spirit because indeed the ailing or suffering body could diminish the spirit. The spirit was vital to a state of being or existing in the world. The spirit was represented by the following characteristics: a particular mind-set, a force within or the need to persevere, a passion or wonder for living, and a need to feel connected. It was the very essence that kept the children and families continuing on in life, and as well, in the face of death.

The second theory, Children's and Families' Lived Experience of Childhood Cancer-Symptoms, depicts the lived experience of cancer in relation to the changing personal meanings that children and families assigned to the cancer-symptom experiences. Symptoms were not viewed as single events or states devoid of any context, but instead viewed as experiences affected by the context in which they occurred and how the experiences made children and families feel. The personal meanings children and families assigned to the symptom experiences had a major impact on how they experienced cancer. The symptom experiences served as a source of knowledge for children and their families, and affected the children's sense of self which in turn affected other individual family members and the family unit's sense of self.

Two core categories form the foundation of the second substantive theory: (1)

Personal meanings of the cancer-symptom experiences; and (2) Passage through the transition periods. "Personal meanings" which emerged as the basis psychosocial phenomenon refer to the meanings children and families assigned to the cancer-symptoms as they were experienced within a particular context. Eight personal meanings emerged as follows: (1) I have a sick stomach...I feel sick, I feel bad; (2) I feel yucky...I feel really sick, I feel really bad; (3) I am sore...boy, my body hurts; (4) I am cranky...I am not myself; (5) I am just experiencing an everyday thing...I am just a little sick; (6) I feel wiped out...my body is just too tired for me to care; (7) I am scared...I don't know what is going to happen to me; and (8) I am hurting...my heart is sad. "Passage through the transition periods" emerged as the basis psychosocial process. It refers to the changing nature of the children's and families' use of the "keeping the spirit alive" strategies and the subsequent way of being in the world as represented by transition periods. Overall, this core category constitutes seven transition periods or changing states. The changing states that could be experienced by the children and their families are: (1) It is just the flu; (2) It is a blur; (3) It hits home; (4) It is not so bad, it is pretty good; (5) It is nasty; (6) It is "dragsville"; and (7) It is comeback time. Nested within the first substantive theory, the second theory and its two core categories are discussed in relation to the basic psychosocial process of keeping the spirit alive. Recommendations for research, education, and practice are identified and discussed.

DEDICATION

This dissertation is dedicated to all the children and families who shared their experiences with me. It was a true privilege and honor to be a very small part of their life-long cancer-symptom journeys. Their spirits will always be close to my heart. Thank you!

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CHAPTER I

OVERVIEW OF THE STUDY

Introduction

This chapter outlines the purpose and research objectives addressed in this study. A discussion of the theoretical framework and assumptions that guided this study is provided. Major constructs of the study are defined. Rationale supporting the study's theoretical framework and research approach is provided. Support for the study and its significance for improving the quality of life in children with cancer are also briefly discussed.

Statement of the Problem

Cancer is the leading cause of disease-related death among children. However, many childhood malignancies once regarded as fatal are now curable (Canadian Cancer Society, 1996; Hockenberry, Coody, & Bennet, 1990; Kazak & Nachman, 1991; Varni & Katz, 1987; Woodgate & McClement, 1998). Today, fewer children are dying from cancer (Faulkner, Peace, & O'Keeffe, 1995). Instead of being viewed as an inevitably fatal disease, childhood cancer is now considered to be a chronic, life-threatening illness.

Survival into adulthood is possible for many children since the initiation of multimodal therapy. Such therapy is not without its costs. The aggressiveness of treatment is associated with many adverse effects or consequences not only for the children, but for the entire family unit (Eiser, Havermans, & Eiser, 1995). Moreover, due to recent advances in cancer treatment, children and their families experience and must deal with an extension of the period of uncertainty regarding the outcome of treatment, be

it restoration of health or eventual death (Martinson, Gilliss, Colaizzo, Freeman, & Bossert, 1990). Hospitalization, surgery, radiotherapy, chemotherapy, remissions, relapses, and the fear of death are all part of the childhood cancer experience which may contribute to the symptom experiences of children. Symptoms including pain, sleep disturbances, fatigue, nausea, constipation, anxiety, and poor outlook are just some of the symptoms associated with cancer (Hogan, 1997). Late effects of cancer treatment may also ensue such as chronic fatigue, impaired intellectual functioning, and limitations in physical activity (Eiser, 1990, 1994; Maher, 1982; Van Dongen-Melman & Sanders-Woudstra, 1986; Varni & Katz, 1987). The short- and long-term illness and treatment symptoms effects can derail the emotional, cognitive, social, and physical development of children (Eiser, 1994; Simms, 1995; Whyte & Smith, 1997). Changes in children's bodies from the effects of cancer and its treatment may affect their sense of self (Ritchie, 1992).

The lengthy and rigorous cancer treatment regimen may take its toll on other family members including the children's parents and siblings (Ross-Alaolmolki, Heinzer, Howard, & Marszal, 1995). Uncontrolled symptoms especially can negatively impact on families, and lead to increased uncertainty, impaired quality of life, confusion, decreased energy, caregiver burden, despair, compromised survivorship, and complicated bereavement (Hinds,1990; Hogan, 1997). Increased symptom distress can escalate the anguish or suffering experienced by families. Moreover, the meanings that family members assign to the symptom experiences may further perpetuate the perception that cancer is a disease always associated with great physical suffering (Hogan, 1997). The family's functioning and sense of self will be affected; indeed, the family unit as a whole

may change due to treatment- and cancer-related symptoms.

Symptom control is defined as the degree to which the severity of the adverse effects of cancer and its therapy for children are contained. It is assumed to have an effect on children's and families' quality of life by helping them experience life that is not all unknown and strange, unpredictable, and threatening (Hinds, 1990). Control of symptoms is thought to facilitate a return to familiar precancer activities, and/or a willingness to experience new activities (Hinds, 1990). In order to improve symptom control, there is a need through research to gain a sound knowledge base of symptom experiences in children with cancer.

Increased research has been directed toward the study of symptom experiences in children with cancer over the last two decades. However, this work is narrow in its focus for three reasons. First, pain and most notably procedural pain, is the cancer-symptom experience given most research attention. Although the literature acknowledges that children with cancer will experience an array of symptoms, systematic study of these multiple symptoms throughout the complete cancer illness trajectory is lacking. Secondly, the study of symptom experiences has been framed mainly within the biomedical and quantitative paradigm.Understanding how children and families interpret and respond to cancer-symptom experiences by adopting a qualitative meaning-centred approach has received minimal attention (Woodgate & McClement, 1998). Nonetheless, how children and their families respond and cope with illness will be affected by their appraisal of the meaning of the illness experience (Brett & Davies, 1988). Thirdly, there is limited research describing what it is like for parents and siblings to respond to and care for

children experiencing cancer symptoms. The effect of the children's symptom experiences on parents and siblings has not been detailed. Considering that the whole family is affected by the cancer experience (Faulkner et al., 1995), understanding the cancer-symptom trajectory from the perspectives of all family members is warranted. Families' social and cultural environments must be taken into account. Understanding how the symptom course changes throughout the cancer illness trajectory and what affect this has on children and their families within a particular context will add to an understanding of symptom experiences and control in children with cancer.

Purpose of the Study

The overall purpose of this study was to explore and describe the childhood cancer-symptom course as interpreted and experienced by children and their families throughout the illness trajectory. An interpretive qualitative research design framed within the naturalistic paradigm was adopted to address the purpose of the study. The researcher sought to look deeply into the experience of the pediatric cancer-symptom experience from the perspectives of children and families in order to interpret and understand the personal meanings and responses that children and families construct around living day-to-day with symptoms throughout the childhood cancer trajectory. The specific research objectives of the study were:

(1) To interpret and understand the meanings children with cancer assign to their symptom experiences;

(2) To interpret and understand the meanings families (parents and siblings) assign to symptom experiences of a family member diagnosed with cancer (i.e., the child

with cancer);

(3) To interpret and understand how children with cancer respond to their symptom experiences;

(4) To interpret and understand how families (parents and siblings) respond to symptom experiences of a family member diagnosed with cancer (i.e., the child with cancer);

(5) To interpret and understand how symptom experiences affect the sense of self in children with cancer; and

(6) To interpret and understand how symptom experiences of children with cancer affect the family unit's and individual family members' sense of self.

Theoretical Framework

The study was guided by the philosophy of interpretive interactionism. Understanding human lived experiences such as childhood cancer-symptom experiences, involves the study of the mutual construction of intersubjectivity among living, thinking, feeling, and acting individuals, as well as the interpretation of symbolic and interactional expressions of individuals' meaningful, turning point experiences (Denzin, 1989; Prus, 1996). Accordingly, adopting the philosophy of interpretive interactionism to guide this study was appropriate as interpretive interactionism supports the study of meaning as meaning that is grounded in the lives of individuals such as children with cancer and their families (Denzin, 1984). The philosophy of interpretive interactionism afforded the researcher the opportunity to study the human lived experience of children with cancer and their families as it was experienced and grounded in their meanings, interpretations,

activities, and interactions.

Two perspectives that support the interpretive tradition are the theory of symbolic interactionism and the pragmatic-emotional theory of meaning or hermeneutic-emotional theory of interpretation. The principles from both these theories were integral to understanding children's cancer-symptom experiences and therefore, are further discussed. With respect to the principles of symbolic interactionism, the focus is on the cognitive components of expressive meaning (Denzin, 1984). Drawing on the work of Mead and Blumer, symbolic interactionism envisions symbolic interaction as the study of ways in which people make sense of their life-situations and the ways in which they go about their activities, in concert with others on a daily basis (Prus, 1996). Significant to symbolic interactionism is the premise that individuals live in a world of meanings. That is, individuals respond to situations or objects on the grounds of the meanings they attribute to such things (Blumer, 1969). Individuals do not solely respond to events, but to the meaning those events have for them (Himelfarb & Richardson, 1982) as was the case for the children and the families who participated in the study. The meanings held by them were products of social interaction and context-bound. Assigning meanings to cancer-related events, most notably symptom experiences, was a continuous interpretive process for the children and their families, and was reflected in the various transition periods that they families lived through and experienced. In fact, participants in this study engaged in an internal dialogue, which according to Himelfarb and Richardson (1982) involves individuals formulating their own symbols and identifying what is meaningful to them. Moreover, the children and their families not only developed ways of viewing and

acting toward each other and other objects, but they also directed, monitored, assessed, and adjusted their own behaviors over time This is consistent with Prus' (1996) assertion that self-reflective beings make self-statements and evaluations.

In order to avoid an overly rationalized view of the children's cancer symptom experiences, the symbolic interactionism perspective was balanced by Denzin's (1984) pragmatic-emotional theory of meaning or hermeneutic-emotional theory of interpretation. According to this theory, self-feelings lie at the core of the meanings conveyed on objects; that is, the self or the feeling subject is at the centre of the process that confers meaning on social subjects (Denzin, 1984). Self-feelings arise out of self-interactions that individuals direct toward themselves and out of interaction with others. "Emotional understanding moves along emotional lines as emotionality, self-feelings, and shared experience enter into the interactional-interpretive process" (Denzin, 1989, p.121). Meaning from this perspective has a dual orientation: "in the interaction process and in the feelings and thoughts of the interpretive subject" (Denzin, 1984, p. 264). The pragmatic theory of emotional meaning acknowledges that the meaning a person confers on an event expresses something in the individual's stream of consciousness that is a feeling or a thought (Denzin, 1984).

Whereas cognitive interpretations and understandings laid bare the essential meanings of the cancer-symptom phenomenon, emotionality provided the conditions for a deep, authentic understanding of the children's and families' experiences. However, one must acknowledge that the two types of meanings were intertwined and could not be easily separated. Indeed, both Baumann (1996) and Denzin (1984) reinforced that in

practice, it is difficult and artificial to separate these two forms of understanding that are not always so easily distinguished. Cognitions are thought through the cover of feelings, whereas feelings are felt and thought through the filter of cognition (Denzin, 1984). Moreover, feeling and thinking are not analytically separated from the perceptions of individuals (Baumann, 1996). Accordingly, throughout the study the investigator assumed that the perceptions of participants constituted interactions of their feelings and thoughts.

Interpretive interactionism afforded the researcher the opportunity to seek new insights into understanding the children's and families' experiences with cancer and led to model development which is in keeping with the factor-searching nature of the study's design. By attending to the voices, emotions, thoughts, and actions of children and their families, the researcher was able to explore how children and their families were guided by the cognitive and emotional meanings that they assigned to their cancer experiences, and how the experience of cancer changed and shaped the meanings they gave to themselves and their personal lives. Understanding the changes that took place was critical because as van den Berg (1966) noted, the beginning of a serious illness is a halt; that is, "normal" life changes and a life that is new and unknown to the ill person and family takes its place. Illness may result in individuals experiencing "epiphanies"or turning point experiences. "Epiphanies" are interactional moments that can either leave positive or negative impressions on people's lives (Denzin, 1989). For the children and families in this study, it was the cancer experience itself and cancer-related events that resulted in changing impressions.

The children and their families experienced many events related to the cancer experience that had an affect on their thoughts, feelings, and responses to subsequent events or interactions as described in detail in the findings (refer to Chapters IV, V, and VI). Events related to the children's symptom experiences greatly shaped the children's and families' assigned meanings. The belief that symptoms may represent the meanings illness has for the involved person (Tishelman, Taube, & Sachs, 1991) was supported in this study. Additionally, because meanings are bound within a relationship that includes the sick person's family (Kleinman, 1988), the family's perception and responses were considered significant. Identifying the types of roles children and their families adopted in managing the cancer, supported the major assumptions of the study's framework. How symptom experiences had come to be perceived and valued by participants affected how they responded to such events as symptom expression, care practices, and coping responses. Understanding behavior by establishing its meaningful context was necessary and in accordance with the philosophy of interpretive interactionism.

Integral to adopting the philosophy of interpretive interactionism is interpreting how the sense of self can be affected by assigned meanings. An illness such as cancer can especially lead to a disturbed assimilation of the body and the self in which the individual's body may become foreign to him or her (van den Berg, 1966). This study revealed that children's and their families' self-definitions were ongoing and dynamic in relation to the changing context of the symptom experiences. Examining the self and meaning as processes was necessary and in keeping with the philosophy of interpretive interactionism (Charmaz, 1990, 1991; Denzin, 1989).

Support for the Study's Theoretical Framework and Research Approach

Approaching the study of symptom experiences in children with cancer from a interpretive, naturalistic paradigm was considered warranted since understanding the experience of cancer has to date been grounded in a biomedical, positivist theory of language. A biomedical, empiricist perspective conceives diseases such as cancer as universal biological or psychophysiological entities that result in physiological and behavioral abnormalities or alterations in biological structure or functioning (Good & Good, 1982; Kleinman, 1988). The primary interpretative strategy used by the practitioner is to link complaints to underlying processes and ultimately to a specific disease entity by means of clinical, laboratory or psychometric procedures (Good & Good, 1982). The goal is diagnosis and explanation as opposed to understanding (Good & Good, 1981). To that end, the practitioner recasts the illness in terms of theories of disorders and reconfigures the patient's and family's illness problems as narrow technical issues and disease problems (Kleinman, 1988). While serving a purpose, the biomedical approach is lacking as it disregards the meanings individuals assign to their illness; the cultural form of a patient's discourse is disregarded.

Although the psychosocial difficulties associated with severe disease have been well documented, a discussion of the actual meaning of changes in patients lives has rarely been presented because of a reliance on the positivist approach. For example, Mathieson and Stam (1995) noted that the research focus of adult cancer experiences has been on the traditional measures of psychosocial sequelae to assess the "impact" of the disease as well the adjustment of the patient. Understanding has been guided by both the

medical model and cognitive adaptation model. Accessing knowledge in relation to the classification of patients according to their emotional reactions and their adjustment to their threatening situations through cognitive activities has been the goal of these models. However, "missing is a description of living with cancer which simultaneously accounts for the individual's experience of illness as well as the organization of a patient's social world and its location in a medical system" (Mathieson & Stam, 1995, p.286).

Similarly, the focus of childhood cancer research has been on identifying psychosocial problems or the presence of maladjustment; that is, research has been deficit-centred (Eiser, 1990, 1994). The use of quantitative methods including psychometric scales has been the choice of methodology in studying children's cancer experiences. Such methods seek to compare children with cancer to "healthy" children. This is problematic because the tools used to assess functioning in children with cancer have mainly been developed for "healthy" children, and therefore may not be valid for children with cancer. While comparisons may be elicited, the understanding of the illness experience from the children and their families does not emerge from such research.

Likewise, the predominant theoretical framework applied in understanding symptoms has been the strict biomedical clinical model or the empiricist, positivist perspective. Although within the last two decades pediatric researchers have recognized that certain symptoms, most notably pain, may be viewed as a complex interplay of the biological, cognitive-developmental, situational, and that certain variables including age, gender, parental anxiety and support, and coping behaviors of children have an affect on pain-related distress in children with cancer (Broome, Bates, Lillis, & McGahee, 1990;

Dahlquist, Power, Cox, & Fernbach, 1994; Jay, Ozolins, Elliot, & Caldwell, 1983; Katz, Kellerman, & Siegel, 1980; LeBaron & Zeltzer, 1984; Weekes, Kagan, James, & Seboni, 1993; Weekes & Savedra, 1988), for the most part symptoms are still viewed or framed in a reductionist manner. For example, the study of nausea and vomiting in children with cancer is often approached by counting the number of times the child vomits; ignored are the meanings children assign to such experiences. Symptom experiences are reduced to an elaborate broadcasting system of signals, rather than being viewed as being shaped both by the individual and their particular socio-cultural context; sensations that can be rationally and objectively measured become the focus (Bendelow & Williams, 1995). This emphasis on studying symptoms solely within a quantitative reductionist, medico-scientific framework has led to a limited understanding of children's experiences with symptoms.

Additionally, symptoms are often categorized into two distinct groups, physical symptoms (e.g., emesis) and psychosocial or psychological symptoms (depression) (Simms, 1995; Varni & Katz, 1987). These categorizations may result in researchers labelling certain symptoms as more relevant than others, resulting in a hierarchical layering of symptoms depending on one's perspective. Yet all symptoms are important and must be considered from the patient's perspective.

Recognizing there are limitations to the biomedical clinical model or positivist perspective, researchers are now advocating alternative paradigms such as sociological and phenomenological approaches to studying illness experiences in children. Alternative approaches would enhance existing bodies of knowledge and help to reclaim symptoms

from the dominant scientific paradigm (Bendelow & Williams, 1995); interpretive, non-positivist approaches would aid in capturing the meaningful experience of the illness reality of the sufferer. This is critical considering illness is embodied in a particular life trajectory, soaking up personal and social significance from the world of the ill individual (Kleinman, 1988). Each time the cycle of symptoms begins, the individual may lose faith in the dependability and adaptability of basic bodily processes that are necessary for our general sense of well-being (Kleinman, 1988). Illness brings with it threats to daily activities, special occasions, career, relationships, and perhaps most distressingly, self-esteem (Kleinman, 1988). To understand the illness reality of the sufferer, researchers and practitioners need to adopt a meaning-centred approach (Good & Good, 1981); this will enable them to dialectically explore the relationship between symptoms (text) and semantic network (context). Instead of being concerned solely with intervening in the somatic disease process, the goal is to treat the patient's experience in order to bring to understanding hidden aspects of illness reality and to transform that reality (Good & Good, 1981). A meaning-centred or interpretive approach to understanding illness and its symptoms recognizes all clinical encounters to be fundamentally hermeneutic or interpretive (Good & Good, 1981). Accordingly, an interpretive, non-positivist framework and research approach was seen to be necessary to the study of children's cancer experiences. This allowed the researcher to view symptoms such as pain as everyday experiences linking the subjective sense of self to the perceived "objective" reality of the world and other people (Bendelow & Williams, 1995).

Theoretical Assumptions Underlying the Study

Arising from and in accordance with the philosophy of interpretive interactionism, several key major theoretical assumptions were acknowledged and emphasized in this study:

(1) Cancer affects the whole human being (Berterö, 1996);

(2) Children's symptoms experiences need to be considered in the context of the family because the family is integral to the expression of symptoms by children (Woodgate & Kristjanson, 1996a). Meanings are bound within a relationship (Kleinman, 1988). For the ill child this includes the child-parent relationship, sibling-child relationship, the child-family relationship, and the child himself or herself;

(3) Having a life-threatening illness affects the individual's quality of life and influences their experience of interaction with others and of the care demanded and given (Berterö, 1996);

(4) Living with cancer is identity-altering; it requires individuals to renegotiate their identity with others (Mathieson & Stam, 1995);

(5) Meanings of symptoms are "standardized *truths* in a local cultural system" (Kleinman, p.10, 1988). These local truths or meanings contribute to one's shared appreciation of what illness is and what is meant when a person expresses the illness experience through established patterns of gestures, facial expressions, and sounds or words. The cultural meanings of illness shape suffering of the individual and family; and

(6) Children can be active research participants, able to describe their thoughts and feelings especially when appropriate research methods are used (Deatrick & Faux, 1989; Faux, Walsh, & Deatrick, 1988; Fine & Sandstrom, 1988).

Definition of the Study's Major Constructs

For the purpose of this study, the major constructs were defined as follows:

(1) Interpretation or "to interpret": Interpretation is the process of setting forth the meaning of an experience (Denzin, 1989). Interpretation brings out the meaning embedded in the text. It creates the conditions for understanding. Interpretation is a temporal process and is always symbolic.

> "The interpretation of symptoms in the longitudinal course of illness is the interpretation of a changing system of meanings which are embodied in the lived experience and which can be understood through the acquisition of their context of relationships, the nature of their referents, and the history of how they are experienced" (Kleinman, p. 18, 1988).

(2) Understanding or "to understand": Understanding is the process of grasping what has been interpreted in a text. It means "to comprehend, or grasp, the meaning of an interpreted phenomenon, and may be emotional, cognitive, or both; an interactional, emotional process, involving shared experience that may produce spurious or authentic understanding; the goal of interpretation is to build authentic, shareable understandings of the phenomenon under investigation; also called verisimilitude" (Denzin, 1989, p.145). Both interpretations and understandings must be conveyed to the reader. Interpretation is the clarification of meaning; whereas understanding is the process of interpreting, knowing, and comprehending the meaning that is felt, intended or expressed by another (Denzin,

1984, 1978). Interpretation precedes understanding.

(3) Meanings: Meanings refer to the phenomenological component of children's and family's experiences. This includes all symbolic images, feelings, thoughts, and statements relating to symptom experiences as expressed by children and their families. Illness experiences and events such as symptom experiences usually result in more than one meaning. Meanings may change as changes occur in situations and relations. Meanings can increase or decrease symptoms, exaggerate or lessen disability, impede or facilitate treatment (Kleinman, 1988). Additionally, meanings are lived in that they refer to the way a person experiences and understands his or her world as real and meaningful. It is those aspects of an event or situation as experienced by the person in it that are described as lived meanings (van Manen, 1990).

(4) Symptom experiences: The construct "symptom" or symptom experiences can be defined and interpreted in a variety of ways as noted by Tishelman and colleagues (1991). One common way of defining the construct is from a biomedical perspective in which symptoms are viewed to be phenomena in response to changes in bodily functions that signal a disease or a phase of a disease (Giardino & Wolf, 1993). This definition is limited in that symptoms are basically seen to be solely a reflection of the disease process, therefore, not supporting the philosophy of interpretive interactionism. Moreover, contributing factors to symptoms experiences such as psychosocial or cultural factors are ignored within a biomedical perspective. Therefore, Tishelman and colleagues' (1991) definition

which is more comprehensive and exclusive was adopted for this study. They defined symptoms or symptom experiences "as expressions of the reality of the patient's world, linked to the stresses and experiences of that person, composed of both cultural and personal meaning" (p.230). The experiences may be in relation to a variety of symptoms such as pain, immobility, fatigue, mood changes, and anxiety, and result from a variety of cancer- and noncancer-related factors. Symptoms are the result of multidimensional processes (e.g., physiological, psychological, cultural) occurring within the context of complex social transactions. This definition of symptom experiences supports a meaning-centred approach to understanding children's symptom experiences. Moreover, such a definition circumvents the problem of the Cartesian mind-body split. That is, it avoids labelling some symptoms as physical symptoms or sensory events (e.g., pain, nausea) and others as psychological reactions (e.g., depression and anxiety) (Woodgate & McClement, 1998). Instead, all symptoms are viewed as biopsychosocial-cultural phenomena.

(5) Responses: Responses refer to all verbal and non-verbal behaviors that children and their families could use and used in response to symptom experiences. Responses are the idioms of illness. Often idioms help to communicate troubles of any kind. Responses are guided by the meanings individuals assign to their illness experience. Of particular concern for this study were responses related to how participants coped with symptom experiences as well as their care and comfort practices.

(6) Sense of self: Sense of self refers to how the individual and families define and understand the self. This includes all the considerations that the individual uses to define the self and distinguish the self from others (Damon, 1983; Damon & Hart, 1982; Eiser, 1985). The self emerges from social interaction; it is a social product (Kagitçibasi, 1986).

Significance of the Study

An understanding of the pediatric cancer-symptom experience from the perspectives of children and their families is still in its infancy. This study provided a means of understanding children's cancer-symptom trajectories from the perspectives of children and families based upon their feelings, thoughts, and symbolic images. Results from this study provide nurses and other health professionals with a deeper understanding of the symptom experience in children with cancer. Quality of care may be enhanced for this population as improved symptom management in children with cancer is conditional upon a sound knowledge base of pediatric cancer patients' symptoms experiences. Findings from this study provide the foundation for a research program specific to children's cancer-symptoms experiences and will aid in future research studies such as the development of valid and reliable symptom assessment instruments and symptom control programs.

Conclusion

The study of pediatric cancer patients' symptom experiences throughout the illness trajectory was a significant research problem warranting research attention. The theoretical framework of interpretive interactionism provided an orienting perspective

that directed the research process toward a qualitative design which valued children's and families' perspectives of the cancer symptom-illness trajectory within the context of the symptom experiences. The next chapter presents background literature which further confirmed support for the research objectives and design.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

In this chapter both theoretical and empirical literature relating to the research purpose and questions is reviewed in order to place this study into the context of the current knowledge. Specifically, the following areas are reviewed: (1) experiences with childhood cancer and the ill child's perspective; (2) symptom experiences in the illness trajectory of childhood cancer; (3) sense of self in children with cancer; (4) coping responses in children with cancer; (5) family: parents' experiences with childhood cancer; (6) family: siblings' experiences with childhood cancer; (7) sense of self in families of children with cancer; and (8) health professionals' experiences with childhood cancer.

Experiences with Childhood Cancer: The Ill Child's Perspective

Within the last decade there has been greater research interest in examining children's experiences with cancer from the perspectives of the children themselves. This new emphasis includes research that explores children's thoughts and feelings about specific cancer events as well as the total cancer experience. Nonetheless, descriptions of the cognitive and emotional meanings of children's cancer symptom experiences are still in their infancy.

Only a few concepts or constructs have received research attention with respect to how children conceptualize cancer-related events or stressors. One such work is Aamodt and colleagues' study which focused exclusively on the meanings children (7-17 years) assigned to treatment-related hair loss (Aamodt, Grassl-Herwehe, Farrell, & Hutter,

1984). Distress was evident in the children's expressed feelings of sadness, anger, hopelessness, and embarrassment. Multiple domains of cognitive and affective meanings related to hair loss were developed, but due to the small sample size (n=8) it was impossible to make any conclusions pertaining to developmental differences.

Another study focused on the construct of health from the perspectives of adolescents diagnosed with cancer (Hanna & Jacobs, 1993). Findings were similar to studies involving "healthy" peers in that the adolescents with cancer, like their "healthy" peers, related health to being active, having abilities, being normal, having a good physical appearance, and feeling good. Adolescents with cancer, however, also perceived health to mean growing and having a future. Further research is warranted that illustrates the similarities and differences in the meaning of health held by adolescents with and without cancer.

Surprisingly, even though research has revealed that the pain due to procedural and treatment aspects of cancer is viewed to be the worst part of the cancer experience by children (> 9 years) (Claflin & Barbarin, 1991; Enskär, Carlsson, Golsäter, & Hamrin, 1997a; Weekes & Savedra, 1988) and that adolescent cancer survivors view pain to be analogous to cancer (Fowler-Kerry, 1990), no study has been undertaken specifically examining how children of varying ages conceptualize pain. However, one descriptive-exploratory study examining children's experiences with leukemia revealed that children with cancer not only conceptualized pain as something physical, but also something emotional (Ross, 1989). The children (5-12 years) noted that there were many sources of pain experienced during the cancer trajectory, including pain from treatment and pain

related to the children's expressed concern for the hardships the disease caused for their families. Children summed up that there were "many things about ALL (acute lymphoblastic leukemia) that hurt a lot, not just the needles and medicine and stuff." These findings lend support to the notion that experience influences concept formation in children. In contrast, studies examining healthy children's conceptualization of pain revealed that only children in the formal operational stage include both psychological and physical elements in their definitions of pain (Gaffney & Dunne, 1986, 1987).

The only other construct examined in relation to children's cancer experiences, is the construct of death. Two classic works lend support to the assumption that experience may play a role in children's understanding of death. These studies found that preschool and school-age children with cancer were aware of the possibility of dying even when adults did not discuss this with them (Bluebond-Langner, 1978; Waechter, Crittenden, Mikkelsen, & Holaday, 1986). Bluebond-Langner (1978) was among the first to suggest that preschool and school-age children with a life-threatening illness such as cancer, have a more mature concept of death than healthy children of the same age. Her study revealed that age and intellectual ability were not related to the speed or completeness with which children gained an understanding of the factual information about their illness. Some three- and four-year-old children of average intelligence knew more about their prognosis than some nine-year-old children, who were still in their first remission, had fewer clinic visits, and hence less experience.

Except for the minimal focus on death, health, and hair loss, no other studies have been undertaken examining how children conceptualize certain cancer concepts or events.

This is of great concern, given that some findings suggest that adolescents with cancer have limited knowledge of the cancer experience (Jamison, Lewis, & Burish, 1986; Kvist, Rajantie, Kvist, & Siimes, 1991). Research to understand how children with cancer process information about their illness and how information processing helps or hinders them to deal with their illness is warranted.

Research has revealed, however, that children with cancer struggle with the question of why they got cancer. That is, thoughts of "why me?" are frequently expressed by children, especially older children and adolescents newly diagnosed with cancer (Aamodt et al., 1984; Bearison, 1991; Claflin & Barbarin, 1991; Enskär et al., 1997a; Greenberg & Meadows, 1991). Thoughts of "why me?" may be attempts by children to understand and make sense of events, therefore, helping them to deal with their cancer diagnosis. Research findings also suggest that children and adolescents with cancer tend to have more positive views about their own chances of recovery in comparison to parents and health professionals (Mulhern, Crisco, & Camitta, 1981). In fact, Hinds and Martin (1988) reported that in order to maintain hope, adolescents needed to possess a comforting or life-sustaining, reality-based belief that a positive future existed for them.

There are few studies examining causal attributions of cancer in children with cancer. One study examining children's (4-19 years) and parents' causal attributions of cancer revealed that about half the children (n=30) reported casual attributions which was slightly less than their parents (Bearison, Sadow, Granowetter, & Winkel, 1993). The children also made more external versus internal types of attributions in comparison to

their parents. Children who made external attributions were also found to cope better than children who did not make this kind of attribution. The authors concluded that children made more external attributions in order to maintain their self-esteem. This finding is in keeping with general causal attribution theory which assumes that positive achievements are attributed to internal factors and negative events to external factors. However, considering the small sample size (n=30), Bearison and colleagues'(1993) findings should be viewed tentatively. Other research revealing that adolescents with cancer had higher external health locus of control scores than healthy peers (Jamison et al., 1986; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980) and generally felt low responsibility for the cause of their cancer (Tebbi, Zevon, Richards, & Cummings, 1989), lends support for causal attribution theory. Ross (1989) also reported that in school-age children with cancer, there was absence of self-attribution. Even preschool children with cancer were reported to reject immanent justice (the belief that negative consequences automatically result from misbehavior), both in themselves and in others (Springer, 1994). This finding contradicts the assumption that younger and less cognitively mature children may exhibit more self-blame for the etiology of illness (Springer, 1994).

In addition to the limited research grounding related to children's thoughts about their cancer experiences, the focus of study on children's feelings during the cancer experience has also received minimal attention. Research has demonstrated that children experience a multitude of feelings including fear, sadness, anxiety, anger, and loneliness in relation to hair loss and other treatment side effects, chemotherapy, thoughts of relapse and death, and concerns about school and relationships (Aamodt et al., 1984; Byrne,

Stockwell, & Gudelis, 1984; Dolgin, Katz, Zeltzer, & Landsverk, 1989; Enskär et al., 1997a; Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997b; Hockenberry-Eaton, Manteuffel, & Bottomley, 1997; Kashani & Hakami, 1982; Krulik, 1987; Munet-Vilaró & Vessey, 1990; Novakovic, Fears, Wexler, et al., 1996; Rudin, Martinson, & Gillis, 1988; Smith, Ostroff, Tan, & Lesko, 1991). However, lacking are detailed descriptions of children's emotional experiences over the course of the cancer illness trajectory. Moreover, how these emotions guide children through the illness trajectory has not been described.

One notable exception is Hinds and Martin's (1988) grounded theory study that explored adolescents' perceptions of how they achieved hopefulness during their cancer experience. The findings revealed that striving for a feeling of hopefulness involved adolescents moving through a series of stages where they learned to deal with their negative and uncomfortable thoughts and feelings. Social and cognitive factors were involved in regulating and evaluating emotional experiences. Although having a feeling of hope was important in dealing with the cancer experience and supports previous research (Aamodt et al., 1984; Novakovic, Fears, Wexler, et al., 1996), it was not enough to sustain adolescents through the cancer experience. Adolescents additionally needed to perceive themselves to be resilient, resourceful, and adaptable. Although focusing on the feeling of hopefulness, Hinds and Martin's (1988) study also described children's thoughts and coping responses in relation to achieving hopefulness which resulted in the development of a model incorporating adolescents' thoughts, feelings, and coping responses.

Except for the findings that suggest younger children may exhibit more behavioral distress than older children (Bradlyn, Harris, Ritchey, et al., 1993; Dahlquist, Power, & Carlson, 1995; Dahlquist et al., 1994; Jacobsen, Manne, Gorfinkle, et al., 1990; Jay et al., 1983; Katz et al., 1980) and that older children and adolescents may be more likely than younger children to experience mixed emotions as opposed to summarizing their cancer experiences either one way or another (Claflin & Barbarin, 1991), developmental trends have also not been identified. This is a concern considering it is assumed that feelings and emotions change as a function of one's maturity as well as social experience. Identifying the causes and functions of certain feelings in children with cancer, and describing how children express their feelings are areas needing further investigation.

In summary, the literature examining experiences with childhood cancer and the ill child's perspective is limited in its investigation of cognitive and affective meanings children assign to their cancer experiences. Most notable is the lack of research examining: (1) how children conceptualize the construct of cancer, and cancer-related events (e.g., pain, death); (2) children's causal attributions of cancer; (3) how children acquire beliefs about their illness experiences; and (4) mediators of children's meanings. Additionally, most of the studies are cross-sectional in nature, rely mainly on standardized instruments not developed in the pediatric cancer population, and rarely access young children's feelings (toddlers and preschoolers). These approaches limit our understanding of children's thoughts and feelings related to their cancer experiences, and preclude a more comprehensive understanding of children's cancer-symptom experiences and cancer experiences in general.

Symptom Experiences in the Illness Trajectory of Childhood Cancer

The literature points to three main areas of study in pediatric cancer symptom research: (1) procedural-related pain; (2) treatment-related nausea and vomiting; and (3) "psychosocial" symptoms relating to the adjustment of cancer. In the area of procedural-related pain, the primary emphasis has been on measuring and/or decreasing the degree of distress (i.e., pain and anxiety) in children who undergo medical procedures (e.g. bone marrow aspirations or lumbar punctures) (Adams, 1990; Bradlyn, Harris, Ritchey, et al., 1993; Jay, Elliot, Katz, & Siegel, 1987; Jay et al., 1983; Katz et al., 1980; Reeb & Bush, 1996). This is a legitimate research area given that children find procedural and investigational aspects of cancer treatment to be worse than the disease itself (Weekes et al., 1993; Weekes & Savedra, 1988; Ross, 1989; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980). To date, most findings suggest a significant relationship between age and quantity and type of distress-related behavior with younger children exhibiting more distress-related behavior in response to painful behaviors and that children exhibit less distress who received behavioral preparation compared to those received routine preparation(Adams, 1990; Bradlyn et al., 1993; Jay et al., 1987; Jay et al., 1983; Katz et al, 1980; Reeb & Bush, 1996).

More recent studies that have, in addition to proxy reporting of children's behaviors included children's self-ratings of their pain and anxiety, revealed that distress behaviors did not correlate with the children's self-reports (LeBaron & Zeltzer, 1984; West, Oakes, Hinds, et al., 1994). This suggests that findings from earlier studies may be related to differences in measurement methods rather than true differences in distress-

related expressions across age categories in children with cancer. In fact, some of the behaviors defined to be an expression of distress, were identified as a form of coping for some children (LeBaron & Zeltzer, 1984). An idiom of distress that may be a sign of maladaptive behavior for one individual, may be a form of coping for another individual (Nichter, 1981). From the perspective of the patient, such behavior may be considered reasonably adaptive (Brody, 1987; Woodgate & McClement, 1998). Data also obtained through patient self-reports revealed no differences between the various age groups, suggesting that younger and older children may experience similar amounts of distress. This reinforces the need to access children's thoughts and feelings (i.e., the meanings they assign to their symptom experiences).

Another area of investigation involves examining the effects of parental presence on children's responses to painful procedures (Blount, Corbin, Sturges, et al., 1989; Blount, Landolf-Fritsche, Powers, & Sturges, 1991; Manne, Bakeman, Jacobsen, Gorfinkle, Bernstein, & Redd, 1992; Naber, Halstead, Broome, & Rehwaldt, 1995). Naber and colleagues' study (1995) was especially detailed with respect to communication patterns between parent, child, and health care professionals. The findings revealed that attention by a parent to the child was shown to reduce a child's distress. However, the type of communication between the child, parent, and health professional was significant. "Talking with the child," as opposed to "talking to the child" was identified as the most child-centred pattern of communication.

Research focusing on pain other than procedural-related pain has been limited. Only a few studies have been undertaken that explore the incidence of cancer- and

treatment-related pain. Miser and colleagues (Miser, Dothage, Wesley, & Miser, 1987; Miser, McCalla, Dothage, Wesley, & Miser, 1987) conducted two surveys, one focusing on the prevalence of pain in pediatric and young adult cancer population (6 months - 24 years of age) and the other examining the prevalence of pain as a presenting symptom in children and young adults newly diagnosed. In the first study, therapy or treatment-related pain predominated in both inpatients and outpatients. Treatment-related pain in relation to mucositis, radiation dermatitis, abdominal pain from protracted vomiting, postoperative state, prolonged post-lumbar puncture headache, and neuropathy predominated in children. Only one-third of the pain experienced by inpatients and less than 20% of the pain experienced by outpatients was due to the cancer tumor. Tumor pain was primarily due to bony invasion. For children, only one third of the inpatient population and one fifth of the outpatient population experienced tumor-related pain. With pain as a presenting symptom, 72 of the 92 patients experienced pain prior to diagnosis. However, following the initiation of cancer treatment there was a short duration of pain (median = 10 days), further reinforcing the finding that treatment-related pain is more prevalent than tumor-related pain in children once cancer therapy has begun. Similar findings were reported by Elliot and colleagues (1991) in that there was a predominance of treatment-related rather than cancer-related pain reported in children. In contrast, tumor-related pain is reported to be more common in adults (Elliot et al., 1991).

Another study that was qualitative and more detailed in nature, focused on the frequency and type of pain as well as treatment of pain in children away from the hospital (Bossert, Van Cleve, & Savedra, 1996). Perspectives of children (4-16 years) with cancer

and their parents were accessed for this study. Findings revealed that children experienced pain in a number of locations, most frequently the "stomach," joints, legs, and back. Chemotherapy was the source of pain most frequently identified. The onset of chemotherapy-associated pain occurred between three days and one month after the treatment with the temporal nature ranging from a brief moment to a few days in length.

The pain that children experience following bone marrow transplants is also now being studied. In a descriptive study that interviewed children (5-17 years old) four times, on the day of transplant and then at weekly intervals, revealed that each child over time experienced variability of pain with respect to location and factors that relieved pain (Pederson, Parran, & Harbaugh, 2000). More importantly, most children reported low and medium levels of pain most of the time post-transplant. Such findings suggest that all types of cancer- and treatment-related pain require more in-depth study. A comprehensive understanding of children's cancer pain experiences will lead to pain-relief strategies that are more comprehensive and specific to the particular pain source.

The focus of the second area of research examining treatment-related nausea and vomiting. This is an important area of study considering research has revealed that adolescents with cancer viewed treatment as impacting their lives more negatively than the disease itself (Zeltzer et al., 1980). With respect to treatment-related nausea and vomiting, researchers have primarily been concerned with comparing the side effects of different chemotherapy agents and evaluating the efficacy of anti-emetic agents and/or nonpharmacological measures (e.g., hypnosis) to reduce nausea and vomiting (Cotanch, Hockenberry, & Herman, 1985; Jacknow, Tschann, Link, & Boyce, 1994; LeBaron,

Zeltzer, LeBaron, Scott, & Zeltzer, 1988; Relling, Mulhern, Faiclough, Baker, & Pui, 1993; van Hoff, Hockenberry-Eaton, Patterson, & Hutter, 1991; Zeltzer, Dolgin, Le Baron, & LeBaron, 1991).

In addition to evaluating the efficacy of anti-emetic agents and/or nonpharmacological measures, researchers have focused on evaluating nausea and vomiting in children with cancer. Most notable is the work by LeBaron, Zeltzer, and colleagues (1988) who undertook a series of assessment and intervention studies focusing on nausea and vomiting. One of their studies investigated whether or not children (5-18 years old) could use a self-report rating scale to quantify somatic symptoms (i.e., nausea and vomiting) in a series of vignettes. A distinct feature of this work was that the researchers asked the children to rate the amount of time they felt the child in the vignettes spent having nausea and vomiting, as well as the extent to which the child was "bothered" by the symptoms (i.e., subjective distress). A 0-10 Likert scale was used by the children to rate amount of time and "bother." Six faces of children showing increasing amounts of distress were also placed as sign posts along the "Bother" scale. Findings demonstrated that healthy children as well as children with cancer as young as 5 years of age were able to understand and use a rating scale. As well, no significant differences were found between the children's and adults' ratings. Findings also showed that for the pairs of vignettes indicating the same time periods, vomiting was consistently rated as occurring for a longer duration and producing more bother than nausea. The researchers concluded that highly distressing symptoms (i.e., symptoms that bother the individual more), may be perceived as occurring for a longer duration than less distressing

symptoms. Although the children's abilities to rate their own symptoms were not assessed in this study, these findings demonstrate that children as young as 5 years of age could understand and utilize a numerical rating scale. Since then LeBaron, Zeltzer, and colleagues have conducted studies in which children with cancer rate the severity and distress of their own nausea and vomiting lending further support that children have abilities to use self-report scales (LeBaron et al., 1988; Zeltzer et al., 1991).

Based on the work of LeBaron, Zeltzer and colleagues (1988), Tyc and colleagues (1993, 1995) also asked children (6-18 years old) with cancer undergoing chemotherapy to rate the frequency and severity of their nausea and vomiting. The children's ratings were compared with their parents' ratings. Parent and child ratings of frequency and severity of nausea were significantly correlated ($p<.01$), but not for emesis symptoms. Most important was the finding that there were highly significant correlations between different dimensions of the same symptoms (nausea frequency versus severity and emesis frequency versus severity) and between similar dimensions of different symptoms (nausea versus emesis frequency and nausea versus emesis severity). The authors suggested that different estimates of nausea and emesis will be obtained if raters are asked to rate their symptoms globally rather than separately and without reference to their descriptive dimensions. This supports the need for more comprehensive self-report scales that capture the multidimensional aspect of symptoms.

Other researchers such as Cotanch and colleagues (1985) and Jacknow and colleagues (1994) have included more than one dimension of nausea and vomiting when attempting to evaluate children's self-reports of these symptoms. In addition to

measuring nausea and vomiting in school-aged children receiving chemotherapy, Geib and Wright (2000) focused on developing a reliable and valid instrument that also evaluated retching in children. In developing the scale, attention was also given to the children's bother of eating, bother of not playing, bother of having to rest, and bother of feeling cranky. Initial testing reveals that the scale is reliable and has acceptable internal consistency, content and face validity, and construct validity ($p = 0.05$). However, further development of the scale as noted by Geib and Wright is warranted in order to demonstrate a more comprehensive understanding of nausea, vomiting, and retching, and the bother of these symptoms in children of all ages and races.

In developing reliable and valid scales specific to assessing nausea, vomiting, and retching in children, researchers also need to arrive at a consensus about the conceptual definitions of the dimensions evaluated in this area. Capturing children's perspectives of nausea and vomiting would help to achieve conceptual clarity. To date, however, pursuing a meaning-centred approach to understanding children's experiences with nausea and vomiting has not been considered. LeBaron and colleagues (1988), cautioned that relying solely on the number of vomits and other symptoms (dystonic reactions) (e.g., see Relling et al., 1993), is inadequate if an understanding of the impact of cancer treatments on the lives of children and adolescents is to be achieved. They concluded that determining the impact and meaning of these symptoms for children and families needs to be explored. As well, they suggested that attention must be given to the influence that the family has on children's symptoms.

Although the majority of research has focused on procedural-related pain and

treatment-related nausea and vomiting, researchers are now directing their attention to other treatment- and cancer-related symptoms. This is important considering in one study it was noted that children experienced problems related not only to pain, but as well to other symptoms including fatigue, nausea, vomiting, and feeling ill (Enskär et al., 1997a).

Acknowledging that little is known about the experience of fatigue, researchers are now seeking to explore the experience of fatigue in children with cancer. Most notable is the work by Hinds, Hockenberry-Eaton, and colleagues who were the first to define and describe fatigue from the perspectives of children receiving cancer treatment (Hinds & Hockenberry-Eaton, 2001; Hockenberry-Eaton, Hinds, Alcoser et al., 1998). In a study that involved twenty-nine children, 7-to-16 years of age, the researchers focused on arriving at a contextual understanding of fatigue (Hockenberry-Eaton et al., 1998). The participants took part in eleven focus groups interviews. Codes were developed in relation to the children's perspectives about the definitions of fatigue, causes of fatigue, and what helped to relieve the children's fatigue. Findings revealed that although the younger children (7 - 12 years) provided fewer detailed responses compared to the adolescent children (13 - 16 years), similarities existed with respect to all: (1) describing fatigue in terms of physical and mental symptoms; (2) feeling sad and mad; (3) experiencing changes in activities; and (4) needing to rest or take more frequent naps to relieve their fatigue. These researchers noted that the themes that emerged from this study provided the foundation for developing a conceptual model for cancer-related fatigue in children (Clarke-Steffen, Hockenberry-Eaton, Hinds, et al., 2001). Future work

including the development of a self-report tool that determines the incidence, defining characteristics, and intensity of fatigue in children with cancer is planned by Hinds, Hockenberry-Eaton, and colleagues.

Work such as Hockenberry-Eaton and colleagues' (1998) study on fatigue point to the importance of studying all treatment- and cancer-related symptoms in children with cancer. As well, the relationship between illness and treatment-related symptoms and the examination of how multiple symptoms are experienced by children is also necessary. However, minimal research was located that involved pediatric oncology patients rating multiple symptoms. One such body of work involved a series of pilot studies in which pre-adolescent and adolescent cancer patients rated their symptoms during their first six months of chemotherapy using McCorkle and Young's Symptom Distress Scale (SDS) (Hinds, 1990; Hinds, Quargnenti, & Wentz, 1992; Hinds, Scholes, Gattuso, Riggins, & Heffner, 1990). Originally developed to measure symptom distress in the adult cancer population (McCorkle & Young, 1987), the SDS demonstrated moderate to strong internal consistency and pediatric participants found it was easy to use. Interestingly, findings revealed that symptoms reported to be most distressing by the participants during the first six months of cancer treatment were "feeling tired," "concern with appearance," and "ability to get around."

In another study that involved the development of two instruments to measure children's (7-13 years, n=75) perceptions of cancer stressors and adjustment to cancer treatments, a variety of symptoms (referred to as stressors by the authors) were assessed (Hockenberry-Eaton et al., 1997). Items on the Childhood Cancer Stressors Inventory

(CCSI) were related to physical, emotional, and psychological concerns such as hair loss, pain, and weight change. Items on the Children's Adjustment To Cancer Index (CACI) included such items relating to children's interactions with school peers, family members and friends, participation in school, other activities, and home life, and feelings about oneself. Findings showed that hair loss (72%), getting sick from treatment (67%), needing to take medicine at home (70%), experiencing pain from treatment (58%), and weight changes as the most frequent stressors. As well, greater than 25% of the participants felt that the most frequently identified stressors bothered them quite a bit to a lot. With respect to adjustment, the bothersome areas of adjustment identified most frequently included changes in school attendance (43%), physical appearance (53%), school attendance (43%), and expected chores around the home (36%). This study found some relationship between stressors such as symptoms and adjustment, but the children's meanings of these stressors or perceptions of cancer experience were not detailed. Additionally items for both scales were derived from the literature and the principle investigator's experience, but were not grounded in the children's experiences. This may have limited how children could respond to their symptom experiences. Further study of adolescents' as well as school-age children's abilities to rate multiple symptoms and the distress caused by all treatment and illness-related cancer symptoms is, therefore, recommended. Identifying possible relationships that may exist between varying cancer symptoms is also warranted such as was demonstrated in a study conducted by Gauvin-Piquard and colleagues (1987). The findings of their study showed that the intensity of pain in hospitalized children with cancer correlated with a depression-like reaction

(Gauvain-Piquard, Rodary, Rezvani, & Lemerle, 1987).

The cancer diagnosis may evoke many feelings such as anxiety, fear, helplessness, depression, uncertainty and hopelessness (Whyte & Smith, 1997). Adjusting to cancer may be manifested through a variety of distressing responses (also referred to as "psychosocial" problems or "psychological" symptoms or "psychological distress") such as anxiousness, loneliness, sadness, depression, and fear (Gobel & Donovan, 1987; Neville, 1996; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986; Van Dongen-Melman, & Sanders-Woudstra, 1986). Accordingly, the third research area in the study of children's cancer symptoms involves studying children's adjustment to potential stressors of cancer and the levels of psychological functioning or distress experienced by children (Anholt, Fritz, & Keener, 1993; Bull & Drotar, 1991; Butler, Rizzi, & Bandilla, 1999; Greenberg, Kazak, & Meadows, 1989; Mulhern, Fairclough, Douglas, & Smith, 1994; Neville, 1996, 1998; Rynard, Chambers, Klinck, & Gray, 2000; Sanger, Copeland, Davidson, 1991; Van Dongen-Melman et al., 1986; Van Dongen-Melman, & Sanders-Woudstra, 1986; Varni, Katz, Colegrove, & Dolgin, 1994, 1995). Such research usually involves children and/or their parents completing standardized instruments that measure constructs such as adjustment, depression, state and trait anxiety, and self-concept (e.g., Spielberger State-Trait Anxiety Inventory for Children - STAIC). To date, findings have been conflicting. At best, one could conclude that children with cancer may be at risk for experiencing increased psychological symptoms, but having a cancer diagnosis does not guarantee maladjustment in children with cancer. Unfortunately, how one defines psycho social maladjustment appears to have a highly

significant impact on its epidemiology (Butler, Rizzi, & Bandilla, 1999).

Qualitative studies although few in number, have helped to capture children's cancer experiences and the distress some have encountered in adjusting to cancer. For example, Bearison's (1991) study described the phenomenological experiences of children diagnosed with cancer. Direct quotes from the children such as "I started getting really sad, and I started pulling my hair out, one bit by bit..." or "It's sad and it's scary, 'cause I thought that I was going to lose my leg" or "When I got sick again, a lot of people noticed that I was depressed a lot. And it's like, I wasn't as cheery as I used to be," eloquently illustrated some of the feelings that children endured throughout the cancer experience. In another study it was revealed that children endured other painful experiences related to cancer (e.g., being called "cancer kid") and that they viewed the cancer experience itself as being analogous to pain (Fowler-Kerry, 1990). However, to date understanding the difference between pain and suffering has been minimally examined in children.

In summary, attention to the symptom trajectory in childhood cancer is in its infancy. The primary focus in on procedural-related pain or the more obvious side effects of treatments. However, when cancer pain is focused on and managed in isolation from other symptoms, poor outcomes such as confusion and increased caregiver burden may result (Hogan, 1997). Accordingly, studying all symptom experiences that may occur during the various phases of cancer is necessary. This includes symptoms that may linger on in childhood cancer survivors. Symptoms resulting from the disease process as well as treatment-related symptoms need to be explored. As well, there is a need to understand

how children experience symptoms in a variety of settings such as school, home, or day care setting. Studying children solely within the health care setting, limits a comprehensive understanding of children's experiences.

Sense of Self in Children with Cancer

Individuals who have cancer are confronted with a nexus of psycho social events which may result in a number of consequences such as loss of functioning, family stress, personal distress, and stigma. Taken together, these events indicate that one's identity will forcibly undergo transformation (Mathieson & Stam, 1995).

Critical to an individual's understanding of his or her self is the act of self-reflection, that is, the ability to reflect on the self from the perspective of other persons. Whether or not young children are able to engage in self-observations, however, is disputed. For instance, Harter (1990) maintained that the ability to appreciate the fact that others are evaluating the self and to reflect about one's attributes is not fully developed until adolescence. Denzin (1977), however, believes that the child, like the adult, "is able to shape, define, and negotiate its relationship to the external world of objects, others, and social situations" (p.10). Children are able to take one another's roles and present definitions of the self.

A theory that could be applied to all children from early childhood to late adolescence has been articulated by Damon and Hart (Damon, 1983; Damon & Hart, 1982). These authors have identified four increasingly complex and differentiated stages of the "self." Their model of self-understanding deals with the cognitive aspect of the self or self-concept, although it also includes evaluative insights that provide the cognitive

bases for self-esteem. Both Damon and Hart believed their theoretical model encompassed all aspects of the self, from the self-as-object to self-as-subject. The "Me" was broken down into four constituent self-schemes: the physical, active, social, and psychological schemes. The "I" was broken down into three subjective processes of awareness: agency or an awareness of one's agency over life events, distinctness or an awareness of one's individuality or uniqueness from others, and continuity or an awareness of one's personal continuity (Damon, 1983; Damon & Hart, 1982).

Four major developmental trends identified from a review of the research on the "self" were inherent in Damon and Hart's model of self-understanding (Damon, 1983; Damon & Hart, 1982). These trends included: (1) an early awareness of self based on one's own activity and contingencies arising from such activity; (2) an early awareness of physical categories of self like gender and size; (3) an age-related shift from defining oneself through external characteristics to defining oneself through internal qualities; and (4) an age-related tendency to integrate the diverse aspects of the self into a coherent system. While the self undergoes hierarchical developmental change throughout the entire childhood period, children at all ages have some understanding of their physical, active, social, and psychological selves. As well, the model supports development that is logical and hierarchical, but evitable (Damon, 1983; Damon & Hart, 1982). Within different social-context conditions, acceptable differences may result (Damon & Hart, 1982), thereby allowing for possible differences in understanding of the self in children with cancer.

To date, however, examining how the sense of self changes in children throughout

the complete illness cancer trajectory has been limited, despite the fact research has demonstrated that cancer poses a threat to the pediatric cancer patient's sense of self (Rechner, 1990). Moreover, in order to maintain their identity, children with cancer try to normalize their world by imagining or actually having a positive appearance, being active, and having abilities such as the ability to go to school (Hanna & Jacobs, 1993; Hinds & Martin, 1988; Hockenberry-Eaton & Minick, 1994; Orr, Hoffmans, & Bennetts, 1984; Weekes & Kagan, 1994). Rechner (1990) noted that adolescents with cancer tried to maintain their identity through normalization , trying to keep their "cancer world" separate from what they defined as their "normal world."

Findings also consistently indicate that children and adolescents report cancer had in some way changed who they were (Bearison, 1991; Claflin & Barbarin, 1991; Smith et al., 1991). The changes in their personal meanings were positive in that they saw themselves as more mature, caring, and empathetic. As well, although wanting to be treated as normal, children reported feelings of being special or different in that they were resilient in the face of serious illness (Aamodt et al., 1984; Hockenberry-Eaton & Minick, 1994; Enskär et al., 1997a; Rechner, 1990; Weekes & Kagan, 1994).

Besides changes to the self and life, Novakovic and colleagues found that adolescents and young adults reported improved relationships with others and better job performance (Novakovic et al., 1996). However, studies have also shown that children report negative changes as a result of their cancer experiences (Smith et al., 1991). In fact, work by Greenberg and Meadows (1991) revealed that children (8-16 years) reported more negative than positive changes in their lives. The negative responses were related to

worries about death, anger at having been ill, and family problems.

Except for the findings that cancer does appear to affect the sense of self in children with cancer, detailed descriptions of the changing self are not evident. Moreover, the majority of research related to children's sense of self has been framed within a deficit-centred approach. The purpose of this research is the evaluation of psychological adjustment or functioning of children and/or the impact of cancer on family functioning (i.e., presence or absence of maladjustment) with self-esteem being one of the variables used to assess adjustment or functioning. To date, findings have demonstrated that self-esteem ratings of children with cancer are within normal range and are not significantly lower than norms or healthy controls. Unfortunately, most of the work is cross-sectional in nature, therefore precluding an understanding of how self-feelings evolve. There is also a reliance on standardized self-esteem scales which may limit the set of response options available to children.

Only one study based on a qualitative paradigm examined how terminally ill pediatric cancer patients' perceptions of self-concept or self-understanding changed over time (i.e., a nine month period) and how children's use of health and illness expressions was related to their sense of self (Bluebond-Langner, 1978). The researcher used qualitative methods with an emphasis on interviews and participant observation. Findings showed that arriving at a certain self-image required that the children (three-to-nine years) not only interpret their own behavior, but also the behavior of others toward them. As the children passed through five different stages of becoming aware of what their cancer meant, they also passed through five different definitions of themselves. The

children defined themselves in relation to how ill they were (i.e., well, seriously ill, seriously ill and will get better, always ill and will get better, always ill and will never get better, and lastly dying).

Children were also not able to proceed to the next stage of self-awareness without first passing through the one before it (Bluebond-Langner, 1978). For example, even if the child understood that with cancer one could experience a relapse, remission, or death, the child still could not consider the possibility that he or she could die, unless the child perceived him- or herself as never getting better. As well, the children's interpretations of themselves varied depending on the type of social, physical, and temporal settings they were in. This study reinforced how the acquisition of information about the self, is increased through the illness experience; experience as opposed to age may be more valuable to a child's understanding of illness. Moreover, children's views of themselves were the result of various kinds of information that they had acquired in interaction with others, as well as through personal experience. Further study is warranted especially with respect to how cancer symptom experiences influences the changing sense of self (Woodgate & McClement, 1997) .

Coping Responses in Children with Cancer

Cancer is believed to present with a complex of potential stressors, such as the life-threatening nature of the illness, the side-effects of treatment, and the reactions of family, friends, and others (Van Dongen-Melman et al.,1986). However, little is known about how children cope with these various stressors. The majority of work in this area has examined children's coping responses to painful medical procedures (Blount et al.,

1991; Broome et al., 1990; Fowler-Kerry, 1990; Manne et al., 1992; Manne, Bakeman, Jacobsen, & Redd, 1993; Manne, Bakeman, Jacobsen, Gorfinkle, & Redd, 1994; Smith, Ackerson, & Blotcky, 1989; Weekes et al., 1993; Weekes & Savedra, 1988; Weisz, McCabe, & Dennig, 1994). Findings from these studies reveal that children use a variety of strategies such as crying, kicking, self-distraction, asking questions, and hand holding. Children had the tendency to use more strategies that focused on attempting to adjust their selves to painful treatments (emotion-focused) as opposed to attempting to alter the painful treatments (problem-focused). Although it makes intuitive sense that children's coping responses would vary according to the particular phase of the painful procedure, findings examining this hypothesis are inconclusive. Whereas Broome and colleagues (1990) reported that children's use of strategies may vary depending on the phase of the procedure with children using more active strategies (e.g., attempting to control, resisting) prior to the procedure and more passive strategies (e.g., inactive, ignoring) during and immediately after procedures, Weekes and Savedra (1988) reported that participants tended to use the same coping strategies before, during, and after procedures. In a study that examined the relation between children's trait-dependent and situation-specific coping behaviors during invasive medical procedures, findings revealed that children with higher distress reported using more coping behaviors suggesting that successful copers utilized fewer but more focused strategies (Phipps, Fairclough, Tyc, & Mulhern, 1998). The researchers in the previous study also noted that there was no single coping strategy that was clearly superior in reducing the children's distress (Phipps et al., 1998).

The study of parental behaviors during invasive procedures is also studied in

relation to how children cope during painful procedures. Parental behaviors including the use of nonprocedural talk, humor, coping-engaging commands, and distraction-coaching (Blount et al., 1991; Manne, Bakeman, et al., 1992; Manne et al., 1994) appear to have an influence on how children cope during the various phases of painful procedures.

Except for the studies dealing with painful medical procedures, few other studies were located that focused on specific cancer stressors. Only one study was found in relation to chemotherapy-induced nausea and emesis (Tyc, Mulhern, Jayawardene, & Fairclough, 1995). This study highlighted the complexity of the coping process in that the preference for and efficacy of coping strategies depended in part on the child's age, gender, severity of symptom distress, time elapsed from last chemotherapy, experience, and whether or not nausea or emesis was the identified problem. Even though the distress resulting from nausea was rated the same as the distress of emesis, coping strategies used for both types of distress were different. Moreover, strategies used for the management of nausea were rated as more effective than those used for emesis.

Aamodt and colleagues (1984) also focused on the stress caused by hair loss. A strength of their study was that they examined all the phases of hair loss and revealed that different coping processes were used during the different phases of the experience. Not surprising was the finding that during hair loss, both problem-focused strategies (e.g., covering hair loss) and emotion-focused strategies (e.g., ignoring hair loss) were used by children. Whereas before and after hair loss, children had more control with respect to actually changing the situation (e.g., making "funny" hair styles), children had less control during hair loss and therefore, tended to rely on strategies directed toward

changing their own feelings. Differentiating between coping strategies used for non-cancer-related stressors and cancer-related stressors has also not received attention in the literature. Only one study was found suggesting that children and adolescents do indeed use different strategies for both types of stressors (Bull & Drotar, 1991).

Instead of focusing on a particular cancer stressor such as hair loss, researchers have also studied how children respond to and cope with the total cancer experience. Findings from such work reveal that maintaining a positive attitude, striving toward normality, and talking to others about their illness are strategies used by both adolescents and school-age children (Bearison, 1991; Enskär et al., 1997a; Rechner, 1990). A limitation of such work is that for the most part, researchers have not examined how coping responses change throughout the cancer trajectory. That is, a process-oriented approach to understanding how children cope with cancer has not been undertaken.

Researchers have also attempted to identify developmental trends with respect to how children cope generally with cancer. To date, research suggests that older children use more cognitive control strategies in comparison to younger children who tend to rely on behavioral strategies (talking to others, playing games) (Brown, Kaslow, Hazzard, et al., 1992; Clafin & Barbarin, 1991; Worchel, Copeland, & Barker, 1987). Findings from studies examining developmental trends of coping responses in children with cancer must be viewed tentatively considering that researchers categorize coping strategies in a variety of ways (e.g., active versus passive, emotion-regulation versus problem-solving), with many items overlapping between the varied categorical systems. Additionally, although research suggests that adolescents use a greater variety of coping strategies compared to

younger children (Brown et al., 1992; Worchel et al., 1987), age may not be the only variable influencing children's coping responses. There is a need to assess the effect of age on coping responses in combination with other variables. For instance, in a study that involved adolescents exclusively, findings revealed that adolescents who were at least 12 months postdiagnosis used more strategies compared to those who were less than 12 months postdiagnosis (Weekes & Savedra, 1988). Hockenberry-Eaton and colleagues also reported that even children as young as six years of age were able to develop strategies when the perception of cancer stressors was more intense (Hockenberry-Eaton, Dilorio, & Kemp, 1995).

One variable that appears to significantly affect how children deal with cancer in general and with respect to specific cancer stressors, is social support. Themes apparent from the literature review include that for children with cancer: (1) parents appear to play a significant support role for children, although other members within children's social network are necessary; (2) both instrumental and emotional supportive behaviors are valued; and (3) some degree of distress is experienced even when supportive relationships are perceived as positive (Woodgate, 1999). What needs further clarification is whether or not certain events or behaviors that help children get through the cancer experience, serve as coping strategies and social support resources. Accordingly, there is the need to study and interpret events or behaviors not a singular entities, but in relationship to other events as well as within the context in which they occur. Studying social support and related constructs or concepts such as social competence and coping as mutually dependent variables as opposed to operationalizing them as independent variables is

warranted (Röhrle & Sommer 1994). This would especially be valuable for children with cancer and their siblings, considering social competence and coping are increasingly receiving research attention in this particular population.

In summary, detailed descriptions of children's coping responses over the course of the cancer illness trajectory is lacking. Gaps relate to the need to identify: (1) coping responses to specific cancer stressors and noncancer-related stressors; (2) developmental trends specific to children with cancer; and (3) mediator variables influencing children's coping responses. Additionally, methodological limitations include the reliance on cross-sectional designs, and the failure to triangulate data sources. Studying children's and adolescents' coping responses longitudinally, however, may allow for more detailed information. For example, Weekes and Kagan's (1994) longitudinal study revealed that children used a variety of coping strategies before and after chemotherapy completion and that coping strategies changed depending on the phase of treatment. Therefore, a longitudinal examination of children's and adolescents' coping responses throughout the cancer trajectory appears warranted. More detailed description of how assigned meanings to cancer symptoms affect children's coping responses is warranted.

Family: Parents' Experiences with Childhood Cancer

Similar to ill children's cancer experiences, parents' experiences with childhood cancer have also been framed within a deficit-centred approach. The majority of research involving parents has focused on the evaluation of psychological adjustment or functioning of parents (mainly mothers) (Fife, Norton, & Groom, 1987; Magni, Silvestro, Tamiello, Zanesco, & Carli, 1988; Moore & Mosher, 1997; Mulhern, Fairclough, Smith,

& Douglas, 1992; Nelson, Miles, Reed, Davis, & Cooper, 1994; Overholser & Fritz, 1990). Multiple standardized tools assessing such psycho social constructs as depression and anxiety are used to assess parents' level of adjustment. To date, findings have been conflicting. At best one could conclude that childhood cancer placed parents at increased risk to experiencing increased levels of psycho social distress, but childhood cancer alone, does not guarantee parental malfunctioning. Other variables including social support (Fife et al., 1987; Magni et al., 1988; Mulhern et al., 1992; Overholser & Fritz, 1990); hospitalization of the child (Mulhern et al., 1992); type of coping (Nelson et al., 1994; Overholser & Fritz, 1990); preexisting problems prior to the diagnosis of cancer (Fife et al., 1987); financial strain (Overholser & Fritz, 1990) may contribute to how parents adjust to childhood cancer.

Interestingly, findings from two studies noted that there was a significant positive relationship between children's adjustment responses and mothers' adjustment responses ($p=0$) (Magni et al., 1988; Mulhern et al., 1992), and that understandably, mothers with children off-therapy and their children had better adjustment responses. Mulhern and colleagues (1992) also noted that depression in mothers was associated with higher levels of child depression. One study that focused exclusively on fathers revealed that the most frequently reported stressors by fathers were related to concerns for their child's future and their child's health (Cayse, 1994). The uncertainty of illness experience seemed to be prevalent in guiding their experiences. However, although these studies assessed parents' level of adjustment, they provided minimal understanding of what parents were going through.

One qualitative study that focused on describing parents' experiences with cancer and cancer symptoms (i.e., pain), revealed that in dealing with their child's cancer and cancer pain, parents experienced a "community of suffering" (Ferrell, Rhiner, Shapiro, & Dierkes, 1994; Rhiner, Ferrell, Shapiro, & Dierkes, 1994). Pain was described by parents in physical terms or metaphors and graphic statements such as "nightmare," "horror," "his feet felt like there were razors cutting them," or "it was almost like seeing him (i.e., the child) dangle from the end of a rope." Having a child with pain was described as unendurable pain. Although parents displayed a total commitment to their children, they also expressed feelings of guilt and failure. Similar to Bossert and colleagues' (1996) findings, parents reported using distraction, imagery, cold compresses, hot tub baths, massage, hot packs, and letting the child gain control to deal with their child's pain. Despite use of these strategies, parents still experienced feelings of helplessness. Many felt unprepared to deal with relieving pain at home and were often quite willing to stay in the hospital to avoid a painful situation at home.

Parents expressed a fear of addiction in relation to their child's analgesic medication which resulted in some parents trying to restrict the amount of medications given. The parents also recommended that health professionals should listen to the patient and family, administer medications and increase the dosage as needed, and establish a means of providing continuity of care by increasing communication between staff and families. The need for a specialized pain service was voiced by parents. Ferrell and colleagues (1994) noted that parents also felt that their child's pain was not taken seriously by health care providers. The pain affected all family members and often

disruption of the family system occurred even in the strongest of families.

That parents experience helplessness in relation to caring for their child's symptoms, seems to be consistent in other areas of research examining child care and illness. For example, in a study exploring the experience of pain in children undergoing surgical intervention, parents while accepting the role of primary caregiver during hospitalization, expressed frustration in not knowing how to do things without hurting their child (e.g., lifting or moving them) (Woodgate & Kristjanson, 1996a). There were instances when parents had indeed caused pain in their child due to a lack of knowledge. Even the more independent parents stated that they needed more help or support especially when they experienced fatigue. Parents also expressed a need to be told more about how to handle their child's pain at home. Feelings of guilt and sadness were also expressed by parents. Although most parents rationalized their child's pain by stressing that the surgery was necessary, parents nevertheless questioned if they had done the right thing in consenting to the surgical procedure. Most parents stated that the pain their child suffered was more than what most people experience in a lifetime and they hoped their child would never have to go through this again.

In another qualitative study, Enskär and colleagues (1997b) also reported that Swedish parents of children with cancer had to watch their child suffer and that this was the most difficult or worst aspect of having a child with cancer. Parents felt powerless in relation to the amount of fear, pain, and suffering that their child was experiencing. The parents also expressed that their child's disease in relation to treatment, hospitalization, and check-ups, governed their everyday life, and had an effect on the parents

opportunities to work, financial circumstances, and ability to get insurance. Parental feelings about and reactions to their child's cancer depended to a great extent on their child's feelings and reactions. Uncertainty surrounded their experiences. Except for studies like this one and others by Ferrell, Rhiner, and colleagues (Ferrell et al., 1994; Rhiner et al., 1994), minimal description of parents' thoughts and feelings in relation to their child's cancer symptom experiences exists in the literature.

How parents cope with the childhood cancer experience has also been mainly discussed in terms of the total cancer experience and not in relation to specific cancer events such as dealing with uncontrolled symptoms. Findings to date show that although parents of children with cancer experience more stressful life change events in the areas of intrafamily strains, marital strains, and finance or business strains than those with physically healthy children, they use similar coping behaviors (Birenbaum, 1990; Enskär et al., 1997b; Thoma, Hockenberry-Eaton, & Kemp, 1993). Information seeking, problem solving, help-seeking, maintaining emotional balance, religion, being optimistic or thinking positively, denying, and accepting are some of the strategies frequently reported (Barbarin & Chesler, 1986; Birenbaum, 1990).

Although experts emphasize or suggest the importance of understanding coping within the family context (Seiffge-Krenke, 1995; Sorensen, 1983), few studies have examined coping in children with cancer within such a context (that is, the whole family unit). In most research, usually the child or parent is the focus. Clarke-Steffen's (1997) prospective longitudinal grounded theory study was framed within a family context and involved parents, siblings, and ill children. Unfortunately, despite being framed within a

family context, many of their findings seemed to be derived mainly from the perspective of the parents. Another study examining the prognostic views of children and their families found that parents and children revealed that hope served to help families adapt to the cancer diagnosis (Mulhern, Crisco, & Camitta, 1981). A major limitation of this work was that siblings were excluded from the study.

In contrast, Kupst's (1992) prospective, longitudinal study examining coping in childhood cancer within the family context, did include parents, ill children and siblings. Findings indicated that: (1) most families with children with cancer coped well in comparison to controls; (2) both parents and children relied on a variety of coping strategies; (3) throughout the course of the child's illness, it was important to maintain a positive outlook; (4) children's coping was significantly related to the adequacy of their parents' coping (p value not reported); and (5) support from family, outside support, and the quality of marital relationship correlated with family coping. Further study of how the family copes as a unit is warranted. Moreover, exploring families' coping responses specific to dealing with cancer symptoms in children is needed.

Research examining whom parents found to be supportive or helpful during their child's cancer experiences identified a variety of different support roles including other parents who had a child with cancer (Brown & Barbarin, 1996; Chesney, Rounds, & Chesler, 1990; Williams, 1995), neighbours (Chesler & Barbarin, 1984a; Williams, 1995), relatives (Enskär et al., 1997b; Hughes & Lieberman, 1990; Williams, 1995), and religious affiliations (Hinds, Birenbaum, Clarke-Steffen, et al., 1996; Williams, 1995; Lauer, Mulhern, Schell, & Camitta, 1989). Of all supportive roles, research revealed that

parents rated their spouses as their most common source of support. Positive supportive behaviors included the ability to confide in each other, share worries openly, and enjoy a mutual sense of caring and intimacy (Chesler & Barbarin, 1984a; Enskär et al., 1997b; Hughes & Lieberman, 1990). Factors that appear to have some influence on spousals' perceptions of perceived support include the number of the child's hospitalizations and the availability of their spouse (Barbarin, Hughes, & Chesler, 1985). Interestingly, Cayse (1994) reported that time spent alone with a spouse was difficult to find for parents of children with cancer. This could be attributed to the increased care involved in managing the therapeutic regimen as was noted in a qualitative study conducted by Clarke-Steffen (1997). Parents had to learn to meet the demands of the illness, its treatment and side-effects, and all of the attending consequences.

Friends were also reported to be a common source of support for parents (Chesler & Barbarin, 1984a; Enskär et al., 1997b; Shields, Schondel, Barnhart, et al., 1995), however, support from friends was assessed to be more important for wives (Brown & Barbarin, 1996; Veiel, Crisand, Stroszeck-Somschor, & Herrie, 1991). In fact, Veiel and colleagues (1991) identified that when it came to psychological support, husbands relied more on their spouses in comparison to their wives. This finding suggests that husbands are less likely to need the support of others or that they are less likely than their wives to share their feelings or seek assistance from others within their social network. Indeed, a study conducted by Larson and colleagues revealed that mothers received significantly more informational ($p<.01$) and emotional support ($p<.03$) than fathers (Larson, Wittrock, & Sangren, 1994).

Findings have been conflicting with respect to parents' perceptions of social support received from health professionals. Whereas some findings revealed that health professionals were very helpful (Chesler & Barabarin, 1984b; Martinson, Kim, Yang, et al., 1995), other findings suggest that their help was not valued or wanted (Chesler & Barabarin, 1984a). One consistent finding reported in the literature review is that parents prefer both emotional support such as being sensitive to their emotional needs as well as their child's, and instrumental or practical support such as providing information on a continual basis and demonstrating competence in care from health professionals (Chesler & Barbarin, 1984b; Hinds, Birenbaum, Clarke-Steffen, et al., 1996; Hughes & Lieberman, 1990; Rhiner et al., 1994). Williams (1992) also reported similar findings in that parents felt that caring (i.e., the ability to listen and to show compassion) was the predominant theme in which parents expressed how professionals could offer support to families. Parents also wanted to participate in their child's care, be told of test results promptly, and staff to hear their concerns about their children. Parents voiced anger when professionals showed a lack of respect for parents' expertise in caring for their ill children.

Romaniuk and Kristjanson (1995) noted that nurses who provided both the "basics" (i.e., providing the bare necessities of care) and the "human touch" (i.e., actions that made nursing care more humane) were perceived to be caring completely by parents. With the latter this included such actions as interacting with the child in a developmentally appropriate manner, showing sensitivity to parents' feelings and concerns, making an effort to answer parents' questions, and demonstrating a willingness

to make time for parents' questions. They also revealed that there were four components to parents' care giving: (1) just being there; (2) providing everyday care; (3) providing illness care; and (4) providing supportive care. These four were termed the process called "making it better." Interestingly in a study that focused on children's pain experiences, "Making it Better" was a theme that children described throughout their hospitalization in relation to how others (i.e., parent and hospital staff) could help make their pain go away (Woodgate & Kristjanson, 1996b).

A particularly important finding noted in the research is that parents did not always have all their counselling, financial, informational, and practical needs met (Sloper, 1996). For example, Mercer and Ritchie (1997) noted that parents whose children had been diagnosed 12 months or longer had more unmet needs (especially financial needs) and that 33% of parents expressed the need for information and contact with other parents once their child completed treatment. Another study revealed that parents who had a child die of cancer also did not benefit from any sources of social support (Morrow, Carpenter, & Hoagland, 1984). In looking at problems parents had in obtaining support, Chesler and Barbarin (1984a) reported that parents who had difficulty sharing their child's diagnosis also reported receiving less support. Parents also expressed numerous concerns in seeking help from others, friends and the community, including a concern about the emotional impact on others and the need for parents to maintain their privacy. Factors relating to the amount of help received included the type of cancer, with parents of children with lymphoma or osteogenic sarcoma reporting they received more support (Chesler & Barbarin, 1984a). Chesler and Barbarin (1984a) suggested that the

effect of visible seriousness and duration of illness and cancer requiring longer treatment trajectories such as lymphoma and osteogenic sarcoma may account for increased help reported by parents of deceased children. While these findings identify that not all social support needs of parents are met, further investigation of how social support influences parents caring for their child's cancer experiences, especially with respect to the cancer-symptom trajectory is warranted.

In summary, this review points to the need for further investigation of parents' experiences with childhood cancer. This includes research examining: (1) parents' assigned meanings to their child's cancer and cancer symptom experiences; (2) how parents care for their child's cancer symptoms; (3) how parents cope with their child cancer and cancer symptom experiences; and (4) how cancer and cancer symptom experiences affect the sense of self in parents.

Family: Siblings' Experiences with Childhood Cancer

The sibling bond is believed to develop from a unique, complex relationship that includes positive aspects such as love, caring, friendship, and cooperation as well as normal feelings of competition, jealousy, and feelings of being left out (Ross-Alaolmolki et al., 1995). Moreover, siblings' responses to illness are influenced by the family unit and how each family member relates to and copes with the illness on a daily basis. Although clinical anecdotes and theoretical literature suggests that siblings suffer in response to childhood cancer and experience deprivation, displacement, injustice, anger, loneliness, and vulnerability (Adams & Deveau, 1987; Bendor, 1990; Whyte & Smith, 1997), systematic research involving siblings is limited.

To date, the research has focused on an examination the psychosocial functioning of siblings and the identification of psychological or adjustment problems with cancer in general (Barbarin, Sargent, Sahler, et al., 1995; Horwitz & Kazak, 1990; Sahler, Roghmann, Carpenter, et al., 1994; Sloper & While, 1996) and in relation to the death of a sibling with cancer (Lauer, Mulhern, Bohne, & Camitta, 1985; Michael & Lansdown, 1986). Findings to date, are conflicting with some studies showing that siblings are at greater risk for negative changes in behavior since the cancer diagnosis or experience more behavioral and emotional problems in comparison to the general population (Barbarin, Sargent, Sahler, et al., 1995; Cadman, Boyle, & Offord, 1988; Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Evans, Stevens, Cushway, & Houghton, 1992; Michael & Lansdown, 1986; Sahler, Roghmann, Carpenter, et al., 1994; Sloper & While, 1996). In contrast, others report the absence of difficulties in coping and adaptation in siblings of children with cancer (Horwitz & Kazak, 1990; Madan-Swain, Sexson, Brown, & Ragab, 1993). At best one could conclude that the outcome of sibling adjustment, is neither simple nor direct (Cohen et al., 1994). As well, a number of factors are associated with how siblings adapt including family cohesion and adaptability (Cohen et al., 1994) degree of family disruption (Sloper & While, 1996), family resources (Sloper & While, 1996), siblings' perceptions of negative interpersonal effects on their lives (Sloper & While, 1996), age and gender of the sibling (Sahler, Roghmann, Carpenter, et al., 1994; Sargent, Sahler, Roghmann, et al., 1995), size of family (Madan-Swain, Sexson, Brown, & Ragab, 1993), and level of sibling knowledge (Evans, Stevens, Cushway, & Houghton, 1992). A limitation of these studies exploring siblings'

experiences is that they rely heavily on proxy reports and standardized psychological scales (e.g., The Achenbach Child Behavior Checklist) with or without siblings' self-reports. As well, most of the research is guided by a deficit-centred model approach.

Studies that examined the impact of childhood cancer from the perspective of the sibling by way of semi-structured interviews, findings revealed that siblings experience a multitude of intense feelings including feelings of deprivation, displacement, injustice, anger, guilt, loneliness, and vulnerability (Bendor, 1990; Chesler, Allswede, & Barbarin, 1991; Havermans & Eiser, 1994; Koch-Hattem, 1986; Martinson et al., 1990). These feelings were often triggered by separation of the siblings from their parents and the ill child. Interestingly, one study revealed that it was not until the ill child's symptoms worsen that siblings realized their ill sibling was really sick (Martinson et al., 1990). This finding supports the argument that experience with illness may be necessary to gather or understand significant disease-related information (Bluebond-Langner, 1978).

Similarly, in a qualitative study that described the changing appraisals of siblings and parents related to childhood leukemia, findings revealed that early symptoms in the ill child were dismissed by siblings or ignored as unimportant (Brett & Davies, 1988). However, as the illness progressed, older siblings noted enough evidence of parental anxiety to concern them, even when they were told that the ill child "had a cold" or were "sick" and had to stay in the hospital to get better. Worry and "keeping an eye" on the ill child was part of the siblings' responses to the cancer. Awareness of painful procedures, the presence of special and protective rules, or restrictions in the family caused siblings to continue to appraise leukemia as actively threatening. Another study revealed that

some siblings expressed that seeing the ill sibling change in physical appearance was the worse thing about the experience and that these images would always remain with them (Havermans & Eiser, 1994). This suggests that the impact pediatric cancer symptoms have on healthy siblings may be significant.

Siblings also have been reported to express concern about their sibling's physical and emotional ability to cope (Chesler, Allswede, & Barbarin, 1991). Chesler and colleagues (1991) noted that in helping the ill sibling, siblings would use strategies that related to companionship and nurturing (e.g., letting the sibling sleep in their room, reading a story). They also tried to be careful around them. Older siblings were reported to be able to perform more varied and complex tasks. Moreover some siblings reported trying to provide additional practical and emotional support for their parents, and often were concerned about burdening parents with their own problems or worries (Chesler et al., 1991; Havermans & Eiser, 1994). The need to "take care of" other family members emerged as major theme from this area of research which suggests that the needs of healthy siblings may go unmet.

Worry about the illness and fear of death as experienced by healthy siblings was also predominant in most work, pointing to the difficulties and suffering that healthy siblings experience because of their ill brother's or sister's cancer experience. Nonetheless, how healthy siblings cope with the cancer experience has been described minimally. Strategies reported to be used by healthy siblings to deal with their stress and anxiety include: keeping busy, denial or repression, cognitive reappraisal, venting or expressing their feelings by screaming or becoming angry and crying; seeking comforting,

doing other things, and talking to other peers with similar experiences (Bendor, 1990; Chesler et al., 1991; Koch-Hattem, 1986). One study noted that no differential coping styles or frequencies of coping strategies were found in siblings of ill children compared to siblings of healthy children (Madan-Swain et al., 1993). Older children were also reported to confront or manage their feelings more directly by reading about the illness or talking (Chesler et al., 1991).

In summary, research related to the experience of having an ill brother or sister with cancer is in its infancy. More work is needed that focuses on healthy siblings' thoughts and feelings about the cancer experience in general, as well as cancer symptom experiences, and how such experiences alter their lives and sense of self.

Sense of Self in Families of Children with Cancer

Exploring how the sense of self or identity within the family unit changes because of childhood cancer has to date, been minimal. Most of what is known about the family unit's changing identity has emerged from research that has involved parents evaluating some characteristic of family interconnectedness such as family cohesion or expressiveness. Again the studies examining this area are primarily cross-sectional in nature. The majority of the findings to date suggest that parents report improved family relations such as higher levels of family cohesion and expressiveness (Birenbaum & Robinson, 1991; Sloper, 1996); improved marital relationships (Sloper, 1996); closer parent-child relationships, especially the mother-child relationship (Kvist et al., 1991). Higher cohesion and expressiveness were also predictive of lower psychological distress and higher social competence in children (Varni et al., 1994). As well, parents who

reported less cohesiveness also reported receiving less help in caring for their children and other tasks (Manne, Lesanics, Meyers, Wollner, Steinherz, & Redd, 1995). Factors that seemed to be related to improved family relations included hospice services for terminally ill children (Birenbaum & Robinson, 1991; Lauer et al., 1989) and stronger pre-existing relationships (Sloper, 1996).

Research also has revealed that change occurs within the family because the diagnosis and demands of the illness require that family roles be dramatically restructured within the family. Families were prompted to examine their values and priorities (Clarke-Steffen, 1997). One study revealed that parents like ill children, reported themselves as becoming more mature and more caring and sensitive because of the cancer experience (Enskär et al., 1997b). Research has shown that siblings frequently report that negative changes occurred in their home and interpersonal relationships since the cancer diagnosis, and that they experienced feelings of loneliness and sadness (Bendor, 1990; Chesler et al., 1991; Havermans & Eiser, 1994; Martinson et al., 1990). However, whereas research reveals siblings experienced negative feelings in themselves and family members, they, especially older siblings, also experienced becoming more compassionate and mature, and families became closer (Chesler et al., 1991; Sargent et al., 1995). However, the detailed experiences of families and the meanings that parents and siblings assign to the changing family unit because of cancer have not been described.

Health Professionals' Experiences with Childhood Cancer

Although clinical accounts and theoretical literature exists describing how health professionals can provide guidance, information, support, and other practical suggestions

to the family with the child with cancer (Brown, 1989), there is little systematic research examining how professionals respond to the child with cancer and the family, and to the children's symptom experiences. To date, the examination of health professionals in relation to children's cancer-symptom experiences have primarily focused on whether health professionals' (mainly nurses) proxy ratings of children's symptom experiences are congruent with children's self-reports (Grootenhuis, van der Wel, de Graaf-Nijkerk, & Last,1996; Manne, Jacobsen, & Redd, 1992; West, Oakes, Hinds, et al., 1994). For the most part, findings reveal that professionals and patients have differing perspectives with professionals' ratings being lower or higher than the children's (Grootenhuis et al., 1996; Manne et al., 1992; West, Oakes, Hinds, et al, 1994). Another area involves assessing the knowledge base of pediatric nurses about cancer pain through survey methods. Findings to date reveal that although pediatric nurses cared for cancer patients regularly, they had a poor understanding of the general principles of pain management for the cancer patient (Schmidt, Eland, & Weiler, 1994). Moreover, they had exaggerated concerns regarding the risk of addiction and respiratory depression associated with narcotic analgesics. As well, they had a poor understanding of basic pharmacokinetic principles of common analgesic agents. Unfortunately, surveys like this one, do not capture how nurses and other professionals respond to and actually care for children experiencing pain and other cancer symptoms.

One study that focused on parents' perceptions about their relationship with the pediatric staff nurse during their child's hospitalization for cancer treatment revealed that parents expressed the importance of parents and nurses working together (Romaniuk &

Kristjanson, 1995). "Working together" varied according to the form of care provided by the nurse. When the nurse was "going through the motion" (i.e., providing the basics) the relationship was one of "territorial caring," that is, the parent and nurse both provided direct care to the child (independent care by the nurse and parent), but they did not provide indirect care (interdependent care by the nurse and parent). When "caring completely" (i.e., providing the basics with the human touch), the relationship was one of "sharing care." That is, parents and nurses both cared directly and indirectly, and this relationship could take on an added dimension of "making friends" - the relationship extended beyond providing care for the child. Parents recognized that nursing care could be influenced by the nurses being too busy, the type of ward (i.e., whether the ward had nurses who specialized in cancer care and who were familiar with the child and family), hospital hierarchy (i.e., how care was affected by the nurse's place in the hospital hierarchy), and secret information (i.e., attempts to keep information from parents).

A study that interviewed both parents and health staff (mainly nurses) reported similar findings. Williams (1992) noted health staff felt support could be offered to parents of children with cancer by "being available." This involved staff being able to sit down, joke with parents, carry others through difficult emotional times, and help parents to cope. Staff also felt it was important to have knowledge that was demonstrated by answering parents questions, telling parents everything that they needed to know, and teaching parents to reach an optimal level of coping. For staff, health professionals were defined as caring when they "knew" the families and offered empathy. Staff acknowledged that lack of time, lack of nursing staff, lack of communication,

inconsistency of staff, and the medical bureaucracy impeded their ability to care. The family was also identified by hospital staff as sometimes being a barrier especially when they directly resisting support. Interpersonal conflicts arose when parents and staff had different ideas about what was best for the children.

In one qualitative study that examined aspects of care and assistance that are important to school-age children with cancer, the researchers gathered data not only from parents and nurses, but also from the children themselves (Enskär & von Essen, 2000). Data analyzed by content analysis revealed that the actions that nurses take and the characteristics of staff were important in making children feel cared for. Important caring aspects were as follows: amusement, clinical competence, continuity, family participation, honest communication, information, participation in decision making, satisfaction of basic needs, social competence, and time. However, while the parents and nurses agreed fairly well on which caring aspects were important, the children presented a different view on what constitutes good caring. Children more often identified social competence, amusement, and satisfaction of basic needs as significant care aspects. In contrast, parents and nurses most frequently identified the importance of information, social competence, and the participation in decision making. Interestingly, satisfaction of basic needs such as the need for good food, pain relief, a quiet environment, a single room, and necessary equipment, was least frequently mentioned caring aspects by parents and nurses.

One study exploring patterns of communication between hospital staff and children with cancer and their families, involved comparing patients' and parents'

perspectives of standard rounds (rounds conducted in the corridor) and bedside rounds in which management was discussed in front of patients and parents (Lewis, Knopf, Chastain-Lorber, et al., 1988). Findings showed that both children and parents preferred bedside rounds. Moreover, it was important that patients and parents have the opportunity to ask questions, and that the information provided be clear. Suggestions such as using more understandable language, reducing the size of groups, and limiting the number or excluding particular individuals were also made. With standard rounds, children perceived that physicians were "hiding something"; discussions excluding the child, signified bad news. Unfortunately this study relied solely on retrospective accounts without direct observation of rounds.

In a study that involved directly observing the interactions of parents, health care professionals (nurses), and children during painful clinical interventions, findings emphasized the importance of nurses being aware of the various child-parent-caregiver interactions and the need to stay focused on the child during painful procedures in order to enhance the child's ability to cope (Naber et al., 1995). Focusing on issues not related to the child, such as scheduling, equipment needs, recent activities, or personal interests, did not appear to contribute to a child's ability to cope or tolerate a painful procedure, and resulted in increased attention. Another study that analyzed interactions in a pediatric oncology unit suggested that clinic visits are more acceptable for children when staff invest personal attention, give appropriate explanations, and handled children sensitively (Inman, 1991).

Even with advances in medical care, caring for the dying child is still part of the

pediatric oncology nurse's role. Death is a social and cultural phenomenon. How we die and the way that we permit others to die are greatly affected or impacted by social and cultural factors (Bluebond-Langner, 1978). However, to date, there has been minimal research describing specific nursing behaviors that are considered essential when caring for the dying child. One study in a series of comparative works examining "expert" behavior in nurses caring for the dying children (including children with cancer) revealed the following behaviors as being critical: connecting, responding to the family, providing comfort, enhancing the quality of life during dying, responding to anger, responding after the death has occurred, enhancing personal growth, and responding to colleagues (Hawkins, 1995). Central to experience were behaviors that acknowledged and incorporated the close relationship that developed between nurses and patients and their families (i.e., connecting). Perhaps this was why pediatric nurses felt that decisions to shift from active to supportive, palliative care was even more difficult when the patient is a child. In many instances, nurses maintained contact with a family for an extended period of time following the death of their child. The essence of a caring relationship underlaid all other components of care. Attending to the physical and psychological pain, yet at the same time being able to recognize the child developmental and emotional need to be loved and nurtured was important. This study relied on retrospective accounts, thus further study is warranted. More information is needed to better understand such unique attributes of pediatric nursing care, such as connecting.

Further work is needed to assess how nurses and other health professionals interact and respond to children with cancer and their cancer-symptoms. This is especially

important considering the increased emphasis on medical technology in oncology patient care settings challenge those caring for patients to provide care that is humanizing and comforting, as well as technical (Brown, 1992). Hogan (1997) stated that "ensuring optimal symptom control is a finite measure of such advocacy and a scared trust that must be nurtured and guarded as we approach the new millennium" (p. 1340).

Conclusion

Interpretation and understanding are critical to social life (Denzin, 1989). To date, however, research directed at children's cancer-symptom experiences has paid minimal attention to the meanings, interpretations, and experiences of the persons central to these experiences. Although symptoms experienced by children throughout the cancer illness trajectory have the potential to alter the sense of self in children and their families, this has not been adequately studied. Moreover, a review of the pediatric oncology literature reveals that the focus has been on the traditional measures of psychosocial sequelae to assess the "impact" of the disease on the patient. Children's cancer-symptom experiences have primarily been studied in terms of the norms and canons of positivistic science. There are few attempts to write and interpret these experiences as they are lived and given meaning by children and their families. This literature review provides firm support for the need to further study children's cancer-symptom experiences, and to study this phenomenon from a qualitative perspective. The next chapter will describe the research design and process.

CHAPTER III

RESEARCH METHODOLOGY AND PROCEDURES

Introduction to the Research Design

An interpretive research design framed within the qualitative paradigm was adopted in the study of children's cancer-symptom's experiences. Underpinnings from the grounded theory and illness narrative qualitative research methods guided the research process and assisted the researcher in the interpretive research process. This chapter describes the research methodology and procedures used to arrive at meaningful interpretations of children's cancer-symptom experiences. Limitations to the study are presented.

The Qualitative Interpretive Research Approach

In qualitative interpretive research one seeks to arrive at building meaningful interpretations of a specific social and cultural problem (Denzin, 1989). Qualitative interpretive research helps to reveal intricate details of phenomena that are not easily communicated through quantitative methodology, and reveal what lies behind any phenomenon about which little is known (Strauss & Corbin, 1990, 1994) such as children's cancer-symptom experiences.

Characteristics critical to interpretive research are the following: (1) it is existential, interactional, and biographical; (2) it is naturalistic; (3) it is based on sophisticated rigor; and (4) it is concerned with social construction including the social construction of knowledge, history, and emotion (Denzin, 1989). The qualitative paradigm supports the assumption that truth is best achieved by entering the participant's

world with the intent of understanding the "context" of behaviour as it unfolds naturally (Lincoln & Guba, 1985). Whereas the natural science approach or quantitative methodology is concerned with "objects of nature," "things," "natural events," and "the way that objects behave," the human science approach or qualitative methodology is concerned with the study of persons or beings that have "consciousness" and "act purposefully" by creating objects of "meaning" that are "expressions" of how human beings exist in the world (van Manen, 1990). Inasmuch as nature must be explained, human life must be understood (Dilthey, 1976 in van Manen, 1990). Human life requires knowledge, reflection, and thought to make it knowable to itself (van Manen, 1990). The qualitative paradigm makes it possible to understand how individuals construct their worlds (Charmaz, 1990).

This study's research questions were best approached using a qualitative research perspective as it allowed the researcher to explicate the meaning of the childhood cancer-symptom phenomenon and understand the lived structures of meanings assigned to cancer-symptoms. The method facilitated the researcher's ability to describe the human dimension of the children's and families' stories of experiencing cancer. It also enabled the researcher to grasp the simple sounds of symptoms, the complex inner language of hurt, desperation, and moral pain and triumph of living with an illness (Kleinman, 1988). Finally, because interpretive research can result in meaningful descriptions and interpretations of social processes (Denzin, 1989), theory development related to children's cancer-symptom ensued.

Adopting a qualitative research approach was also appropriate because the use of

qualitative methods, especially observational and interpretive research procedures, have increasingly been recognized by professionals as essential to strengthening an understanding of children's cognitive, emotional, and behavioral development (Jessor, Colby, & Shweder, 1996). It is recommended for researchers who are interested in understanding what children and adolescents think about a particular experience (Beck, 1990; Bernheimer, 1986; Deatrick & Faux, 1989; Fine & Sandstrom, 1988; Pass, 1987). The need for more qualitative research, however, does not imply that researchers should stop conducting research framed within the quantitative paradigm. Both paradigms are needed to investigate the whole of the human experience (Beck, 1990). Whereas the quantitative paradigm is needed to control phenomena and to predict outcomes of interventions, qualitative research is needed to identify the characteristics that make the phenomenon what it is (Beck, 1990). While quantitative research is valuable, over-reliance on one type of research method leads to biases (Morrow & Richards, 1996). Children need to be ethnographically observed in the different social organizations that make up the shifting contexts of their social lives (James & Prout, 1995). Accordingly, a move away from a strictly quantitative research base to increased use of context-sensitive qualitative research procedures is being advocated (Graue & Walsh, 1998; Krahn, Hohn, & Kime, 1995).

Because the overall purpose of this study was to discover meaningful descriptions and interpretations of children's and their families' experiences with the cancer-symptoms throughout the cancer-symptom trajectory, a qualitative research method that supported a process-oriented perspective was necessary. Tenets from the grounded theory

qualitative research method were thus used to shape the research process. The grounded theory method advances the understanding of human and social processes through the development of theory that is inductively derived from the study of the phenomenon it represents (Strauss & Corbin, 1990, 1994). Theoretical assumptions of grounded theory that were congruent with the study's questions included viewing and accepting: (1) the importance of theory, grounded in reality, to understanding of a particular phenomenon; (2) the nature of experience as something continually evolving; (3) the active role of persons in shaping the worlds they live in; (4) an emphasis on change and process, and the variability and complexity of life; and (5) the interrelations among conditions, meaning, and responses (Strauss & Corbin, 1990). The grounded theory method not only led to description of data, but more importantly resulted in interpretation of data by the development of concepts or core categories and their relationships to each other. Adopting a grounded theory approach to the study of children's cancer-symptom experiences was appropriate as to date, no substantive theory exists.

A second type of interpretive work, the development of illness narratives, was also used to discover and further facilitate discovery of meaningful descriptions and interpretations of the children's and their families' experiences with the cancer-symptoms. The narratives helped to confirm the paradigmatic relationships of the categories related to theory development. Illness narratives are variants of biographical writing or biographical research. Biographical research has evolved from an array of traditions including psychology, literary circles, history, and anthropology as well as feminist and cultural thinking (Creswell, 1998). With illness narratives, the researcher

sought to retell and inscribe stories of the children's cancer-symptom experiences as told by the children and their families. Combining underpinnings of illness narratives with the grounded theory method was justified considering an essential step of grounded theory is to create a story line or a conceptualization of a descriptive story about the central phenomenon of the study. Approaching children's cancer symptom experiences from an illness narrative perspective was most appropriate as it provided a basis for understanding how illness affects the children's and families' biographies by contextualizing illness events and illness symptoms (Hydén, 1997). What distinguishes illness narratives from other forms of qualitative research is that narratives are centred primarily on the self (Viney & Bousfield, 1991). An understanding of the child's and family's changing sense of self within the context of childhood cancer was facilitated.

Research Setting

In addition to participants' homes, the study was conducted in the outpatient unit of the Manitoba Cancer Treatment and Research Foundation (MCTRF) and the pediatric oncology inpatient unit of Children's Hospital. Both the outpatient unit of MCTRF and the inpatient unit of Children's Hospital are the two main pediatric cancer treatment areas for children residing in the province of Manitoba. A description of these settings is detailed in this section.

(1) Manitoba Cancer Treatment and Research Foundation (MCTRF)

The MCTRF clinic that the children attended, provided outpatient services for both adults and children with cancer. Its main floor was where children and adults were seen for their check-ups and where they received their chemotherapy. The layout of the

clinic's main or first floor included one long main hallway. Rooms located to one side of the hallway included the laboratory room where patients' blood specimens were taken and tested, and the chemotherapy room where chemotherapy was initiated in all adult and child patients. Rooms or areas located on the other side of the hallway included two waiting room areas and a check-in area for families. Approximately eight examination rooms were located on both of two smaller hallways that were adjacent to each waiting room area.

Although each area or room in the clinic had an official purpose such as checking in families or testing blood, each area also had a non-official purpose assigned to them by the families. For instance the area where blood testing was done was deemed as one of the areas where parents could carry on serious conversations with other parents. Another example are the examination rooms that in addition to their official purposes of a place for check-ups and medical procedures, also served as a place where parents and children could reflect on the past week prior to seeing the physician. The hallway itself served many functions including a meeting place and a party area when parties were held for the children. The hallway also served as one of the main spots where pictures of children attending the clinic were placed. In fact, except for the treatment rooms all the areas had pictures of children on the walls.

The clinic was originally built specifically for adult cancer patients. Children did not start using the clinic until the mid 1960's. Before that time, children were seen in the outpatient clinic at Children's Hospital. Understandably with the increase incidence of cancer in adults and children and the increase in outpatient care over the last two decades,

the clinic space at MCTRF had become inadequate. However, at the time of this study, the clinic at MCTRF was where the children received the majority of their care and where families spent a good deal of their time. Most days the clinic had limited space and on days when clinics ran simultaneously for both children and adults, it was impossible to find a free room because all treatment rooms usually were in use. At times this became a problem for those families who needed or wanted to spend some time alone for whatever reason. Understandably the need for a new clinic was long overdue and at the time that the researcher was conducting the study, a new clinic was being built.

The atmosphere of the clinic could best be described as a "happening" place. It was a place full of people, emotions, talk, and action especially within the waiting rooms. This made it easier for the researcher to blend in. Often the researcher was mistaken for a family member of one of the cancer patients. Families, volunteers, and staff were coming and going and all seemed to know where they were going. To describe the clinic as "busy" even when it was quiet would be an understatement. Most amazing was how everyone maneuvered themselves and got around without interrupting the natural flow of the clinic despite all the going-ons. It was also amazing that no child ever got run over or knocked down by some machine. Families knew the clinic so well that they could have been blindfolded and yet still manage to get around with ease.

Although children and adults shared the clinic space on certain days, the clinic nonetheless became the domain of the children. The children's presence overpowered that of the adults attending the clinic. Both waiting areas could be used by adult and children patients, but for two days of the week, one of the waiting areas was basically designated

the waiting area for children and their families. The waiting room designated as the "children's safe area" contrasted sharply to the other rooms of the clinic. This room was so much more full of life compared to other areas. Art work, toys, a television, video games filled this area. It was extremely cluttered with children and their families packed into the area like they were sardines. The room was only approximately 10 by 12 feet in size. On the regular scheduled clinic days for children, the "designated" children's waiting room area was overflowing. It was hard for everyone waiting to get a chair. The waiting room area was the meeting place for both children and parents. It was in the waiting room that parents could share their stories with other parents. As well, children could also update each other in this area and checkout the other children's hair loss and growth.

Even more important was that the designated children's waiting room area served as the children's play area. It was at the tables located at the centre of the waiting room area that the children and sometimes their siblings would play board and video games and make crafts while they waited to be seen by their physician or while they waited for their treatments to be started. Under the careful guidance of the Child Life Therapist, the place strived to be a safe area where children could feel more like "regular kids." Even the nurses shooting in and out to monitor the intravenous lines did not disturb the "kid-like" atmosphere of the waiting area. The only time this atmosphere was disturbed was when a child presented with symptoms that were obvious to those in the waiting area. For example, when a child would state that they were "feeling sick," parents as well as other children would rush to get the child a basin to throw-up in and would make sure that the

child could lie down.

During the time the researcher spent at the clinic, the children had accumulated a fair number of crafts. Each craft had its own story attached to it and represented a specific period in the children's cancer-symptom trajectory. Many of the crafts that the children made became holiday or birthday or "thank you" gifts for the children's friends and families. Sometimes when the researcher visited the children's homes, the researcher was shown the children's crafts. The amount of crafts that were made during the time the researcher was there, could have easily been enough for an Arts and Craft Show Cancer Charity Event. Even children receiving chemotherapy or some type of blood product per intravenous who were well enough would be gathered around the tables making crafts. Those not feeling well enough, would lie on the one of the two couches that were situated near the tables. When children needed to lie down on the couches, there was even fewer spaces for parents and others to sit. However, no one ever hesitated to give up their seat for a ill child. The children themselves would still try to be part of the circle of other children just by watching them make crafts or play games. Sometimes too, some other individual be it a child or parent or sibling, would under the careful instructions of the ill child, make a craft for them.

When children were feeling "really sick" they would often go to lie down in the chemotherapy room. In contrast to the waiting room, the chemotherapy room was not viewed as a "fun" place by the children or families. However, it provided a much needed quieter environment both for the children and families. In fact, it was often the children who wanted to stay in this room when they felt "really sick" (refer to Chapter V for

definition). At the entrance of the chemotherapy room was the nurses' or admitting desk. This desk, although small, served as a look-out tower for all patients entering and leaving. As well, it provided a place to observe patients within the room. Regardless of how busy the area got, there was always someone behind the desk, be it the unit clerk or a nurse. The chemotherapy room was where most of the chemotherapy was initiated. It was about the size of two waiting rooms. The room was encircled by chairs and couches with the middle of the room being clear of objects. Because of the openness of the room, the researcher did not feel as comfortable as her presence seemed more obvious; it required the researcher to be even more discrete.

The chemotherapy room also brought the adult patients in closer proximity to the children. At times both the children and adults avoided each other, other times, they interacted with each other, and families of adult patients became part of the children's community where long-term relationships were established. As was the case with the waiting rooms, parents would share stories with other parents as well as sometimes with the adult patients. Not surprisingly, the adult patients as well as the nurses for the most part gave the impression that the children's suffering was more legitimate, and more justified. Therefore, the children were treated in a more careful manner. Although the atmosphere of chemotherapy room was less child-centred, staff nonetheless tried hard to treat the children like *"kids"* by just how they spoke to them. They were genuinely interested in the kids' life outside the clinic and would always ask them about things that were important to them such as school. And as always, the clinic's clown would always make a trip to the chemotherapy room to entertain any children.

Three smaller treatment rooms were also situated in the chemotherapy room near the nurses' desk. These rooms were for those patients who felt *"yucky"* (refer to Chapter V for definition). The rooms although really small, nonetheless served the purpose of being even quieter places to rest. Often when the researcher attended clinic, the first treatment room would be occupied by one of the children. The first room was more suited for the children because it not only had its own television attached to the wall, but also had a lounger chair where younger children could cuddle with a parent while lying on a parent's lap or where older children could rest. It was not uncommon to see the lights off in this room as well as in the other two treatment rooms.

Although the three treatment rooms in the chemotherapy room functioned as resting areas, they also had two additional functions. First, in addition to the examination rooms, it was in these three rooms where *"bad news"* was delivered. Secondly, the treatment rooms were used to put intravenous needles into children who had difficult veins. Accordingly, it was not uncommon to hear cries coming from these rooms even with the doors closed. The cries could be from the parents receiving bad news or from the children getting the intravenous started. So while these rooms served as a restful quiet comforting area, they could also be a place of discomfort and pain depending on the context. One of the problems with "closeness" of the clinic's environment was that the children's responses to painful procedures were often impossible to be kept away from the other children and families. As well, other families would often be well aware of when families received bad news because of them entering one of these three rooms with a physician.

Considering the size of the clinic and the sensitive nature of the talk that could occur during clinic visits, there was little privacy for families to grieve about specific losses or to discuss personal family issues. Yet families continued to tell their stories. More importantly those families not involved in a particular family's exchange or interaction would assume a physical presence that tried to support or protect the privacy of the grieving or upset family. This ranged from getting involved in some activity with their own children to going to coffee with another family. At times it also involved them becoming part of the family's interaction when it was evident that the family needed the help. The intuition and sense of knowing how other children and families were feeling and managing was remarkable in all families attending the clinic. In interaction with the families, it became evident to the researcher that they were in fact excellent field researchers. The families, including the children of all ages, had observational skills that any research team would envy. Each child and adult could clearly identify the "*new*" family, the family with the dying child, the sick child, the returning family, and so on. Gaining a sense of the depth of the families' understanding about other families was truly evident in the field notes and unfortunately is beyond the scope of discussion in this research report.

Overall the outpatient clinic was more than a treatment area to children and their families. It was the common ground or meeting place where children and families could get to know one another, learn from each other, and tell their stories to others who "*truly understood!*" In spite of or because of its size, some families felt that the physical closeness of the environment to some extent facilitated social contact and helped families

feel closer with each other. The outpatient clinic, like the inpatient unit, was a home to them where they could see members of their newly extended family and provide support for them. The outpatient clinic was especially important to families as not all were involved in formal cancer support groups, nor did hospitalization always allow families to connect with one another. The type of support that families could get from each other during the outpatient clinic visits was deemed important by the families:

> *Mother: I think it (making the most of life) is something you can learn. We noticed too in the waiting room if there is a majority of us who have that attitude, it can be contagious, then we can influence each other. Where if you come into an environment where there is a bunch of negative vibes...And we do influence each other in that area!*

> *Mother: You hear nightmares like you know the first week, I just heard nightmares (in the outpatient clinic), everybody's got a story, and we didn't want to hear that, we needed something positive to hear, and we weren't hearing anything positive.*

The importance of the clinic with respect to support was reinforced by families whose children's clinic appointments became fewer and fewer such as when treatment was completed. For these families they had less of a chance seeing the "*regulars*" or other families who became part of their circle of friends. Moreover, as the children moved further and further away from treatment and the "*regulars*" moved on, families often felt less and less like a "*community*" or one "*big extended family*" and more like strangers. It was often difficult for them to sit and wait in clinic when none of their friends were in attendance. Parents and children would sometimes express that "*things were not the same*" which truly reinforces it was the people and not the structure of the clinic that made the place.

In spite of the many negatives of the clinic including its busy atmosphere, lack of privacy, and the painful cries of the children, a sense of caring was felt throughout the clinic. Interestingly families even years after treatment would return to the annual Christmas party. Their return reinforced the love they had for the people they met at the clinic. Although expressed in different ways, all children and families shared the sentiment that as bad as cancer was, there were always the new friends, families, and staff that made cancer bearable, even good at times.

Lastly, although the many hours of fieldwork in the clinic was at times stressful for the researcher, it nonetheless proved to be invaluable to understanding the children's and families' cancer-symptom experiences.

(2) Inpatient Unit of Children's Hospital

The inpatient unit provided services for all hospitalized children diagnosed with cancer. It was the only inpatient pediatric cancer unit of the university-affiliated Children's Hospital. Usually only children requiring cancer care were to be admitted to this unit. Exceptions included: (1) children who had had a bone marrow transplant necessitating admittance to the Bone Marrow Transplant unit; (2) children who were extremely ill necessitating admittance to the Children's Hospital pediatric intensive care unit; and (3) children who had surgery necessitating admittance to one of Children's Hospital pediatric surgical units. However, once the children who were critically ill or required surgery became stable, they then would be transferred to the pediatric oncology inpatient unit. This was because the nurses and physicians who worked on the inpatient pediatric oncology knew the children and their families and were experts in pediatric

oncology care. The care that the children received included care related to diagnosing cancer, receiving chemotherapy or radiotherapy, treating complications such as infections, symptom and palliative management, and caring for the dying child. Because the children's immunity was often compromised, many of the children admitted to this unit would have to be isolated to their rooms. Depending on the reason for hospitalization, hospital stays varied from children requiring only 24 to 48 hours of hospitalization to children staying months on the unit.

The design of the unit itself, was based on a U-shaped configuration with the patients' rooms situated outside all along the "U." The patients' rooms either had single- or double-bed occupancy. The treatment, conference, and supply rooms were located inside the "U." The nurses's desk was located at the bend of the U-shape. Significant to this was that generally the children considered the "sickest" were admitted to the rooms closest to and facing the nurses' desk where they could be more closely supervised. In fact there were a couple of rooms located near the desk that children and families had labeled as the *"dying room"* because it was in these two rooms where they observed most of the children dying. Even children as young of four years of age knew about these rooms because some of their "new" friends had died in these rooms.

Just as children and families knew which children were the *"sickest"* or dying because of the room they were admitted to, they also knew when families were going to be told bad news because of the room in which families would enter into with the pediatric oncology team. This room, designated by some families as the *"bad news room,"* was located near the end of the hallway. It had a couch, a couple of lounger

chairs, and some coffee tables to make the atmosphere more comfortable in nature. There was also a blind on the large glass window of the door that helped to ensure the family's privacy. A "do not disturb" sign would also be put up when meetings with families and the health team took place here. All the families had been in this room at least once during their children's cancer diagnosis. Although the reasons for going into the room varied from receiving the news of their children's diagnosis, to being told that their children's treatment was not working and so on, they all remembered how it felt entering and leaving the room, and hence could sense what other families were experiencing when they entered the room. They all including the younger children knew "the look" of despair on the families' faces.

Although many of the children were on isolation and therefore, could not make use of the unit's playroom or the hospital's child-centred activities, staff including the nurses and child life therapist would try to make the children's stay on the ward as friendly and child-centred as was possible. For the children requiring lengthier hospital stay, staff would try to ensure that the children had enough child-friendly and developmentally appropriate objects in their rooms such as toys, books, or crafts. Each room had a television. The unit also had a couple of portable video players for movies or video games that the children would take turns sharing. Staff would do special things for the children such as hang up pictures that represented something significant to the children or bring in a couch to their rooms so that the children's parents could rest on and cuddle with their children. Birthdays and holidays were never forgotten by staff. On a daily basis, someone from the Children's Hospital main playroom would come up to see

the children to see if the children needed any special toys or had any messages to announce on the hospital's daily afternoon television show. The hospital clown who followed them at the outpatient unit would also come up to see the children who were isolated. If the children felt well enough, the hospital school teacher would come up daily and work with the child in his or her homework. A computer was also available for children to work on. Some of the children also were given a desk to work on. The children and families themselves also would bring specific personal belongings from home that helped them to feel more at home, more like a "normal" environment.

Like the outpatient clinic in MCTRF, the inpatient unit served as a form of support for children and their families. It was another place where the *"new family"* or *"second family"* could be there for the other families. Unit staff too was a part of this extended family. Relationships that developed between families and staff were often very deep and close. Although for some this unit may have been the only place where they interacted with each other, strong bonds nonetheless developed. In fact some families found that the bonds they established with some of the staff and other families were stronger than the bonds that they had with their own blood relatives. This would make sense considering it was on this unit where families and staff were witnessed to and experienced the real highs and lows of life. It was on this unit where children could be at worst point of the cancer-symptom trajectory in that they were extremely ill with increased symptom distress. It was also on this unit where some of the children with cancer would spend their final days. Yet this unit also represented a sign of hope and life because families were witnessed to or experienced recoveries that were sometimes

described as "*miracles*." Again like the outpatient unit, it was the families and staff that made the unit home to the children and their families. Although the physical surroundings were valued, the relationships provided the true comfort that children and their families needed.

(3) Participants' Homes

During the course of the study, the researcher was privileged to be invited into the homes of the families participating in the study. For many of the families, especially the families studied longitudinally, the researcher had made at least four visits to each home. It was during such times that the formal interviews would take place. However, the home visits also allowed the researcher to see how families interacted as a family unit away from the "official" treatment areas. How children and families interacted and functioned all depended on the degree of symptom distress experienced by the children. For instance when the children were feeling really well, almost free of all symptom distress, they would have so much more energy and would be so much more animated and talkative. It was during such times too that family members would focus less on the ill children and would not be as "careful" around them. In contrast when the children were feeling "*really sick*", the home became more like a hospital unit in which the focus of the family was providing medical and nursing care to the child. It was during such times that one area of the home would be designated as the "sick area" where children would spend most of their time with their mothers. The family functioned less as a complete unit and more as dyads such as the mother-child dyad, the sibling dyad, or the father-healthy children dyad.

The visits also provided the families a chance to show the researcher what they

were like as a family; that is, they wanted the researcher to see a different side to them. Quite often this meant showing the researcher family pictures of significant events in their lives or personal objects that they valued. It was also a chance to meet the family pet. Most interviews with the parents took place around the kitchen table over a pot of coffee, whereas most of the children preferred to be interviewed in their own bedrooms. The children especially took a lot of pleasure in showing the researcher their bedrooms because their bedrooms and the personal belongings in the rooms reinforced who the children were or reinforced that they had a life other than one which was focused on cancer. Prior to and after each interview the families would first take time to share events in their lives that were not necessarily cancer-related. Again it was their way to share a part of their lives that were not cancer-related; it was a way to feel like a "normal" family.

Participants

This section delineates the sampling selection process and the sample criteria used to access potential participants. A description of the children and families who participated in this study is provided in Chapter IV.

(1) Sampling Selection Process

Children diagnosed with cancer and their families (parents and siblings) were the primary participants for this study. Approaching children's cancer-symptom experiences from a family perspective instead of an individual perspective (e.g., the child with cancer or the parent) was deemed necessary not only because the family is integral to the expression of symptoms by children (Woodgate & Kristjanson, 1996a), but because the

effects of illness on families and individual family members are not simply unidimensional or linear, but multifaceted and reciprocal, impacting the total family unit (Wright & Leahey, 2000). Approaching the family unit as opposed to the individual unit was in keeping with the study's theoretical framework of interpretive interactionism.

Children's physicians, nurses, social workers, child life therapists, physiotherapists, occupational therapists, x-ray and laboratory technicians, radiology technicians, nursing aides, unit clerks, and volunteer support workers were also part of the study's sample. Sampling of these individuals was important because how they responded to the children and families had an effect on children's and families' responses to cancer-symptom experiences. Professionals' and para-professionals' input served to expand on the children's cancer-symptom experiences and provide for richer, detailed data. However, the sampling selection process was determined by the type of children and families participating in the study and not the professionals or para-professionals.

Child and family participants were selected using the grounded theory method of theoretical purposeful sampling. Whereas the power of statistical sampling depends on selecting a truly random sample which will permit generalization, the power of purposeful sampling lies in selecting information-rich cases for study in depth (Patton, 1990; Sandelowski, 1995). The concern in this study was with the representativeness of emerging concepts, themes, and ideas and not with the representativeness of the sample. This method helped to optimize the probability of describing the full range of the phenomenon (Field & Morse, 1985; Strauss & Corbin, 1990, 1994) and maximized the

researcher's ability to identify emerging themes that took adequate account of contextual conditions and cultural norms that helped lead to theoretical saturation of children's cancer-symptom experiences (Patton, 1990). Further discussion of theoretical saturation is provided in the Data Analysis section of this Chapter.

In order to capture core experiences that cut across participant variation (Patton, 1990), the researcher endeavoured to obtain a sample that varied with respect to child-related characteristics such as age and gender. As well, phenomenal variation of the children's cancer-symptom experiences was sought. Because it was recognized that symptoms would vary depending on the type of cancer as well as the illness trajectory stage, children with different cancer diagnoses and who were at different stages or time frames of their cancer trajectories (e.g., newly diagnosed, active treatment, remission, relapse, palliative) were sampled. Examining the complete illness trajectory was warranted considering that various dimensions of illness (onset, course, outcome, and degree of incapacitation) are assumed to affect the family differentially (Rolland, 1984, 1987).

In accessing child and family participants, the pediatric oncology nurse clinician of Children's Hospital was designated as the intermediary between the researcher and participants. In addition to other responsibilities, the nurse clinician acts as a liaison between the outpatient pediatric oncology unit of MCTRF and the inpatient pediatric oncology unit of Children's Hospital. Therefore, this individual was considered appropriate in the role of intermediary. The nurse clinician was responsible for approaching potential participants (i.e., parents), and asking for their permission to allow

their names to be released to the researcher. To allow for consistency and to prevent overburdening the nurse clinician, a short script was prepared that she referred to when accessing participants (refer to Appendix A).

(2) Sample Criteria

Specific inclusion criteria of child and family participants for entrance into the study were as follows:

Children with cancer:

(i) who were between five years to 18 years of age;

(ii) who understood and spoke English;

(iii) who had verbal and written consent provided by their legal guardian;

(iv) who had parents fitting the criteria for inclusion in the study;

(v) who had cancer (no specific type/stage of cancer was specified);

(vi) who were at least two months post-diagnosis in order to allow time for families to adjust to the child's diagnosis and prevent any undue stress; and

(vi) who voluntarily gave their assent.

Families - Parents:

(i) who understood and spoke English; and

(ii) who voluntarily gave their verbal and written consent.

Families - Siblings:

(i) who were five years or older;

(ii) who understood and spoke English;

(iii) who had verbal and written consent provided by their legal guardian; and

(iv) who voluntarily gave their assent.

Specific inclusion criteria of professionals, para-professionals, and volunteers for entrance into the study were as follows:

(i) who were professionals, para-professionals or volunteers in the designated study areas (i.e., cancer clinic or inpatient unit) assuming responsibility for some aspect of the children's care; and

(ii) who voluntarily gave their verbal consent.

Data Collection Methods

In support of the study's framework and overall purpose, during data collection the researcher attended to capturing: (1) the intersubjective nature of human behavior; (2) the viewpoints of those whose worlds they purport to examine; (3) the interpretations or meanings that people attach to themselves, other people, and other objects of their experiences; (4) the ways in which people do things on both a solitary and interactive basis; (5) the attempts that people make to influence others; (6) the bonds that people develop with others over time and the ways in which they attend to these relationships; and (7) the processes, natural histories or sequences of encounters, exchanges, and events that people develop an experience over time (Prus, 1996). In addition to theoretical sampling with concurrent data collection and analysis, theoretical saturation or completeness was achieved by triangulating data collection methods. Data collection methods involved:

(1a) <u>Open-ended Interviews</u>

In order to arrive at an understanding of how children and their families

experienced the symptom-cancer trajectory, open-ended interviews were planned. The interviews allowed the researcher to discover the meanings child and family participants assigned to the symptom experiences. Whereas the "why" question is the focus in logical positivism and scientific sociology, in interpretive research (nonpositivistic) "how" social experience is organized, perceived, and constructed by interacting individuals is the concern (Denzin, 1989). The traditional interview-respondent situation is transformed into a sharing, conversational interaction; sharing of experiences helps to create trust (Denzin, 1989). The qualitative open-ended interview may be used as a vehicle to develop a conversational relation with a interviewee about the meaning of experience (van Manen, 1990). A true conversation emerges when a certain topic of mutual interest develops and those involved become, in a sense, aroused by the notion to which they are now both oriented (van Manen, 1990). The interviewee becomes the co-investigator of the study (van Manen, 1990). In interviewing, it is also important that the researcher stay close to experience as lived (van Manen, 1990).

All children and their families (parents and siblings) were given the opportunity to participate in open-ended interviews. Except for certain family members from 13 families, all family members meeting the sample criteria of the 39 families participating in the study took part in the formal interviews. Where the whole family unit had not participated in formal interviews the following reasons were provided: (1) fathers were not available due to employment commitments (n=5); (2) siblings were not available due either to a lack of time, logistics, or because they did not want to be interviewed (n=5); and (3) children were not available due either to being too ill or because their parents did

not want their children to be interviewed as they felt it would cause them too much stress (n=3). During the course of the study a total of 230 open-ended interviews were conducted. The adults' interviews lasted anywhere from 40 to 180 minutes. The children's interviews lasted from 20 to 120 minutes with the younger children usually participating in shorter interviews. The majority of interviews involved the 15 families who were followed longitudinally. Multiple interviews were planned as it allowed the researcher to follow-up on significant themes, validate the researcher's interpretations, and assess how perceptions change over time.

Family members took it upon themselves to decide whether they wanted to be interviewed individually or with some other family member(s). Some parents preferred and requested to be interviewed together and some of the parents requested that they be present while their ill children were being interviewed. As well, some siblings preferred to be interviewed with their other siblings. In such instances where family members requested to be interviewed together, the researcher honored their request. When joint interviews occurred, the researcher tried to ensure that all members involved were given the opportunity to voice their views and perspectives. While joint interviews had the disadvantage of participants potentially hiding certain information, joint interviewing provided the researcher with the opportunity to observe how participants interacted and responded to each other. Discovering and understanding relational possibilities and mutually created meaning is a strength of joint interviewing (Morris, 2001).

The total number of times that mothers were interviewed was 117, for fathers it was 46, for siblings it was 48, and for the children it was 103 interviews. Despite the

researcher's attempt to have more fathers and siblings involved in interviews, they were reluctant to be part of the process. Interestingly the fathers felt that they would not be able to contribute too much to the study because they did not provide a lot of the children's direct care. Siblings sometimes did not participate because they found the whole experience to difficult to share. Their sadness was most evident. The smaller number of interviews that fathers and siblings participated in was also reflective of the finding that both fathers and siblings felt more like outsiders during the child's illness. Fortunately, having additional methods of data collection, especially participant observation and informal interviewing aided the researcher in capturing the responses and perspectives of the fathers and siblings.

All open-ended interviews began with a grand tour question. Additionally, an interview guide with a list of potential questions based on key themes identified from the literature and from the researcher's experience in caring for ill children was used (refer to Appendix B, C, D). The guide was patterned after Charmaz' (1990) grounded theory interview question format and includes four basic types of questions: informational (e.g., "What types of symptoms does your child have?"); reflective (e.g., "What has it been like since your child became ill?"); feeling (e.g., "How did that make you feel?"); and lastly ending questions or questions devised to end the interview on a positive note (e.g., "If you could have three wishes, what would you wish for?"). The questions served as probes to enhance or extend information as well as to keep the interviews focused on the topic (Field & Morse, 1985). Additional probes used included: the use of silence; "pumps" (e.g., sounds such as "uh-huh" or "um"); calls for examples, calls for reactions to the

researcher's reformulations of what was said; and simple questions to facilitate conversation (Lincoln & Guba, 1985). Open-ended questions that encouraged narrativization was encouraged. For instance instead of asking "when did X happen?," which asks for a distinct piece of data, the question "tell me what happened?" which asks for more detailed information (Riessman, 1993), was asked.

Although an interview guide had been developed, the open-ended technique allowed the researcher to focus participants' responses into areas previously not anticipated or areas deemed significant by the participants (Field & Morse, 1985). The objective here was to elicit from participants what they felt was significant. Questions asked in subsequent follow-up interviews were based on emerging categories and themes identified in the first set of interviews. The emerging analysis directed subsequent questions asked. In keeping with the qualitative interview, both the researcher (interviewer) and interviewee tried to interpret the significance of preliminary themes in follow-up conversations (van Manen, 1990).

Additionally the goal of research interviewing was to maintain enough flexibility to elicit individual stories that may vary a great deal, while gathering information with enough consistency to allow for comparison between and among participants (May, 1991). Open-ended interviewing assumes that meanings, understandings, and interpretations cannot and should not be standardized (Denzin, 1989). The phrasing of the questions and the order in which they are asked varied for each individual. Variation in the type of questions asked for each participant is not considered to be an "error" but, instead is considered endemic and unavoidable (Mishler, 1986). The intent was to avoid

the standard approach (i.e., structured, survey interview format) which is behavioral and antilinguistic, relies on the stimulus-response model, and decontextualizes the meaning of responses (Mishler, 1986). Instead, the interview was unstructured in recognition that an interview is a joint product of what interviewees and interviewer talk about together and how they talk with each other. As Mishler (1986) noted, an interview is a form of discourse in which analysis and interpretation are based on a theory of discourse and meaning. Each participant brought with them different perspectives and circumstance, just as the researcher did to each research-participant relationship, hence the reason for variation in questions.

Interviewing took place in participants' homes or in a quiet, private area in MCTRF or Children's Hospital. The choice of setting was determined by the participants based on what they felt most comfortable with; this helped to assist in the development of rapport and trust between the researcher and participants. All interviews were tape recorded in order to preserve their authenticity and to facilitate a detailed narrative analysis. Field notes were made during the interviews which included describing the nonverbal behaviors of the participants (e.g., participants' responses to the researcher) and the context in which the interviews took place. Notes were recorded briefly during the interview process, and expanded on after the interviews.

(1b) **Strategies for Child Participant Interviews**

Recognizing that basic developmental processes shape one's capacity to respond in an interview setting, additional strategies were undertaken with child participants to facilitate them in expressing their thoughts. Most important was the building and

maintaining of a trusting relationship between the researcher and the children. Establishing trusting relationships take time, therefore, with each new family the researcher would let the children get to know the researcher before commencing any interviews. Once the researcher felt that the children trusted her, she then commenced with the interviews. During the interviews, creating the right psychological climate was critical and therefore, the following strategies recommended by Ross and Ross (1984) were undertaken: (1) ensuring that the child was aware that he or she could stop the interview at any point; (2) ensuring that the child did not feel that the interview process was a test; (3) allowing the child as much time as they desired in responding to questions; (4) ensuring there were no feelings of disapproval on the part of the researcher; (5) handling silences carefully; and (6) not placing demands on the child to respond in a certain way. One of the outcomes of the child interviews was to ensure that the children came out of the research experience feeling reasonably pleased with themselves and with enhanced self-esteem. To that end, the researcher tried to ensure that children viewed their participation positively throughout the research process.

Tammivaara and Enright (1986) also stressed that in establishing rapport with child informants, researchers must monitor the assumptions they intentionally or unintentionally embed in the informants' answers, just as they must monitor the assumptions they intentionally or unintentionally embed in the researcher's ethnographic questions. To ensure that all the power and authority during the interviews were not held by the adult researcher the following strategies recommendations by Tammivaara and Enright (1986) were used by the researcher: avoidance of directing the child's behavior;

not doing all of the initiating within the interview; playing dumb; using projective techniques; alternating interview settings; and respecting children's own knowledge. Refer to Table 1 in Appendix E for a summary of strategies that the researcher considered. Although the researcher had a list of strategies, she also found that in interacting with the children, each situation was unique. Accordingly, adaptability to the characteristics of each child and situation was essential.

(2) Participant Observation

Participant observation as a data collection method is believed to afford the researcher the opportunity to get closer to the lived experiences of participants. By putting the researcher in close, sustained contact with others, the researcher can gain insight into their viewpoints and practices through ongoing commentary and other interactions at valuable vantage points (Prus, 1996). In order to appreciate certain aspects of the children's and families' cancer-symptom experiences, the data collection method of participant observation was another major method used in this study. Because symptoms are often manifested in spontaneous behaviors (Garbarino & Stott, 1990), observation was a method well suited for this study. The goal of participant observation was to capture a thorough understanding of participants' behaviors in response to the symptoms (e.g., symptom expression, care practices, coping responses). As well, it served to provide insights as to what affect interpersonal relationships had on the children's symptom experiences.

The researcher assumed the role of moderate participation. With this type of participation, the researcher sought to maintain a balance between participation and

observation, while trying to remain fairly unobtrusive or nondisruptive in a particular setting. In comparison to pure observation, participant-observation involves a more active and interactive and ambiguous role as the researcher tries to fit into the setting (Prus, 1996). It involved, as van Manen (1990) noted, assuming a relationship that is close as possible while retaining an alertness to events that allows the researcher to constantly step back and reflect on the meaning of those situations. Close observation requires that one be an observer and participant at the same time, and maintain a certain orientation of reflectivity while avoiding a more artificial attitude that a reflective attitude tends to infuse itself in social situations (van Manen, 1990).

Throughout the study, participant observation as a method was undertaken during various periods, sites, and during different points in time in order to maximize differences (e.g., clinic, home environment, hospital, interview periods). Observation sampling focused on the responses of and interactions between children and their families, and when appropriate, health professionals. The researcher carried out approximately 960 hours in her role as a participant observer in the outpatient clinic. Time spent in the outpatient clinic involved two 6 hour days per week for a period of approximately 20 months or 80 weeks. Additionally the researcher acted as a participant observer when the children were hospitalized. Although the exact hours for the time spent observing children during any hospital stay were not calculated, the researcher observed anywhere from one to five hospitalizations for each of the children followed longitudinally. During each hospital day, the researcher observed the children daily or every second day that the children were hospitalized. Each observation day lasted anywhere from two to five hours.

To assist in getting a complete picture, the researcher asked questions similar to Spradley's (1980) descriptive matrix which focuses on questions based on nine major dimensions of every social situation: space, object, act, activity, event, time, actor, goal, and feeling. Observations were unstructured in order to permit flexible exploration. All data pertaining to the observations were recorded in the form of unstructured field notes. Recording took place during breaks in-between observation periods and were further expanded on at the end of each data collection day. A total of 1500 double-spaced typed pages with one inch margins to all sides, tops, and bottoms of the pages were recorded in response to the researcher's time spent in the outpatient and inpatient units. These field notes did not include notes specific to observations made in the children's homes. Notes specific to observations made in the children's homes were attached to the interview notes.

Acknowledging that being a participant observer in the child's world could pose difficulties, certain strategies were employed to lessen potential problems. This included the researcher trying to bracket assumptions related to adult superiority in order to increase the possibility of entering children's worlds as an active, fully participating member (Mandell, 1988). In order to minimize the social distance between the adult researcher and child participants it was important for the researcher to view the child participants simply as social members. Child participants were considered to be equal participants in the research process and were allowed to make decisions related to the research study (e.g., when and where observation should take place). Differences between the adult researcher and the child participant were also reduced by gradual and "reactive"

field entry strategies in which the researcher displayed a much more muted, passive role and ambiguous status (Siegert, 1986). In order to be accepted by the children, the researcher entered their world according to the role they prescribed. The researcher tried to be as non-threatening as was possible or to reduce any potential threat within reasonable limits. Threat in this instance as conceptualized by Lofland and Lofland (1995) referred to threats to beliefs, self-confidence, and existing social arrangements by means of argument, ridicule, sarcasm, disinterest and so on. Fortunately both the children and parents of every family became very comfortable early on with the researcher's presence. They continued on in their interactions with each other without feeling or acting "on guard" because of the researcher's presence.

The method of participant observation proved to be a very valuable means to collect data about the cancer-symptom experiences especially when the younger children were the focus. This may have been related to the fact that younger children communicate through their behavior even more powerfully than through their words (Garbarino & Stott, 1990).

(3) Informal Interviews

As part of the participant observation experience, informal interviewing took place and involved asking questions during the course of the ongoing fieldwork (Spradley, 1980). Children, families, and health professionals were questioned informally during periods of participant observation. Questions flowed from the immediate context and helped to verify what meanings the participants themselves assigned to their situations (Patton, 1990). Again the informal interviewing proved to be invaluable not

only for gaining an understanding of the children's perspectives but also the adults' perspectives.

(4) Rating Scale

To measure the intensity of the children's symptoms, a visual analogue scale (i.e., VAS) was originally planned to be used during the formal interviews and when appropriate, during periods of participant observation (refer to Appendix F). The VAS is 10-cm line with two endpoints. Anchored at the ends are the words "no _____ (symptom)" and "as bad as it can be _____(symptom)." The VAS has shown to be a practical, sensitive, reliable, and valid tool in measuring dyspnea in children with asthma (Carrieri, Kieckhefer, Janson-Bjerklie, & Souza, 1991) and post-operative pain in school-age children five years and older (Dahlquist, 1990; Ross & Ross, 1988). The VAS is considered useful for children with limited language skills and the unsegmented response continuum allows the child to rate his or her symptoms within the context of the maximum number of points that the child can discriminate (Ross & Ross, 1988).

Information obtained from the children's ratings were meant to increase an understanding of the children's experiences. However, as discussed in the findings, children early on in the study became very frustrated using the rating scale as to them the ratings could not sufficiently reflect how they were feeling. They could not see the point of using the scale and in fact, lost interest. Even using variations of the VAS such as asking the children on a scale of one to ten (with ten being as bad as the symptom could be) to rate their symptoms or use of the Wong-Baker Faces self-report graphic scale (Wong & Baker, 1988), did not make a difference in the children's use of the scale. In

fact, some of the children became "turned off" when being asked to rate their symptoms and would affect the quality of the interactions with the researcher during that specific time period when they were asked. Accordingly, use of the scale was dispensed with early on in the study.

(5) Focus Groups

Once the majority of the individual interviews had been completed with the children and siblings, audiotaped focus group interviews were conducted by the researcher. Three interviews were arranged and involved one group of five adolescent males with cancer, another group of four adolescent females with cancer, and lastly one group of three adolescent female siblings. Although the goal was to conduct numerous group interviews that would account for the varied age range of the children and siblings in the study, this did not occur due to difficulties in scheduling the interviews. Nonetheless, the three group interviews added to an understanding of the children's perspectives. Questions originating from the individual interviews as well as questions developed that were based on emerging themes from the data analysis, were used to guide the focus groups. The purposes of the focus groups were: (1) to provide instances of interchange between contrasting perspectives; and (2) to provide some quality controls on data collection (Berg, 1998; Hoppe, Wells, Morrison, Gillmore, & Wilsdon, 1995; Lofland & Lofland, 1995; Patton, 1990). Groups helped to validate the researcher's data analysis, and to ensure that the emerging categories remained closely linked to the data. Focus groups are especially useful for studies of complex issues involving many levels of feelings and experience (Carey, 1994; Hoppe et al., 1995). They provide access to both

actual and existentially meaningful interactional experiences (Berg, 1998). Focus groups interviews are especially considered valuable source of qualitative interview data with school-age and adolescent children (Deatrick & Faux, 1989) (refer to Appendix G for focus group strategies).

(6) Reflexive Journal

A reflexive journal was maintained by the researcher. This provided the opportunity for reflection of the researcher's values, assumptions, feelings, and thoughts as well as information about present methodological decisions (Lincoln & Guba, 1985). The journal helped to keep the researcher focused on addressing the research goals by challenging the researcher to consider what changes or follow-ups needed to be made during the course of the study in order to arrive at an accurate representation of the children's and family's experiences. It also provided a means of debriefing for the researcher, and a way to deal with any experiences that she found stressful.

(7) Demographics

Demographic profiles of all child and family participants were prepared to further add to the description of participants. Information was gathered mainly from the parents and children (refer to Appendix H), although in some instances the researcher needed to get some of the information from the children's medical charts. Because professionals and para-professionals were not the focus of the study, demographics were deemed not necessary for them.

Research Procedure

The researcher first obtained written permission to conduct the study from the: (1) Ethical Review Committee, Faculty of Nursing at the University of Manitoba; and (2) Access Committee of Children's Hospital. Written permission from MCTRF was also obtained to access the children's medical charts (refer to Appendix I for letters of permission). Verbal permission to access the outpatient pediatric oncology clinic of MCTRF and the inpatient pediatric oncology unit from the head nurses and physicians responsible for the care in those areas, and from the Director of Patient Services at Children's Hospital and the Director of Nursing at MCTRF was also obtained.

Once permission was obtained from the appropriate personnel, potential child and family participants who were presently receiving treatment for cancer at the outpatient oncology unit of MCTRF or the inpatient unit of Children's Hospital were recruited with assistance from the designated nurse intermediary, the pediatric oncology nurse clinician. The nurse clinician would first phone potential participants (parents) to get their permission to release their names to the researcher. After getting their permission, the researcher phoned the parents to explain the study to them (refer to Appendix J). If the parents agree to participate, a written consent was provided for them to sign upon meeting them in person (refer to Appendix K). Next, at a time deemed appropriate by the parents, the researcher then explained the study to their children in terms that they could understand (refer to Appendix L). For children to participate in the study, the researcher also had to obtain their agreement or their assent. Assent is associated with one understanding the procedures and general purpose of the research as well as having the

desire to participate (Rae & Fournier, 1986). Obtaining a child's assent is deemed to be necessary for all pediatric psychosocial research. The possibility of discovering a breakthrough in psychosocial care must be overridden by maintaining the psychosocial integrity of the child (Macklin, 1992; Miller, 1993; Rae & Fournier, 1986; Weithorn & Scherer, 1994). For assent, children needed only to have a elementary understanding of what they would be required to do, have a basic comprehension of the purpose of the research, and be capable of expressing a preference regarding participation in that research (Rae & Fournier, 1986). This is in contrast to consent in which one has to have the sophisticated abstract evaluating capability and an understanding of the conditions surrounding the research (Rae & Fournier, 1986). Assent forms were provided for those children who wanted to participate in the study (refer to Appendix M). The study was also explained to the siblings (refer to Appendix N), and assent forms were prepared to the siblings (refer to Appendix O). With respect to health and other professionals as well as para-professionals, the researcher had arranged numerous meetings for them to explain the study and to answer any questions prior to commencing the study. During explanation of the study, their verbal consent to participate in the study was obtained. Explanation sheets of the study with disclaimers were also available in each of the study's settings (refer to Appendix P).

Once parents, children, and siblings agreed to participate, the researcher focused on establishing rapport with them. Plans for the first interviews with parents, children, and siblings were arranged based on the family's choice and time frame. The initial interviews allowed the researcher to get a beginning understanding of participants'

thoughts and feelings. This understanding helped to guide the researcher through the complete research process. Observation periods were then planned with input from children and families. Subsequent formal interviews and ongoing observation periods were arranged based on the emerging categories derived from ongoing data analysis, and as deemed necessary by the children and families. Throughout data collection, the researcher emphasized to all participants that they could withdraw at anytime from the research study.

Important throughout this qualitative research project was acknowledging that the study should not be viewed in a static fashion. It was critical that the researcher was ready to change lines of action and methods and reconceptualize problems as the themes began to emerge. Qualitative researchers must constantly assess their methods, assess the quality of incoming data, and note the relevance of data to theory (Denzin, 1978).

Data Analysis

Data analysis involved the following two forms of interpretive work: (1) applying the grounded theory method of constant comparative analysis to identify the basic psychosocial phenomenon and process related to children's and their families' experiences with childhood cancer-symptoms; and (2) semantic and hermeneutic analyses to depict illness narratives. From this analysis, two substantive theories emerged that were grounded in a meaning-centred approach.

(1) Constant Comparative Analysis

The grounded theory method of constant comparative analysis is a research method developed by sociologists Barney Glaser and Anselm Strauss for the purpose of

studying social phenomena from the perspective of symbolic interactionism (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1994). The goal of this method is to describe the meaning of the basic psychosocial process of a particular phenomenon that exists within individuals or groups in order to arrive at explanatory models or theories of human behaviors or processes that are derived inductively (Morse & Field, 1995; Strauss & Corbin, 1990). Analysis occurs ongoing with data collection and is based on the recognition that making comparisons within the data is critical to theory development (Glaser & Strauss, 1967). Making comparisons involved the researcher moving back and forth among data sets to discover patterns or categories and to determine the absence, variation, or presence of categories (Hutchinsin, 1986); comparing and contrasting emerging categories with other categories from each participant and between participants was undertaken. Critical to making comparisons of emerging categories, was the ongoing process of coding or giving meaning to all units of information. The process of coding as defined by Strauss and Corbin (1990) involved: (i) open coding in which data was broken down and then categorized in terms of its properties and dimensions; (ii) axial coding in which connections were made between categories and subcategories; and (iii) selective coding in which the relationship of the core categories of the basic psychosocial phenomenon and process were clarified with all the emerging categories related to the core categories. Asking questions and make memos related to code notes and data comparisons was part of the process of coding. Depending on the evolving findings, codes were revised and previously coded data was re-coded. The children's own words were used when possible in labeling the major categories, especially in relation to the

meanings children assigned to the symptom experiences (refer to Chapter V). Relying on the children's own words was supported by the researcher so that those reading this study could not only discover what was important to the children but also really hear how the children spoke. It was a chance to give children a voice as for too long the experiences of children have been represented by the adult voice. The researcher wanted to provide the reader with the opportunity to get as close as possible to the children's experiences. Although in its infancy, reliance on children's own words and dialects in depicting their experiences with illness is, according to Bearison (1991), one way to teach others the value of listening to children on their own terms. While there is the possibility that in the future the labels assigned to the major categories may need to be revised to keep pace with children's changing dialects, what should remain fairly consistent are the meanings assigned to the categories.

Just as there was triangulation of data collection methods, so too was there triangulation of data analysis which occurred at the aggregate level (e.g., analysis of participant's perceptions); interactive level (e.g., how participants' perceptions are generated out of interactions between participants); and collectivity (e.g., analysis of how families' role demands dictate certain perceptions and interactions) (Denzin, 1978). In applying the constant comparative approach, the researcher attempted to "saturate" all emerging categories. This involved the researcher continually looking for examples of data that represented all categories. Data collection and analysis was terminated when: (1) no new information or insights emerged, that is, all categories were deemed saturated or complete; (2) the category development was dense, insofar as all of the paradigm

elements were accounted for; and (3) the relationships between categories were well established and validated (Creswell, 1998). The end result was the generation of two substantive theories specific to children's cancer and cancer-symptom experiences. The student's dissertation chair (Dr. L. Degner) reviewed all categories of the theories to help confirm and clarify the organization and relationships of the derived properties and categories of the substantive theories. Theoretical completeness of the data was achieved midway through the project but longitudinal data collection from key participants continued in order to identify any potential changes over time.

(2) Illness Narratives

The focus of this study's analysis was to identify the main psychosocial phenomenon and process of children's and families' cancer-symptom experiences, thus warranting grounded theory analysis. However, in order to arrive at a more comprehensive understanding of the phenomenon under study, the researcher felt that narrative analysis was also justified. It was the process of narrative analysis of the children's and families' experiences that helped to confirm the paradigmatic relationships of the theoretical categories that emerged from this study. Narrative analysis was most helpful in arriving at a meaning-centred approach to understanding the children's cancer-symptom experiences. "Depicting illness in the form of narratives is a way of contextualizing illness events and illness symptoms by bringing them together within a biographical context. By weaving the threads of illness events into the fabric of our lives, physical symptoms are transformed into aspects of our lives, and diagnoses and prognoses attain meaning within the framework of personal life " (Hydén, 1997, p. 53).

Narratives do not merely reflect illness experience, but rather contribute to the experience of symptoms and suffering (Kleinman, 1988). The stories are highly personalized, embedded as they are in individual lives and experience (Garro, 1994).

In developing the illness narratives the following steps described by Creswell (1998) were applied: (i) identifying an objective set of experiences and then developing a chronology of the individual's life; (ii) discovering epiphanies; (iii) isolating narrative segments and categories with-in the interview story; (iv) isolating major patterns and meanings within the narrative segments; (v) reconstructing the individual's biography; and (vi) lastly, preparing a narration. Critical to reconstructing the children's and families' biography was arriving at the core narrative. The core narrative represents the essential meaning of the story in terms of informational content, its interpersonal impact, and the language in which it has been told (Viney & Bousfield, 1991). Preparing the core narrative in illness narratives involved arranging the illness symptoms and events in temporal order and relating them to other events in the participant's life (Hydén, 1997). Systematic reading of each interview transcript for themes with awareness of similarities, differences, and inconsistencies helped to draw out the core narrative. Listening not only to the content of the children's narrative report, but also to the children's spontaneous use of language was critical in the examination of narratives (Steward, Bussey, Goodman, & Saywitz, 1993). The children's symptoms were evaluated and interpreted in the larger context of illness meaning because the significance ascribed to various symptoms influenced the information children and their families perceived and communicated about particular illness episodes. Bearison (Bearison, 1991) viewed

narratives from children with cancer as a means to understanding children's experiences with cancer from the children's perspective. Bearison found that the narratives provided the children with an outlet to construct and understand the self, and reflected their struggle with cancer and their attempt to resolve it.

(3) Descriptive Measures

Information from the demographic forms was analyzed by means of descriptive measures and provided a summary of the main characteristics of the children and families.

Establishing Trustworthiness

Lincoln and Guba's (1985) trustworthiness criteria specific to naturalistic or qualitative inquiry was used to critique the rigor of the study's findings. In achieving trustworthiness, the researcher was concerned with trying to convince those interested in the phenomenon that the study's findings are worth noting in that they contribute to an increased understanding of the phenomenon and that the findings are meaningful and grounded in reality (Lincoln & Guba, 1985). Four components to achieving trustworthiness were strived for in this study: credibility; transferability; auditability; and confirmability.

(1) Credibility

The first component of trustworthiness, credibility, is concerned with arriving at an accurate, truthful description of participants' experiences (Lincoln & Guba, 1985). Findings are considered to be credible when others going through the same or similar experience as did the research participants, would be able to recognize the interpreted

data as their own (Sandelowski, 1986). As well, other researchers or readers should be able to recognize the experience after having only read about it in a study (Sandelowski, 1986). The researcher, as the reconstructor of the raw data, needs to show that he or she has represented multiple constructions adequately in that the data are credible to the constructors of the original multiple realities (Lincoln & Guba, 1985). As well, the emerging theory should be able accurately describe the major core categories of the substantive area.

A variety of strategies were used to establish credibility in the study's findings. Most important was the strategy of member checks, that is, sharing one's interpretation with the participants in order to ensure that one's interpretations were an adequate representation of the participants' realities (Lincoln & Guba, 1985). Triangulation of data sources, prolonged engagement in the field, and persistent observation also helped the researcher to adequately and accurately learn about the phenomenon under study (Lincoln & Guba, 1985). Whereas the purpose of prolonged engagement was to render the researcher open to multiple influences, the purpose of persistent observation served to identify those characteristics in the situation that were most salient to the phenomenon under study and to focus on them in detail (Lincoln & Guba, 1985). Prolonged engagement provided scope; persistent observation provided depth (Lincoln & Guba, 1985). The researcher also explored aspects of the research process and data analysis with her dissertation supervisor, Dr. L. Degner throughout the study. As a form of peer debriefing, this served to: (i) help keep the researcher "honest" by being exposed to questions that challenged her with aspects of the inquiry pertaining to substantive,

methodological, legal, and ethical issues; (ii) provided opportunities to test working hypotheses; (iii) provided opportunities to develop and test subsequent steps in the emerging design; and (iv) provided the opportunity of catharsis of thoughts or feelings that may be interfering with the researcher's ability to carry out the study (Lincoln & Guba, 1985).

Additionally, with respect to approaching validation or credibility in the narrative work, the researcher was concerned with whether the narratives were persuasive and plausible, that is, was the interpretation reasonable and convincing. These criteria were achieved when theoretical claims were supported with evidence from participants' accounts (Riessman, 1993).

(2) Transferability

The second criterion, transferability or applicability, is concerned with how the findings can be transferred to or have applicability in other contexts or informants (Lincoln & Guba, 1985). Fittingness is the criterion in which the applicability of qualitative study is evaluated. A study meets the criterion of fittingness when the findings "fit" the data from which they are derived (Sandelowski, 1986). As well, a study meets this when its findings "fit" into contexts outside the study situation (Sandelowski, 1986). In qualitative research, however, this may be difficult to achieve due to the generally small sample sizes inherent in qualitative research. Moreover, a substantive theory is thought to be valid only for the studied population. However, by providing detailed, accurate descriptions of a process related to a particular phenomenon, this may enable one to predict processes in similar circumstances (Hutchinson, 1986). Accordingly it was the

responsibility of the researcher to provide sufficient descriptive data that will enable the reader to make a decision about whether or not the findings are transferable to another setting (Berterö, 1996; Lincoln & Guba, 1985). This included providing the widest possible range of information (i.e., thick description) which was achieved through purposeful sampling. As well, thick description included detailing: (i) the context of specific acts; (ii) the intentions and meanings that organizes the action; (iii) the evolution and development of specific acts; and (iv) the action as a text that can then be interpreted (Denzin, 1989).

(3) Auditability

The third criterion, consistency or auditability, is concerned with whether similar findings would result if the study was replicated with the same or similar participants in the similar context (Lincoln & Guba, 1985). However, considering that variability is expected in qualitative research, consistency is defined in terms of dependability (Krefting, 1990). The concept of dependability implies trackable variability, that is, variability that can be ascribed to identified sources such as changes in the informant's life situation or increased insight on the part of the researcher. Although another researcher will not arrive at exactly the same conclusions, findings may be comparable (Sandelowski, 1986). To achieve dependability, the researcher included atypical or non-normative situations in the findings. Leaving a clear decision trail of the research process from beginning to end was also necessary, and included detailing the coding procedures and extensive memos, allowing for examination of the "decision trail" used by the researcher. Because grounded theory methodology is very systematic and clear in its trail,

dependability should be apparent (Berterō, 1996). However, one does not seek to arrive at an exact account of what happened with respect to personal narratives because there is no reason to assume that one's narrative will or should be the same from one setting to the next (Riessman, 1993).

(4) Confirmability

The last criterion, confirmability, is concerned with whether or not data stem from the participants and the context of the inquiry, and not from the biases of the researcher (Lincoln & Guba, 1985). That is, the findings must be grounded in data. Member checks and keeping a reflexive journal helped to ensure confirmability. However, in striving for confirmability, it was important not to disregard the fact that the researcher does in fact help to co-construct the data with the participants. As Prus (1996) pointed out, to understand what people intend and why they act as they do, the researcher must enter into their experience. The researcher must become part of the intersubjectivity. Subjectivity is valued in that subjective involvement of researchers with participants is necessary and that much emphasis is placed on the subjective reality or the participants' perspectives (Sandelowski, 1986). Detached, unemotional, purely cognitive interpretation is impossible in interpretative research (Denzin, 1989). The researcher must try to look at the world from the eyes of those he or she studies and to record it faithfully from the participants' views (Prus, 1996).

It is also important to point out that qualitative or human science objectivity and subjectivity are not mutually exclusive categories. Objectivity in human sciences research means that the researcher remains true to the object (van Manen, 1990). Subjectivity

means that the researcher needs to be as perceptive or insightful as he or she can be in order to show the object in its full richness (van Manen, 1990). It also implies that the researcher is strong in his or her orientation to the object of study in a personal way, while avoiding the danger of becoming self-indulgent and carried away with his or her unreflected preconceptions (van Manen, 1990). Human science researchers must also accept that lived human experience is more complex than the result of any singular description and that there is always an element of the indescribable to life (van Manen, 1990). Human science strives for precision and exactness by aiming for interpretive descriptions that exact fullness and completeness of detail (van Manen, 1990). "Human science research is rigorous when it is "strong" or "hard" in a moral and spirited sense" (van Manen, 1990, p. 18). Human science research is also rigorous in that it is prepared to be "sensitive" in its effort to bring the range of meanings of life's phenomena to our reflective awareness. In contrast, rigor in natural science research or quantitative research is seen to be an indication of refinement of measurement and perfection of the research design and not compromised by "subjective" distinctions (van Manen, 1990).

Lastly, in striving for findings that are trustworthy, the researcher needed to function adequately as a "human instrument." The qualities that the adult researcher brings to the research setting will affect the participant-researcher relationship and his or her ability to function as a "human instrument." Characteristics that uniquely qualify the human as research instrument include: (i) responsiveness to all personal and environmental cues; (ii) adaptability to assessing any other factor; (iii) holistic emphasis in understanding the phenomenon under study; (iv) knowledge base expansion beyond

mere propositional knowledge to the realm of the felt, silent sympathies, unconscious wishes, and daily unexamined usages; (v) processual immediacy (i.e., the ability of the human to process data immediately); (vi) opportunities for clarification and summarization; and (vii) opportunities to explore atypical responses (Guba & Lincoln, 1981 in Lincoln & Guba, 1985). In order to achieve trustworthiness, the researcher strived to maintain such characteristics.

Limitations

A strength of the study's sample was that it varied with respect to phenomenal variation of the children's cancer-symptom experiences. The children's cancer diagnosis, treatment, and illness phase varied. However, although the researcher sought to capture core experiences that cut across participant variation, this was not always possible and therefore, certain child- and family-related characteristics were under-represented (refer to Chapter IV for a summary of the sample's characteristics). Most notably was the demographic characteristic of race. The majority of children and their families who agreed to participate were Caucasian (95%). Fathers and siblings were under-represented in the study's formal open-ended interviews in comparison to the number of mothers and children interviewed. While the researcher was able to meet the sample criteria of involving children who ranged in age from five to 18 years of age, there were fewer child participants of preschool-age. Although in the process of data collection and analysis theoretical saturation was achieved, further research that addresses the limitations of this study's sample will add to the study's findings and may result in a more comprehensive theoretical understanding of children's cancer-symptom experiences.

In addition to limitations related to sampling, three sources of bias associated with qualitative research, had the potential to occur that could ultimately limit data quality. The first potential source of bias stems from the effects of the researcher on the data collection site (Miles & Huberman, 1984). This type of bias occurs when the researcher disrupts or threatens ongoing social relations. Participants in these situations will switch into an on-stage role or special persona. Children especially may be more vulnerable to respond in socially desirable ways in an effort to please adult researchers (La Greca, 1990). However, the researcher believes that this type of bias, social desirability response bias, did not result and may be attributed to a number of strategies employed by the researcher. Most important with respect to the children was reinforcing to them that they were the experts and that not all children answer in the same way (Brown & Haylor, 1989). Other strategies that helped to reduce this bias included prolonged engagement in the field, using unobtrusive measures where possible, making sure one's mandate was unequivocal to informants, interviewing in a variety of settings, and not inflating one's importance as a researcher. Making counter-suggestions (i.e., repeating questions in alternative ways) when interviewing also helped to check the firmness of a belief and response validity (Faux et al., 1988).

A second source of bias referred to as "elite bias," can occur when the researcher over represents data from articulate, well-informed, usually high-status informants and under represents data from intractable, less articulate, lower status ones (Miles & Huberman, 1984). Selecting only those children perceived as emotionally and psychologically healthy may contribute to biased results (Faux et al., 1988). In order to

reduce the potential for "elite bias" the researcher increased the number of participants in the study and looked purposively for contrasting cases (negative, extreme, countervailing) (Miles & Huberman, 1984). Unfortunately because an intermediary was necessary to access children and their families, the researcher could not control any potential bias that the intermediary may have had in selecting potential participants. Some of the parents of preschool children also contributed to the potential for some degree of "elite bias" by requesting that their preschool children not be interviewed. The major reason for not wanting their children to be interviewed was related to a fear that the researcher's talking to them about cancer would only cause distress in their children. Observing the children in their environments helped to reduce the potential for "elite bias."

The third source of bias stems from the effects of the site on the researcher (Miles & Huberman, 1984). Specifically, there was the potential for the researcher to "go native" because of the closeness of the researcher-participant relationship and the researcher's sustained contact in the field. "Going native" involves the researcher losing his or her awareness of being a researcher and being seduced by the participants' perspectives (Bryman, 1988). To avoid this, the researcher spent time away from the research site, made field notes in order to examine one's behaviors, and triangulated data collection methods in order to arrive at a more comprehensive understanding and avoid stagnation in one's thinking and responses. Also important was the process of peer debriefing or the sharing of one's ideas with a peer for the purpose of exploring aspects of inquiry (Miles & Huberman, 1984). Peer debriefing in combination with a reflexive journal helped the researcher to reflect on her presence in the research setting.

Ethical Considerations

Involving individuals in social or human science research may make them more vulnerable to the possibility of their basic rights being violated. Children as research participants, especially younger children and chronically disabled and terminally ill children may be even more vulnerable to social research (Biggar & Glass, 1992). Increased vulnerability in children may result from: (1) limited cognitive abilities and experiential background; (2) limited social power; and (3) an ambiguous legal status as minors that both protects and limits their rights (Thompson, 1992).

Therefore, in order to ensure that the children's basic rights as well as the rights of their parents and the professionals participating in the study were preserved, the researcher was guided by four ethical principles throughout the researcher process. The first principle that the researcher strived to maintain was concerned with respecting the individual and acknowledging the individual as an autonomous being. Respect for the children included respect for privacy, confidentiality, intimacy, and veracity (Miller, 1993; Weithorn, & Scherber, 1994). Critical to this principle is recognizing that autonomous actions and choices should not be constrained by others and that participants must be afforded the opportunity to make informed choice without pressure or coercion (Beauchamp & Childress, 1983).

The second principle, the principle of nonmaleficience, required the researcher to minimize the risks of harm to participants (Beauchamp & Childress, 1983; Thompson, 1992). Harm may involve physical or mental "hurt" including pain, anxiety, and bodily injury (Miller, 1993). The risk of harm or the probability of occurrence of hazard to any

child involved in research must be recognized such that suitable preventive precautions and alleviating measures be available and appropriately used (Miller, 1993). Associated with the second principle is the third principle, the principle of beneficence. Generally this principle refers to the duty to help others or to confer benefits. Equally important is the duty to balance possible goods against possible harms of action (Beauchamp & Childress, 1983; Macklin, 1992; Thompson, 1992). Hence the researcher had the responsibility to remove or minimize existing harms and to provide or maximize benefits to all involved in the study; it required the researcher to be thoughtful and act carefully (Beauchamp & Childress, 1983).

The last principle, the principle of justice, entailed the obligation to treat equally those who are equally situated, and to treat differently those who differ in relevant ways (Thompson, 1992). This required impartiality and fairness in responding to participants. Specific strategies employed in this study that further supported these four ethical principles included:

(1) <u>Informed and Voluntary Consent</u>

The researcher provided verbal explanations of the study's purposes, data collection methods, use of the data, and risks and benefits to all adult as well as all child participants. Written explanations were also provided to all adults and for children able to read. Although the ability for children to understand the research process has been questioned, findings from a study that examined the capacity of children, adolescents, and adults diagnosed either with cancer or obesity, demonstrated that chronological age was not related to related to knowledge of the elements of informed consent (Susman, Dorn,

& Fletcher, 1992). More specifically, the researchers found that there were no differences in the knowledge-of-participation-in-research scores between the older (14-21 years) and younger (7-13 years) participants. All were most knowledgeable about those elements of consent that assessed concrete information (e.g., freedom to ask questions and the benefits of participation), but were less knowledgeable about those elements that assessed abstract information (e.g., scientific versus therapeutic purposes and alternative therapies). More than half of the participants knew their role as participants. However, a limitation of this study was that although the ages of the participants ranged from 7-to-20 years, the majority of those participating involved children between 11-to-18 years of age. Hence, valuable qualitative differences between the early school-age children and older adolescents may have been missed. Accordingly, in explaining the cancer-symptom study to children and adolescents, the researchers took special precautions in order to account for potential developmental as well as experiential differences amongst the children and adolescents participating. This included use of different explanation and consent forms for younger and older children (refer to Appendices L, M, N, O).

To facilitate the children's understanding of the informed consent and the research process, the researcher took special care in how she described her presence to child participants. In previous work, researchers have explained their role as a researcher to children who did not comprehend the term "researcher" or had vague notions of research in such terms of being a "reporter" or "someone working on a project" or as "a big kid going to school" (Bluebond-Langner, 1978; Fine & Glassner, 1979; Fine & Sandstrom, 1988). Identification of the researcher as a nurse needing to learn more about what it is

like to be ill, has also been reported as being helpful in clarifying to children why a study is being conducted (Faux et al., 1988). For the purposes of this study and for those children who had difficulty understanding, the researcher explained the research activity in relation to doing a school project that would help nurses and doctors better care for children. Relating the explanation to events commonly understood or experienced by concrete-operational children is considered appropriate (Broome & Stieglitz, 1992). As well, developmentally appropriate information was provided. The children's concerns and questions concerning the research process were focused on by the researcher (Rae & Fournier, 1986).

In explaining the consent, the researcher also reinforced to all participants that participation was strictly voluntary and refusal to participate would in no way affect their association with the Manitoba Cancer Treatment Foundation or Children's Hospital. Even when written consent was obtained from the children's parents or legal guardians, assent from the children nonetheless was obtained. Insofar as children are regarded as autonomous, the National Council on Bioethics in Human Research (NCBHR) task force which was established to assist those faced with difficult decisions arising in the ethics of research involving children, supports the need for children's assent (Miller, 1993). Because participation in this research study would not result in direct therapeutic benefit to the child participants, the researcher had planned to honor any refusal made by the children. Fortunately all the potential parents who were contacted for the study, had respected their children's choices. Extra precaution to avoid undue pressure being placed on the children was particularly important because children are more susceptible to subtle

social influence by adults (Broome & Stieglitz, 1992; Weithorn, & Scherber, 1994). As Fine and Sandstrom (1988) noted, children must be given a real and legitimate opportunity to say that they do not want to participate in the research study. The researcher in this study acted accordingly.

Honouring withdrawal from certain questions or observation events as requested by child participants was reinforced throughout the research project. The researcher took precautions to avoid pressuring child participants and to remind them on a regular basis that they could withdraw from the study whenever they wanted to. This was important considering Susman and colleagues (1992) reported that while children and adolescents (7-20 years) demonstrated an understanding of many aspects of the informed consent, they were less clear about their ability to withdraw from the research situation. Additionally, the researcher was not known to the study's patient population and had no clinical relationship with them which also put less pressure on them to participate.

(2) Confidentiality and Anonymity

In maintaining the confidentiality and anonymity of all participants a number of measures were undertaken. This included replacing all names of participants with code numbers or pretend names and ensuring that only the researcher, her supervisor (Dr. L. Degner) and the data transcriber had access to the raw data. While undertaking the study, all data was stored in a locked cupboard and computer protected by a password known only to the researcher. In order to reduce a source of potential stress, all adult and child participants were also informed of these measures. It was also important to note that children (especially older children) may discern more sensitively the subtle cues,

demands, and judgements of their performance that occur during research, and may be adversely influenced as a result of feeling compelled to divulge confidential information (Thompson, 1992). Being aware of this made the researcher approach child participants in a more careful and cautious manner. Being sensitive to children's and families' need for privacy was also honoured. This included ensuring confidentiality and privacy during data collection, and continual verbal reassurance of this during the research process (Faux et al., 1988).

The researcher was also aware that the issue of maintaining confidentiality and anonymity was not always as simple as it appeared to be. For example, conflict could result between parents and children when parents want to be informed of their children's responses, but the children do not want to share their thoughts or feelings with them. For the purposes of this study, the researcher reinforced to all participants that information obtained throughout the study would be kept confidential unless those involved give their permission to share their information with those requesting it.

Another dilemma that could arise is when the child reveals that he or she has a problem, yet does not request help. When this occurs, Moore and colleagues (1996) noted that the researcher has to decide either to actively engage in helping the child, thereby potentially hampering the participant-researcher bond or uphold the child's confidentiality. For the purpose of this study, the researcher took the stance that if any child was in danger and required help then the researcher would inform his or her parents and the appropriate personnel.

(3) Participant Burden

The time required for participants to be involved in the study in itself may have been burdensome to them. Therefore, the researcher was sensitive to the need to terminate interviews or participant observation periods and continue the research process at a later time if fatigue or distress of participants was evident.

(4) Potential Risks and Benefits

Although risks for this study were deemed minimal, there was still the possibility for risks to occur. This included the potential for children to develop induced anxiety or stress, fear of failure, a lowering of self-esteem, reactions to intrusion of privacy, conflict or guilt, and embarrassment (Koocher & Keith-Spiegel, 1994). Moreover, it was important to recognize that some participants may have had significant difficulty coping with their cancer experience which in turn would only be compounded by the research experience. Fortunately, neither any of the child participants nor adult participants appeared to experience physical or emotional stress as a result of participation in the study. Debriefing participants after every interview session helped to reduce the potential for increased distress. Also, if any of the participants had difficulty coping, a referral to the appropriate health professional or counselling services was planned with the family's permission.

In order to reduce the potential for risks to occur, the researcher was watchful for signs of potential adverse outcomes. If signs were evident, it was planned that every effort would be made to remove potential factors that could lead to children experiencing risks. For example, if the children while being interviewed displayed overt, nonverbal signs of

anxiety, and increasing reluctance to reply even with the researcher's probing then the researcher had made plans to terminate the interview. In addition to ongoing assessment, respect, caution, and sensitivity was practiced to help ensure that the researcher did not risk crossing into participants' private spheres (Berterö, 1996). Additionally, during risk analysis, the significance of critical developmental periods must also be considered (Conrad & Horner, 1997). A table noting these critical periods had been prepared to assist the researcher throughout the research process (refer to Appendix Q).

Leaving the field can be difficult for participants as well as the researcher (Taylor, 1991). Moreover, the better the rapport and the closer the relationships, the more participants may feel used when the researcher leaves the research scene. Therefore, to reduce the chance for any harm occurring because of termination, the researcher ended the relationship with each family gradually. The families also had input into when termination should take place. Participants were also given the option to contact the researcher if they had any unresolved issues related to the study. Participants were also given the option to request a copy of the study's results.

Considering the nature of the study design, it was recognized that there was the possibility for the researcher to face unanticipated ethical dilemmas that may put participants at risk. This includes the possibility of the researcher observing children receiving care that could be improved on and/or instances in which participants would ask the researcher to intervene or act as a go-between on their behalf. If such situations did occur, the researcher planned to make suggestions to families that would help them deal with the problem through other avenues. In this way, the researcher could still be

perceived as a source of help, yet not become too enmeshed in the issue. Refusal to help may have alienated the major participants and possibly destroyed the research process (Field, 1989). However, any incidence observed by the researcher that constituted breaking the law (e.g., child abuse) or that put the child in direct harm, would have resulted in the researcher immediately removing the child from the source of harm and notifying the appropriate authorities. It was also planned that all data involving harmful or dangerous incidences would be discarded from data analysis. Significant to dealing successfully with potential dilemmas is proceeding with the sensitivity and integrity that they dictate. Building honest partnerships with participants was essential. Fortunately such incidences were never witnessed by the researcher.

While no harm to children took place, it was deemed that there were no direct benefits to participants because of the nontherapeutic nature of this study. However, there is the possibility for benefiting future children diagnosed with cancer in that the knowledge gained from this study may be used to improve the children's quality of care. Miller believed research involving children should be pursued so as to gain knowledge which may benefit not only individual children but children as a group (Miller, 1993). van Manen (1990) also felt that hope, increased awareness, moral stimulation, insight, a sense of liberation, a certain thoughtfulness, and so on may also be experienced in human sciences research. Intense, in-depth interviews may lead to new levels of self-awareness, which may lead to positive changes in life style (van Manen, 1990). Moreover, it has been documented that interviewing children about their experiences including experiences with cancer for the purposes of research may benefit them (Bossert et al., 1996; Faux et al.,

1988; Thompson, 1992). Most children want to tell their story (Bearison, 1991) and this needs to be recognized. Indeed, the researcher's past research experience suggests that both parents and children enjoy participating in qualitative research and found the experience to be positive (Chalmers, Kristjanson, Woodgate, Taylor-Brown, Nelson, Ramserran, & Dudgeon, 2000; Woodgate, 1998a, 1998b; Woodgate & Kristjanson, 1996b). Parents and health care providers may also appreciate the opportunity to discuss and share their experiences in caring for children with cancer. Although interviews may evoke painful memories or feelings, as previously discussed, it may be beneficial to let participants speak about them.

Involving children in the decision-making consent process has additional positive benefits. These include giving children: (i) the much needed practice in making important life decisions; and (ii) some control over what happens to them (Weithorn, & Scherber, 1994). Children may gain greater feelings of competence and effectiveness, increased sense of self-esteem, reduced depression, and decreased anxiety (Weithorn, & Scherber, 1994). Miller (1993) believed that to exclude children in research just because they are children, is to treat them unjustly. To enhance these positive aspects of research participation, the researcher strived to conduct the study with as much sensitivity as was possible.

Conclusion

An interpretive qualitative research design based on underpinnings from the grounded theory and illness narratives qualitative research methods was an appropriate perspective to adopt considering the purpose of this study was to interpret and understand

the personal meanings and responses that children with cancer and their families construct around living day-to-day with symptoms throughout the childhood cancer trajectory. The study's method allowed for the advancement of theory development specific to childhood cancer-symptoms. Illness narratives helped to confirm the paradigmatic relationships of the categories that emerged from this study. By examining children's and families' thoughts, feelings, and actions as expressed in interviews and observed through behaviors, further knowledge about children's and their families' experiences with cancer-symptoms evolved. The next three chapters, Chapters IV, V, and VI describe the major findings of the study.

CHAPTER IV

PRESENTATION OF THE FINDINGS

Introduction

The original intent of the study was to develop a substantive theory about how children with cancer and their families experience symptoms in relation to childhood cancer. However, it was obvious from the outset of the study that the children and families could not separate the symptom trajectory from the "whole" childhood cancer experience. They needed to talk about the overall or complete cancer experience regardless of my attempts to narrow discussion, which necessarily led to the development of the first substantive theory: Keeping the Spirit Alive: The Spirit Within. This substantive theory provided an understanding of how children and families experienced the "whole" cancer trajectory and its many rough spots including those linked to children's and families' experiences with the cancer-symptoms.

However, throughout the process of constant comparative analysis it also became apparent that the symptom experiences in and of themselves were important to families; the symptoms helped to shape the families' overall experiences with cancer. There was a relationship between the symptoms and cancer evidenced by the fact that children and families had difficulty in talking about one without referring to the other. Accordingly, it was important to refer to the children's trajectories not exclusively as symptom trajectories or as cancer trajectories, but rather as cancer-symptom trajectories. Part of understanding how children and families experienced childhood cancer was facilitated through the meanings children and families assigned to the symptom experiences. The

personal meanings attributed to the cancer-symptoms and the process of transitioning through the transition periods emerged as two core categories that led to the development of the second substantive theory: Children's and Families' Lived Experience of Childhood Cancer-Symptoms. This second theory provided direction in comprehending how children and families experienced cancer within the context of the symptom experiences. Creating illness narratives especially facilitated an understanding of their experiences and helped to identify and confirm key categories guiding both substantive theories. The development of substantive theories as opposed to formal theories was appropriate for this study's level of inquiry which was specific to the study of children's symptom-cancer experiences. Whereas formal theories are broader, encompassing many different types of situations and levels, substantive theories are midway between the broad and narrow and encompass fewer situations (Strauss & Corbin, 1990).

The focus of this dissertation report is on the second substantive theory. However, a brief discussion on the first substantive theory is provided as it lays the foundation for the second theory and facilitates an understanding of the relationship that "cancer, the illness," and "cancer, the symptom phenomenon" have with each other. Hence, the major findings of the study are organized and presented as following three chapters: (1) the substantive theory, Keeping the Spirit Alive: The Spirit Within, which describes children's and families' overall experiences with cancer (Chapter IV); (2) the substantive theory, Children's and Families' Lived Experience of Childhood Cancer-Symptoms, which describes the lived experience of cancer in relation to the changing personal meanings that children and families assign to the cancer-symptom experiences

(Chapter V); and (3) the substantive theory, Children's and Families' Lived Experience of Childhood Cancer-Symptoms, which describes the lived experience of cancer in relation to passage through the transition periods, and how the personal meanings and transition periods relate to theory of Keeping the Spirit Alive (Chapter VI). Taken as a whole, the three chapters of findings address the study's research questions: (1) identifying the meanings and interpretations children and their families assign to the symptom experiences; (2) identifying how children and their families respond to the symptom experiences; and (3) identifying how the children's and families' sense of self are affected by the symptom experiences. Additionally, the findings sections are in keeping with the study's theoretical framework, the philosophy of interpretative interactionism, in that the findings emphasize the importance that the children's and families' meanings, interpretations, responses, and sense of self have for interpreting and understanding a complex phenomenon such as the cancer-symptom trajectory.

The findings were derived from all of the 39 families participating in this study, although more attention is given to the 15 families who were each followed for approximately one to two years. A description of the sample's characteristics is provided at the beginning of this chapter. In order to protect the anonymity of the children and families who participated in the study, all names identified in statements that support the findings are pseudonyms.

Description of Child and Family Participants

Demographic information describing the study sample is presented in Table 3. Table 3 describes the characteristics of all 39 families participating in the study including a separate section describing the 15 families followed longitudinally.

TABLE 3. DEMOGRAPHIC PROFILE OF CHILDREN AND THEIR FAMILIES

Characteristics	Total Sample: N=39	Longitudinal Families: N=15
Children with cancer		
Gender: Female	21 (54%)	8 (53%)
Male	18 (46%)	7 (47%)
Age (on entry): 4-5 years	5 (13%)	3 (20%)
6-11 years	19 (49%)	6 (40%)
12-18 years	15 (38%)	6 (40%)
Grade: Kindergarten	4 (10%)	3 (20%)
1 - 6	18 (46%)	6 (40%)
7 - 12	15 (38%)	6 (40%)
Other	2 (5%)	-
Race: White	37 (95%)	15 (100%)
Aboriginal	-	-
Asian	2 (5%)	-
Other	-	-
Diagnosis: ALL - Standard	15 (38%)	6 (40%)
ALL - High risk	6 (15%)	2 (13%)
AML*	1 (3%)	-
Lymphoma	7 (18%)	4 (27%)
Central nervous/ brain tumors	3 (8%)	1 (7%)
Solid tumors	8 (21%)	2 (13%)

Abbreviations: ALL - acute lymphocytic leukemia; AML - acute myelogenous leukemia. ***AML:** One child was diagnosed with both ALL and AML.

Table 3 continued ➜

TABLE 3. DEMOGRAPHIC PROFILE OF CHILDREN AND THEIR FAMILIES

Characteristics	Total Sample: N=39	Longitudinal Families: N=15
Children with cancer		
Time since diagnosis (on entry): 1-6 months	11 (28%)	8 (53%)
7-11 months	6 (15%)	5 (33%)
1 year	4 (10%)	1 (7%)
2-3 years	10 (26%)	1 (7%)
4-5 years	4 (10%)	-
6-7 years	1 (3%)	-
8-9 years	1 (3%)	-
≥ 10 years	2 (5%)	-
Treatment: Chemotherapy	22 (56%)	9 (60%)
Chemotherapy & Surgery*	7 (18%)	2 (13%)
Chemotherapy & radiation	2 (5%)	-
Chemotherapy, radiation, & BMT	3 (8%)	3 (20%)
Chemotherapy, radiation, & surgery	4 (10%)	-
All types	1 (3%)	1 (7%)

Abbreviations: BMT - bone marrow transplant.

***Surgery:** only includes surgery specific to removal of the cancerous lesion or tumor. It does not include biopsies or treatment-related surgery such as central line insertions.

Table 3 continued ➜

TABLE 3. DEMOGRAPHIC PROFILE OF CHILDREN AND THEIR FAMILIES

Characteristics	Total Sample: N=39	Longitudinal Families: N=15
Children with cancer		
Relapses:	5 (13%)	2 (13%)
Health Status on exit from the study: Relapse	-	-
Remission	35 (90%)	13 (87%)
Death	4 (10%)	2 (13%)
Families		
Parents: Two parent	34 (87%)	12 (80%)
One parent (mother)	5 (13%)	3 (20%)
One parent (father)	-	-
Other	-	-
Occupation* - mother:		
Laborer	4 (10%)	1 (7%)
Clerical	6 (15%)	1 (7%)
Professional/ Management	7 (18%)	2 (13%)
Homemaker	12 (31%)	4 (27%)
On leave	4 (10%)	4 (27%)
Other	6 (15%)	3 (20%)
N/A*	-	-

***Occupation:** Pertains to the individual's employment status at the time that the study was conducted. **N/A:** Pertains to family situations where mothers are deceased or not involved.

Table 3 continued ➜

TABLE 3. DEMOGRAPHIC PROFILE OF CHILDREN AND THEIR FAMILIES

Characteristics	Total Sample: N=39	Longitudinal Families: N=15
Families		
Occupation* - father:		
Laborer	15 (38%)	6 (40%)
Clerical	1 (3%)	-
Professional/ Management	15 (38%)	4 (27%)
Homemaker	-	-
On leave	-	-
Other	4 (10%)	2 (13%)
N/A*	4 (10%)	3 (20%)
Family Income:		
≤$10,000/yr	-	-
$11,000-$20,000/yr	9 (23%)	4 (27%)
$21,000-$30,000/yr	5 (13%)	3 (20%)
$31,000-$40,000/yr	10 (26%)	5 (33%)
$41,000-$50,000/yr	3 (8%)	1 (7%)
$51,000-$60,000/yr	4 (10%)	-
$61,000-$70,000/yr	2 (5%)	-
≥$71,000/yr	6 (15%)	2 (13%)
Siblings: None	5 (13%)	1 (7%)
One	16 (41%)	7 (47%)
Two	9 (23%)	4 (27%)
Three	9 (23%)	3 (20%)
Four	-	-
Five	-	-
More than five	-	-
Residence: Urban	26 (70%)	7 (47%)
Rural	13 (30%)	8 (53%)

***Occupation:** Pertains to the individual's employment status at the time that the study was conducted. **N/A:** Pertains to family situations where fathers are deceased or not involved.

A total of 39 families participated in this study. The researcher maintained contact with the majority of the 39 families throughout the course of the study by interacting with them during their follow-up appointments in the outpatient clinic. However, 15 families were followed more intensely. These 15 families were not only followed longitudinally over a period anywhere from 12 to 24 months, but were involved in multiple formal and informal interviews and observed more frequently compared to the other 24 families. A total number of six families who were invited to participate in the study declined. The major reason given by these families for declining was that they felt "*it was not a good time for them or their children.*" Additional reasons included being too busy or fearing that their children would become too distressed. From brief conversation with these families, the researcher sensed that in addition to the children's cancer diagnoses the families were experiencing other stressors in their lives and that partaking in the study would only add to their stress. In addition to the families who declined the researcher's invitation to participate, there were many families never approached by the nurse intermediary. The nurse intermediary was very protective of the families attending the cancer clinic and assumed for many reasons that such families would not make "*good*" participants.

Of the 39 children, the majority of the children were diagnosed with either leukemia or lymphoma (71.5%). Although most children did not vary per race, a variety of ages and educational levels were included among the 39 children. Most of the 39 children had two parents (87.2%) and siblings (87%). All the children received chemotherapy either alone or in combination with some other type of treatment. At

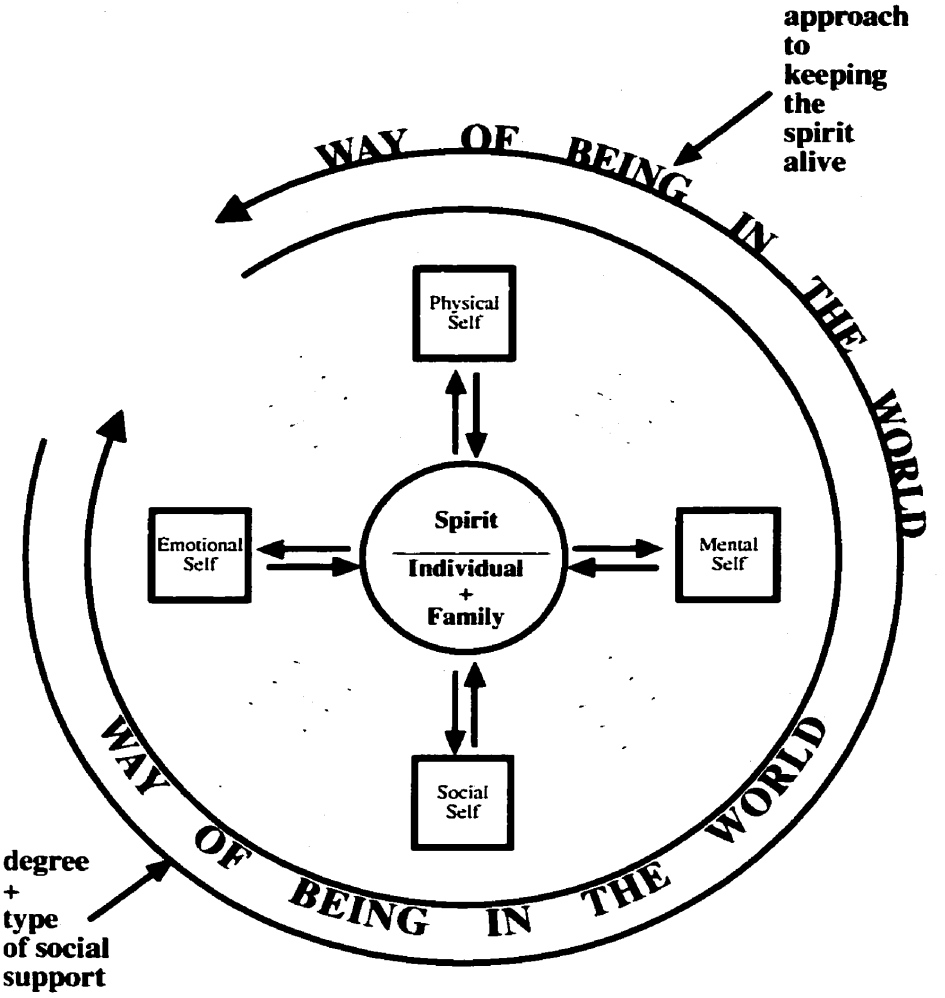
completion of the study, most of the 39 children remained in remission (89.7%). Similar trends were found for the 15 children followed longitudinally.

Keeping The Spirit Alive (The Spirit Within): An Introduction to the Theory

This chapter presents an overview of the substantive theory: Keeping the Spirit Alive and its main categories. The purpose of this chapter is not to provide a detailed account of the first substantive theory, but to set the stage for discussion of the second substantive theory. The theory of "Keeping the Spirit Alive" is representative of how children and families responded to the "whole" cancer experience within the context of the children's changing cancer experience (see Figure 1, p. 142). Summary of the major categories of this theory has been provided in Table 4 at the end of this chapter (p.162).

Specifically, the model describes how the children and their families used the process of keeping the spirit alive in response to them having to experience the central problem or phenomenon of the cancer-symptom trajectory: Getting through all the rough spots. The process of keeping the spirit alive was manifested in the form of strategies. Two intervening conditions were identified that influenced use of the process and its strategies: (1) the degree and type of social support; and (2) children's and families' approach to keeping the spirit alive. The major consequences of children and their families taking or not taking action in having to get through all the rough spots of the cancer-symptom trajectory related to how children and their families existed in their worlds. That is, the process of "keeping the spirit alive" in response to having to "get through all the rough spots," affected the children's and families' "way of being in the world." For all the children and the families, a way of being in the world was a dynamic

experience; that is, their lives had changed and were changing, and life was no longer as predictable as it had been in the past.



Getting Through All The Rough Spots:
Basic Psychosocial Phenomenon

Keeping The Spirit Alive:
Basic Psychosocial Process

Way Of Being In The World: Consequences Of Keeping The Spirit Alive
(i) Living Through It
(ii) Sense Of Self
(iii) Sense Of Well-Being

Figure 1 Keeping The Spirit Alive: The Spirit Within

The Basic Psychosocial Phenomenon of the Theory:

Getting Through All the Rough Spots (*A Rough Ride Ahead with Many Bumps...*)

One of the most significant categories in the *paradigm model* is the category identified as the central phenomenon. The phenomenon is the central idea, event, or happening, about which all other categories are linked to or in which the theory is developed (Creswell, 1998; Strauss & Corbin, 1990). The phenomenon that had the greatest effect on the children and families was identified as "getting through all the rough spots" and is shown on Figure 1 as zigzag lines surrounding the physical, mental, social, and emotional self. In this section "all the rough spots" is discussed first, followed by discussion of "getting through it." "It is never over with" a key characteristic of the phenomenon is also discussed in this section.

(1) All the Rough Spots

It would be an understatement not to refer to the cancer experience itself as a major event for children and their families, full of pain, suffering, and the fear of death as exemplified by the following:

> *Sibling of a child diagnosed five years ago: I'd say it's pretty major. Like it's almost not time consuming but it's a long haul. It's not something that you can cure overnight. It takes a while. You just have to go with the flow and...Like it's just a big issue. That's all that really stands out.*

> *Child with cancer (4 ½-year-old female): Actually, I thought that for a long time when I had it in the beginning, I just thought I was going to die because of this silly cancer.*

Cancer was seen as something that was huge and never ending as noted by one adolescent who was comparing cancer to other illnesses that her family had experienced:

I mean the cold or flu wasn't an everyday thing like cancer is...cancer is an everyday thing (child referring to the never ending, ongoing nature of cancer).

Morever it became a much larger experience as each day passed:

Child with cancer (15-year-old female): It is a learning experience as well as a life experience and it will be a lot more other things in the long run.

Parents also acknowledged how the experience grew:

Mother: It's a bigger, bigger, big, big picture.

Contributing to this huge experience was that children and families experienced a hardness to living life. Indeed, the increased "hardness" to life that children and families experienced was evident by the fact that they frequently used the adjective *"hard"* in their conversations while describing events experienced:

Mother: Yeah. There's an ugly side to it. There's, there is a hopeful side to it but it's hard, (pause) hard...It's hard. It's hard on the parents, it's hard on the siblings, it's hard on, especially hard on the kids, physically, emotionally, mentally and on it goes. It's a big, big, picture.

Sibling (7-year-old female): I would tell like it's really hard because you have to get needles and maybe a central line and stuff like that.

Child with cancer (11-year-old male): Having cancer is hard.

Child with cancer (11-year-old male): (pause) Well it's really hard to take care of, like taking the blood out and everything, it grosses them (referring to his family) all out. Well he (his father) gets grossed out but he just can't handle it.

Mother: It is very hard, yeah! You feel like you are not yourself. You feel like you are to blame. I want to cry, but I can't because she is here you know.

Father: Yeah, (sigh) it was hard, like (pause) I mean it was plain and simple, it was hard...No, it is hard on the family like it is a lot of (pause), either way like it is hard for my wife and it is hard for me.

The road ahead for children and their families became so hard for them that at

times it seemed or was simply overwhelming for them as is evident by the following comment made by a 16-year-old female with respect to being diagnosed with cancer:

> *Child with cancer: Yeah, I just don't know, like kind of feeling like I'm not going to be able to be a normal teenager because it's weird cause I was always very healthy and nothing ever happened to me. I was a klutz but I was never in the hospital. I've never been in the hospital before now. And then like, all of a sudden, it's just like crazy and I can't, I can't go to parties with my friends. I can't go. And then I'm sixteen and I can't drive. Well I can drive, I can get my licence I just, I can't, I don't really want to bother right now?* ***I HAVE TOO MUCH ON MY PLATE****, you know? So it just kinda sucks that I'm sixteen and I have all this to...*
> (Note: Words that are capitalized and in bold are words that the individual had emphasized in his or her speech).

Another example of the difficult road that families had to travel was provided by a mother when talking about her son's cancer treatment progress:

> *Mother: The doctors described it like two steps forward and one step backwards. I describe it more as 150 steps backwards and two steps forward.*

Underpinning all this "hardness" was the very fact that children were diagnosed with cancer:

> *Mother: The hardest part is to have your child sick, yeah. It's behind everything, all the changes are because she is sick...*

> *Mother: I think everything that you mentioned but I think the* ***hardest*** *thing a mother has to go through is when you realize how sick your child is...You are hurting inside and you have no control.*

> *Interviewer/Researcher: What is the worst part about having cancer? You told me some of the good things, what is the worst thing about it?*
> *Child with cancer (11-year-old male): (pause) Having it!*

The diagnosis of cancer in and of itself was not the only cause of the children's and families' suffering. It became apparent early on in the study that children and families had a difficult time identifying the defining event of the cancer-symptom trajectory or the

event that had the greatest effect on their lives. Although children, siblings, and their parents had no difficulty discussing what it was like to live day-by-day with the presence of childhood cancer, they had a difficult time pinpointing what it was about cancer that made the experience, as all participants described it as *"hell on earth"* or *"scary"* or *"devastating"* and *"so hard."* Parents as well as the ill children and siblings expressed that there were many difficult events or aspects about the cancer-symptom trajectory that caused them to suffer. Accordingly, part of the phenomenon that children and families experienced was the very fact that there was so much to endure in relation to the cancer-symptom trajectory; that is, there were many rough spots or *"many bumps in the road"* that made life *"harder"* to live:

> *Mother: It's the whole, the whole picture. It's the whole...it's the everything. Everyday you wish you never had to experience it.*
>
> *Father: It's all together (in response to identifying what is the worse thing about cancer)...Everyday we, me and my wife, we think about it (about their child being sick).*

Comments made by parents such as *"there's always something"* or *"it was just not one thing"* or *"it is the treatment and all that comes with it"* illustrated that there were many aspects to cancer and difficult events that families had to face. As one mother noted, it was hard to give one response to any questions asked by the researcher as she *"experienced a multitude of feelings for each question."* Everything about childhood cancer affected the families. Aptly expressed by some of the parents, it was *"the whole enchilda!"* or *"the whole gamut"* or *"astronomical."*

Like their parents, children with cancer shared similar thoughts. *"The whole thing*

sucks" was a frequent statement made by children of all ages. Additional comments made by children were indicative of the many negative sides of cancer and the complexity of the illness:

> *Child with cancer (7 ½-year-old male): Uh...I'd tell them I missed my friends, I hate getting the pokes...The pokes really hurt...you miss school...*
>
> *Child with cancer (9-year-old male) It is everything!*
>
> *Child with cancer (11-year-old male): It's a very bad disease!*
>
> *Child with cancer (16-year-old female): Oh, the worst thing about having cancer. Okay, sorry. Um, the worst thing about it kinda being looked at different by people on the streets and like the symptoms and um...Not really just, feeling different and the symptoms...I guess basically everything about it, but I don't know...*

The "*many bumps in the road*" or "*rough*" spots contributing to the hardness included such events as: experiencing the diagnosis and getting past the diagnosis; dealing with the fear of death; adjusting to the multiple changes that take place; balancing family life with hospital life; keeping the family unit together; waiting for the "cure"; and adjusting to the "ups and downs" of the childhood cancer experience.

Dealing with the symptom experiences of the children was another major event or bump in the road for these families that influenced and contributed to other difficult events. Often the children and their families would emphasize that the symptom experiences greatly contributed to the difficulty or "hardness" of the cancer experience and that the symptoms were significant to how cancer was experienced:

> *Child with cancer (16-year-old female): Symptoms are the big part of cancer! Well because there's a lot of symptoms. So I guess and I feel that most the time at least once a day I have a headache or at least once a day I feel nauseated or, you know whatever. And that really sucks. Like I've only thrown up once but...*

Although the rough times or spots were numerous and varied, all the rough spots were associated with the following five characteristics or dimensions: (i) uncertainty; (ii) a multitude of feelings and the joy and unspeakable sadness; (iii) restrictions; (iv) extra work; and (v) the loss. Definitions of these characteristics are provided in Table 4. Each of these characteristics while contributing to the hardness of cancer-symptom trajectory in their own unique way, were interrelated. The degree of intensity of each characteristic had an effect on the other which subsequently determined the overall hardness of events related to the cancer-symptom trajectory.

(2) Getting Through

All the rough spots and the associated hardness alone did not capture the overall phenomenon or problem experienced by the children and families in relation to childhood cancer. Instead the overall major phenomenon was identified by children and parents as actually having to "*get through*" all the rough spots. Not only did they have to acknowledge that there were many rough times, but they also had to experience having to actually get through the rough spots in order to truly get a sense of what the cancer-symptom phenomenon encompassed. This included all rough times from dealing with hair loss to dealing with the death of a child. "Getting through" as opposed to "getting over" the rough spots was necessary in order for children and families to be able to move on; to regain some sense of freedom from the cancer:

> *Child with cancer (14-year-old female): It is getting through it,* ***NOT OVER IT!*** *It is getting through in two ways. I guess getting over it makes it seem like you are always there and you are always trying to get over it. I don't know I have weird little visions in my mind of things, it is like a barricade. And for me it is not going over it and getting past it, it is going through it ripping it all down and*

tearing it into pieces. Like I don't want it to be something whole that is just behind me but is something that I destroyed and ripped down and is just not there any more. Getting over it, it is still there , it would just always bother me, I don't know. Like even though it is behind me, it is still there. Yeah! With getting over it, it would still be whole even if it was behind me. It would still be whole because you don't get over it as a whole thing, you go through piece by piece like treatment by treatment, page by page, section by section, it is not a whole thing.

The importance of viewing the cancer phenomenon as a "getting through" experience was repeated throughout the children's and families' narratives; it was not uncommon for children and families to refer to the notion of "getting through" or "going through" and "gone through" in relation experiencing all the rough spots and times. For example:

Father: ...and that's how I got through it otherwise I wouldn't have gotten through it.

Father: Everybody (referring to everyone in his family) is going to have to try to get through this together.

Mother: Like you do have to go through a lot of treatment yet.

Mother: It was the chemotherapy we were riding through, like trying to get through, and step by step, step by step, page by page.

Child with cancer (16-year-old female): Cancer is a terrible thing for a person to have and definitely hard to go through for anyone it touches.

Child with cancer (4 ½-year-old female): Cause I wasn't through with it (the cancer treatment).

Sibling (14-year-old female): Then when you see her like going through the chemotherapy and everything you can't really see how its getting better but...

Even one of the children's poem on a wall in the chemotherapy room had the following line in it that reinforced the getting through part of the cancer phenomenon: "*Even times when really bad thoughts hurt...they want to get through this BIG MESS!*"

As part of the phenomenon, "getting through" each rough spot involved children and their families moving forward and accepting each new obstacle resulting from the cancer-symptom trajectory including the cancer- and treatment-related symptoms. In "getting through" it was important for children and their families to experience the rough spots and push ahead regardless of the degree of uncertainty, feelings, restrictions, work, and losses experienced. Getting through each event further helped children and their families to feel more certain that they could deal with or manage the cancer experience and achieve the desired goals:

> *Child with cancer (14-year-old female): I mean I looked at the road-map (treatment regimen) the first time, you know the first time they ever showed it to me, it was like I am never going to get through this. "Do you see how long this thing is! It is like each page is two months, I am never going to get through this, never going to do this." Then I finished the first page and it was like "wow" I get to flip the page. And then I didn't really look at it and suddenly I went back to it and it was like wow, the second page is gone too! And then I looked back you know one half of the third page is gone. There are only six pages altogether or something like that. The fifth, the last page is like a whole year of just monthly treatments. And I was like I past the half-way point. So I am like two and a half, I am a half done, I am more than a half done. Then I kind of look back and you know, I can't believe I have already done all this, like it seems like it has been not that long I guess.*

Regardless of what children and their families focused on in "getting through," in the end they all had to focus on discovering the process that best helped them to get through the rough times. Although originally labeled or identified as the basic psychosocial process, it became obvious through the course of the study that having to get through or getting through was in fact part of the phenomenon or problem:

> *Sibling (17-year-old female): No, you kind of get sick hearing that (having to get through it) because my parents always say that. It is retarded cause you know you have to get through it,* ***LIKE EITHER WAY!*** *You are looking for an easier way*

or a better way to get through than just get through it, that is retarded. Unless you have terminal cancer and you have decided like not to get treatment or whatever, you have like , you are going to get through it either way, you know because that is just like stating the obvious!

Accordingly, "having to get through" was not sufficient enough to stand on its own as the basic psychosocial process as is supported by the following statement:

Sibling (17-year-old female): Obviously you have to get through it, I mean there is no getting around that. But I think the thing to do is just to try and make it as easy as possible or better like work around it.

Experiencing the numerous difficult times necessitated that children and families learn a process that would facilitate them in "getting through" as is evident by this comment by an adolescent in response to the question about how she dealt with having cancer:

Child with cancer (14-year-old female): Just dealing with it, putting up with it, getting through it! I guess it is just you learn to deal with it and learn what you have to do, (pause) learn how you are going to feel...

(3) <u>It is Never Over With, *A Never-Ending Journey of Rough Spots Along the Way*</u>

Presented as a theme, this key characteristic of the basic psychosocial phenomenon emphasizes that children and families will always have to experience getting through some rough spots in relation to the cancer-symptom trajectory; that is, even when the cancer treatment is completed and the children remain in remission. Regardless of the outcome, there would always be physical and emotional scars to remind children and families of the cancer; the basic psychosocial phenomenon of cancer would forever be with the children and families. For example, there was always the "hardness" related to dealing with the fear that the children's cancer would recur:

Mother: And even at the end it is not finished because then you still have to come for blood work, you still have to deal with it. Obviously the word you want to hear is that it is gone. And the words you want to here repeated afterwards is that it is still gone and it hasn't come back, like so.

Father: So I don't think the worry is going to be over probably for the rest of our lives. Because the thought of it recurring, we all know that cancer can recur at any time.

Father: If I could have cancer and I could take it from Jane and if I had to die I would rather do that because it, it is not right. And it will be over when they are putting me in a box and shoving me in the ground and she is crying because dad died when he was eighty or ninety years old. That is when it will be over for me.

The Basic Psychosocial Process of the Theory: Keeping the Spirit Alive

Equally important in the paradigm model is the category referred to as the basic psychosocial process. Basic psychosocial processes are derived from psychological and social processes, interactions or structures that are present within human interactions. They can best be described or depicted as a compatible change in strategies or patterns of behaviors that are carried out to achieve some desired outcome in relation to the phenomenon or problem under study (Berg, 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1994). The strategies are actions or interactions that result in response to the central phenomenon (Creswell, 1998). In response to the phenomenon of "getting through all the rough spots," "keeping the spirit alive" emerged as the basic psychosocial process. In addition to describing this process, this section defines: (1) what is meant by "spirit"; (2) "keeping the spirit alive" strategies; and (3) a key characteristic of the phenomenon, "You have to do what you have to do."

The process of "keeping the spirit alive" is depicted in Figure 1 by short arrows leading to and from the spirit and the four types of sense of self. Just as "getting through"

was frequently expressed throughout the narratives, so too was the importance of having or maintaining some degree of "spirit" as is reinforced by common statements such as "*at least (name of the child) still has his/her spirit with them*" or "*it is important not to give up the spirit!*"

Keeping the spirit alive referred to the children's and families' ability to not let the cancer-symptom trajectory get the better of them, or more specifically to not let the cancer destroy their spirit because indeed the cancer experience and all it rough spots could diminish the spirit in the children and families. No matter how rough the times became, it was important for the spirits of the children and all other family members not to be totally overpowered by the cancer-symptom experience as the spirit was vital to a state of being or existing in the world. It was vital to the children's and families' sense of self. In fact, during times of decreased physical, psychological, or emotional strength, it was especially important to maintain the strength in one's spirit. Keeping the spirit alive became a priority for the families:

> *Mother: She has a wonderful attitude, wonderful spiritual attitude, mental attitude, and that's excellent,* ***BUT IN ORDER TO MAINTAIN THAT, YOU HAVE TO,*** *you have to have your down time. I need her (daughter with cancer) to understand that when I see that she is fighting.*
>
> *Mother: It just amazes me, the depth of it you know. Like you think of her personality and how you've raised her and that. You hope that if you're faced with something so awful as a life-threatening disease that* ***THEY CAN FIGHT AND MAINTAIN SOME SENSE OF SPIRIT!*** *But the, the depth of her courage was really quite amazing, quite amazing. I don't think that I could hope to expect that from too many people. You know what I mean. And for such a young person you know.*
>
> Although parents experienced strong emotions when their children had to

experience the discomfort and pain from the cancer and its treatment, seeing the children lose part of their spirit was even more difficult to bear, even if it was temporary. Parents noted "*it was hard.*" But, as long as the children were able to maintain their spirit, parents and siblings were able to get through the cancer-symptom trajectory; that is, the cancer experience was more tolerable when the child's spirit remained intact. Even for children who were dying it was important and possible for children and families to maintain a sense of spirit. As well, it was important for families to keep the spirits of their dead children alive as this helped to build up spirits of each family member; the child's lingering spirit helped to keep the family going on as is evident by the following:

> *Mother: Oh, there are reminders of Tommy (dead child) in the house, it is strange. Like Lyn (the child's sister) found his slurpee spoon in the freezer the other night. She was O.K. with it. At first when Tommy died, it was tough going for her. But now she is O.K. The kids are busy, but are able to talk about Tommy. He'll always be with them (his siblings). He is still the hero and the fight is still going on!* ***THE ESSENCE OF HIS SPIRIT WILL ALWAYS BE WITH ME, WILL ALWAYS BE THERE.*** *The other day I felt him holding my hand in church. And when we went fishing with the "A" family (another cancer family) it was the first time without him, it was strange for all of us! But it was a sunny day and we all said "Tommy must have been responsible!"*

(1) <u>Definition of Spirit</u>

Spirit in this instance emerged as that very thing or essence within children and families that helped them to "get through" all the rough spots of the cancer-symptom trajectory; it was the spirit that helped children and families continue living, even in the face of death. The spirit represented a sense of an awareness of being in the world that involved more than just existence, but actually surviving and living.

The bi-directional nature of the "keeping the spirit alive" arrows in Figure 1

denote that both the spirit and sense of self interact to maintain a sense of spirit which in turn strengthens the self (refer to Chapter I for the definition of sense of self). However, while the spirit was connected to the individuals' and family's sense of self, the spirit could not be equated with it or any part of the self such as personality. Instead the spirit existed as a distinct entity. The spirit was viewed as one of the many components that made the individual or family unique; that made them who they were as illustrated by the following:

> *Father: Cathy was always a beautiful child. She was beautiful in* every way, *her looks, her hair, her spirit, her physical prowess, and so on.*

Additionally, children and families associated the spirit with the following four characteristics: (i) a particular mind-set or state of mind; (ii) a force within or a need to persevere; (iii) a passion or wonder for living; and (iv) a need to feel connected. The spirit as noted by one child was just not one thing but was "a combination of positive attitude, determination, perseverance,..." (refer to Table 4 for definitions).

(2) <u>"Keeping the Spirit Alive" Strategies</u>

Keeping the spirit alive was manifested in the form of the following strategies: (i) Coming to know what to expect; (ii) Holding on to the belief of getting through it; (iii) Putting it in its place; (iv) Taking one day at a time; (v) Being present; (vi) Taking care; (vii) Taking time for oneself; and (viii) Cherishing the good moments (refer Table 4 for definitions). All these strategies served to protect and strengthen or uplift the spirit. Children and their parents and siblings all relied on these strategies. The strategies could be used directly by the individual to help maintain his or her sense of spirit. Or, the

individual could use the strategies to help maintain or keep the spirit alive in others. As well, the strategies could also be used to maintain the sense of spirit within the family. Use of these strategies were especially important during those times when children and families were having to get through a lot of hard times or rough spots such as increased symptom distress. How successful one was at applying these strategies helped determined how children and families existed in their worlds or their way of being in their worlds.

(3) <u>You Have To Do What You Have To Do, *My spirit will do whatever to get through it and that means we do the best we can!*</u>

This theme emerged as a key characteristic of the "Keeping the Spirit Alive" process and its strategies. It reinforces that while all the children and families relied on the same eight strategies to get through the cancer-symptom trajectory, they nonetheless approached each strategy in their own unique way. Moreover, it was important for families to find ways that worked best for them, "*to find the best system*" or "*doing whatever it takes*" to get through the rough spots.

Intervening Conditions of the Theory Associated with Keeping the Spirit Alive

Intervening conditions refer to those factors that influence the use of the process-related strategies by facilitating or constraining the strategies taken within a specific context (Creswell, 1998; Strauss & Corbin, 1990). The conditions are depicted in Figure 1 on the outside of the model's circles. Arrows extending from the conditions pass through the outer circles to the core of the theory or the spirit; this is to underscore their influence on how children and families experience the phenomenon and process of the cancer-symptom trajectory. Although it is recognized there may be additional conditions

that influenced the process of keeping the spirit alive, for the children and families in this study the following two categories of conditions became especially predominant in determining how they got through the cancer-symptom trajectory: (1) the degree and type of social support; and (2) children's and families' approach to keeping the spirit alive.

(1) Degree and Type of Social Support, *My Circle of Family and Friends and the People you Meet Along the Way*

The degree and type of social support refers to the many different types of social support experiences that affected children's and families' responses to getting through the rough spots. Social support that was perceived as satisfactory and necessary helped children and their families deal with the cancer-symptom trajectory and helped them to keep their spirit alive, even during the times when children were not feeling well. Six types of social support experiences significant to children and families were identified: (i) support from my family or "*my family stands by me*"; (ii) support from other families; (iii) support from my old and new friends; (iv) support from hospital and clinic staff; (v) support from religion; and (vi) financial support (refer to Table 4 for definitions). Of all types of social support, it was the family unit that was most important to influencing the ill children's and all other family members' ability to get through the cancer-symptom experience:

> *Father: Yeah it's different for everybody but the one thing is "hang in there!". You got to make sure that your wife is number one for you and help each other through it because if you haven't got the support from each other, you are in trouble. Like it's long and make* ***sure*** *that you have each others support and keep it there.*
> *Father: Yeah, I think so, some ways, in a lot of ways it's brought us closer I think. Um (pause) there are some scars there and (pause) they show up every once in*

awhile, the behaviour or (long pause) I think the close family is kind of what got us through it.

Most of the families became closer because of having to get through the cancer-symptom trajectory:

Child with cancer (14-year-old female): We (talking about another child with cancer) found that first of all it brings you a lot closer to your family because they are the ones that are with you, for all of it, for everything like that. And she said "you know by the end of treatment," not all the time, but for the most part, and me and her both agree on it that we would rather rent a movie and sit home and watch it with our families, then go out and sit in someone's basement with our friends...Well, you kind of knew that your family cared but, it is just that they never really had a chance to show you. It kind of gives them a chance to show you.

Child with cancer (11-year-old female): It made us closer.

As well, "*keeping the family together*" was just as equally significant to children and families as it was to get through the cancer-symptom experience:

Father: That's what went through my mind. Its like "Oh my God! My child is sick, oh my god, what's going to happen to the family?" It was like a double-barreled shot gun going in two different directions its like "Oh what are we going to do?

Father: Um (pause) we got to work at it (keeping the family united)...Yeah, you've got to work at it, you can't stop.

Unfortunately, not all family units remained intact:

Child with cancer (11-year-old male): (sighs) My dad, um (long pause) he left us. All fathers do that actually because they think they can't handle it.(pause) Well not all fathers but my dad he left the first of January (sighs).

In addition to the five types of social support, the following three characteristics emerged: (i) Even though we are different, we are not alone; (ii) I need to give back; and (iii) I would not change anything. These three characteristics reinforced the significance

and importance that the intervening condition, social support, had on the children and families because of the cancer-symptom trajectory (refer to Table 4 for definitions).

(2) Children's and Families' Approach

The second intervening condition, children's and families' approach to keeping the spirit alive, refers to the approach children and their families adopted with respect to keeping the spirit alive. The approach was determined or based on how they defined or viewed getting through the cancer-symptom trajectory. A commonly held view for all families was the belief that they had no choice in getting through the cancer-symptom trajectory. Accordingly, the children and their families approached getting through by moving forward and plodding on. The strategies of keeping the spirit alive were readily adopted in order for them to be able to move forward and moreover, attack the very nature of cancer that was threatening their sense of spirit. While all families believed that they had no choice in the matter of getting through the cancer-symptom experience, additional views were also adopted that added to how they approached the keeping the spirit alive strategies. Specifically, families at times viewed the cancer-symptom trajectory either as a challenge and test of one's strength, or as an overall loss and devastating defeat. These additional beliefs resulted in families applying the strategies even more intensely (refer to Table 4 for definitions).

Consequences of Keeping the Spirit Alive: A Way of Being

Consequences refer to the outcomes that result in relation to use of the process and strategies to manage or deal with the central phenomenon (Creswell, 1998; Strauss & Corbin, 1990). Consequences may result from taking action as well as by not taking

action. The main consequences that children and families experienced in response to keeping their spirits alive were related to how children and their families existed in their worlds or their way of being in their worlds. Specifically, this category was referred to as "a way of being in the world" and was represented by three subcategories: (1) how children and families lived through the cancer-symptom trajectory; (2) how it affected their sense of self or the changing sense of self; and (3) the degree of well-being experienced by children and their families. A way of being in the world is shown in Figure 1 as the outer circle of the model with bi-directional arrows. Again the bi-directional nature of the circle allows for a way of being in the world that is fluid-like, influenced by the types of rough times experienced as well as the keeping it alive strategies. That is, a way of being in the world is dynamic and not fixed. For example, living through it, ranged along a continuum from barely surviving cancer, to surviving, to moving beyond surviving, to living, and lastly to celebrating life. Like living through it, changes in the self did occur, were dynamic, and were associated with how one lived through the cancer. For example, living life through the cancer-symptom trajectory as opposed to just surviving life, only reinforced the child's and family's sense of self. A sense of well-being or the degree of comfort experienced by the children and families also occurred along a continuum, from feelings of being at ease with oneself and one's condition, to feelings of extreme distress, lacking any sense of solace and inner peace. Lastly, three key characteristics emerging from the data also helped to define this category: (i) Cancer is only one part of my life; (ii) My life is on hold; and (iii) Life is never the same. (Refer to Table 4 for definitions).

Conclusion

This chapter provided a overview of the first substantive theory: Keeping the Spirit Alive. Most significant about this theory was that it was important for children and families to experience "getting through" as opposed to "getting over" all the rough spots of the cancer-symptom trajectory. Considering symptoms were identified as "rough spots" by children and families, this theory provided an understanding of how symptom experiences could make life difficult for children and families. However, a more thorough understanding of what role the cancer-symptoms played in the children's and families' lives is provided in the next two chapters which describe the substantive theory: Children's and Families' Lived Experience of Childhood Cancer-Symptoms.

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
Basic Psychosocial Phenomenon: **"Getting Through all the Rough Spots"**	• Represents the complexity and "hardness" of the cancer-symptom trajectory; that is, cancer was full of many "hard" and difficult times for children and families. •Many different types of rough spots • Additionally not only did children and families have to acknowledge or encounter the rough spots, but they also had to confront them one by one, and step by step. They had to "get through" them as opposed to "get over" them	•All rough spots shared five key characteristics: i. Uncertainty - referred to a state of not knowing and living in the unknown. Skepticism, a lack of security, indecisiveness, and self-doubt were all part of feeling uncertain. ii. Multitude of feelings - referred to the children and families experiencing a multitude of feelings in relation to the rough spots. Most prominent were the feelings of sadness and joy. Feelings described like a "*roller-coaster experience.*" ***Siblings especially experienced cancer as a "sad" experience.** iii. Restrictions - referred to the psychological and physical limitations and barriers that resulted because of the rough spots. The restrictions affected every aspect of daily life. *"Life on Hold!"* iv. Extra work - referred to the new roles, activities, and responsibilities that resulted because of the rough spots. This included extra physical, mental, social, and emotional work. v. Loss - referred to the multiple losses experienced because of the rough spots. Associated with the feeling that something had been taken away. The range of losses included loss of independence and function, missing work or school, missing friends and family members, and the ultimate loss: death.
•**Subcategory: It is Never Over With,** ***A never-ending journey of the rough spots***	•Refers to the never-ending experience of having to get through all the rough spots. That is, even when treatments are over and the children remain in remission, children and families will always experience cancer-related rough spots.	**Table 4 continued➡**

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
Basic Psychosocial Process: **"Keeping the Spirit Alive"**	•Referred to the children's and families' ability of not letting the cancer get the better of them or not letting the cancer destroy their spirit. The individual's and family's spirit became vulnerable because of all the rough spots. The process was manifested in the form of eight strategies.	•While all children and families relied on the process and all its eight strategies to get through the rough spots, they approached each strategy in their own unique way.
	•Spirit emerged as that very thing or essence within children and families that helped them to "get through" all the rough spots of the cancer-symptom trajectory.	•Characteristics of the Spirit: i. A particular mind-set - referred to a particular state of mind that helped the individual get through the rough spots. There was no one right or correct type of mind-set; each individual had their own unique mind-set which reflected how one looked at life. ii. A force within or a need to persevere - referred to a quality within the individual that caused them to fight or continue on despite all the rough spots. The "fighter within!" iii. A passion or wonder for living - referred to having or living a life that was meaningful; having a passion meant having some reason to live. iv. A need to feel connected - referred to being connected to others in the world and valuing/experiencing life in the context of caring connections.
•Subcategories: "Keeping the Spirit Alive" was manifested in the form of eight strategies.	**•Eight strategies:** i. Coming to Know what to Expect - referred to the children and families developing a knowledge base about the world of cancer in which they were now a part of; it was important for them to come to know everything about the cancer-symptom trajectory.	•need to be attentive •involved watching, observing, listening •becoming accustomed to the new routine •knowing what to expect helped the families to plan ahead to some extent •learning to expect the unexpected •sometimes families experienced information overload - timing and readiness to find out was critical •sometimes it was better not to know

Table 4 continued➡

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Subcategories:** **"Keeping the Spirit Alive" was manifested in the form of eight strategies.**	**Strategies cont** ii. Holding on to the Belief of Getting Through It - referred to children and families developing and maintaining an overall belief that they were going to get through all the rough times.	•difficult to do at times •had to overcome and confront many fears •having a strong religious faith helped •knowing others had a strong belief helped •especially important to children that parents believed that the children had the strength to get through it •having faith in oneself
	iii. Putting it in its Proper Place - referred to children and families uncovering reasons and giving meaning to having to experience "getting through cancer"; in effect it involved trying to make some sense out of a "horrible" situation.	•some reasoned that getting through was necessary for the survival of the family unit •some reasoned that it helped to strengthen the individual and family, and helped one to feel more connected to one's family •some reasoned that it happened to them because they could better deal with it compared to others •reasoned that things could always be worse •some reasoned that God would not have let cancer happen to them if God felt that they could not handle it •some reasoned that life made no sense
	iv. Taking One Day at a Time - referred to children and the families having to live life more in the present or in the very moment; it involved focusing all their energy in getting through the cancer on a day to day basis	•involved balancing the present with the past and future •having some plans for the future meant there was hope •sometimes involved living "minute-by-minute" •involved learning to wait for things •helped families to appreciate the importance of just being in the world
		Table 4 continued→

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•Subcategories: "Keeping the Spirit Alive" was manifested in the form of eight strategies.	**Strategies cont.** v. Being Present - referred to the need for children and their families to be with others; be there for others; and just be there for oneself. Being present was important to feeling a sense of connectedness as opposed to feeling alone or abandoned in the world.	•important to be around significant others •really important for families to "be with" and be there for their children •involved accepting and understanding the other person •"being there" sometimes involved just sitting beside the individual •"just being"involved the individual maintaining some sense of presence in the world
	vi. Taking Care - referred to the need for children and families to try to ensure an environment that was physically and psychologically safe for those they loved. It involved doing whatever one could do to prevent any distress or harm happening to the ill children as well as every other family member.	•involved focusing on protecting the children and others •need to be vigilant -staying on guard and watching over for impending danger •finding ways to make children and others comfortable
	vii. Taking Time for Oneself - referred to the children and other family members finding and taking time for themselves; it involved trying to take some sort of break from the cancer.	•need for some personal space •involved doing things that were important to the individual •need to think about other things in life besides cancer
	viii. Cherishing the Good Times - referred to children and families not only experiencing some good amongst all the bad times, but also learning to appreciate and welcome the good times; it involved finding and experiencing some joy in life.	•involved cherishing any good news; experiencing planned and unplanned events that resulted in pleasure/joy •realization that there were "good days" as well as "bad days" •experiencing "*special moments*" **Table 4 continued➡**

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Intervening Conditions: Social Support**	•Social support referred to the many different types of support experiences that helped children and families to keep their spirits alive.	•"Even though we are different..." referred to individuals not feeling that they were "alone" in getting through the cancer experience and this was because of the support they received within the family unit and from other families. Despite all the differences between individuals and families, they shared getting through the cancer experience. •"Need to give back" referred to the importance of not only receiving social support but also providing social support; it was important to children and families to be able to help others going through the cancer-symptom experience. •"I would not change anything" referred to the importance support played in the families' lives; it was this support that made cancer bearable. Moreover, some would not have changed anything because of the support that they received and all the new people that had entered their lives.
	•Included six types: i. Support from my family - referred to knowing that the family would always be there for the individual family member and that the individual family member would be their for the family unit. •having a strong family base prior to the cancer experience was critical for the ability of families to get through all the rough time and to survive as a family	•most important form of support •difficult for the family when the child was hospitalized as it meant that the family was not together •maintaining the family unit was just as important as beating the cancer •fathers and siblings both expressed the desire to be more involved in the children's care - at times they felt like outsiders •support in the form of meeting information, practical, and emotional needs

Table 4 continued➡

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Intervening Conditions: Social Support**	**Types of support cont.** ii. Support from other families - referred to the support received from other children with cancer and their families. Families viewed other cancer families as "*My new family*" or "*My second family*." They were members of a new community	•involved a special understanding between families •"being there" for other families during the difficult times was valued •encouragement from other families was valued •death of other families' children extremely difficult to get through
	iii. Support from my old and new friends - referred to friends that children and families had before and after the cancer diagnosis.	•practical support from friends was very important •emotional support in the form of understanding and not judging •discovered which friends were their true friends - often it was the people one least expected •just "being there" for the children and/or family was what was valued the most
	iv. Support from hospital and clinic staff - referred to the support children and families from the professional care givers. Also referred to as "My new family" or "My second family."	•important to establish bonds with professional care givers - to feel connected •practical and emotional support was equally valued •difficult to break away from the second family" - experienced a loss
	v. Support from religion - referred to support derived from maintaining a belief in some type of God.	•those who were "religious" seemed more at ease, despite all their suffering •for the most part religious faith helped families to be more accepting of the cancer, but they still experienced the hardness •at times became angry with God
	vi. Financial support - referred to the support that enabled families to deal with any additional financial costs that resulted because of the cancer.	•adequate finances made life a lot easier •all families experienced additional costs such as travel and parking expenses •compounded by a loss in income related usually to the mothers quitting their jobs to care for their children •all families experienced some financial strain

Table 4 continued→

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Intervening conditions: Children's and Families' Approach**	•Referred to how children approached the "keeping the spirit alive" strategies; determined by how they viewed getting through the cancer experience. •Included three types: i. Just having to do it!: "You have no choice!"	•all adopted the approach of "just doing it." •at times families would adopt additional ways to approaching the strategies •adopts the strategies without question - readily adopted •applied in a careful manner •moved forward, plodding on
	ii. "A test of one's strength": The challenges	•approach the strategies with more intensity •wanted to prove to others how strong they were •"rising above the situation" •more positive attitude to life
	iii. "An overall loss": Devastating defeat	•again approaches the strategies with more intensity, but for different reasons •families had not given up - they just approached life and cancer with greater urgency •more negative attitude to life - many barriers

Table 4 continued➡

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Consequences of Keeping the Spirit Alive:** **"A Way of Being in the World"**	•"A way of being" referred to how children and families existed with in the world in the context of having to get through all the rough spots of the cancer-symptom trajectory; influenced by the ability to keep the spirit alive. As one mother expressed: "There is a difference between just surviving cancer and actually living through cancer!"	•"Cancer is only one part of my life" reflected that although cancer became a big part of the children's and families' lives, it was still considered by them to be only one part of their life. Except when the symptom trajectory became really intense, cancer did not totally over take their lives. Although difficult at times, the children and families, did to varying degrees try to incorporate other non-cancer events into their lives •"My life is on hold" referred to not being able to immediately continue on to the same degree as in the past with their present day to day plans of life such as going out with friends, continuing with school or work, going to their favorite restaurant or participating in their favorite activities such as cheer leading or just playing with friends. Although all children and families expressed that there was more to them then their experience with cancer, they nonetheless all experienced some degree of their life being put on hold. All families were in a period of waiting or they experienced numerous waiting periods. •"Life is never the same" referred to how the children's and families' way of existing in the world changed forever because of the cancer-symptom trajectory. From the moment cancer entered their lives, it became apparent to children and families that the world as they knew it, would change forever. **Table 4 continued ➡**

TABLE 4. KEEPING THE SPIRIT ALIVE: CATEGORIES

CATEGORIES and SUBCATEGORIES	DEFINITIONS	CHARACTERISTICS
•**Consequences of Keeping the Spirit Alive** **Subcategories: Represented by three subcategories**	•**Subcategories:** i. Living through it - referred to how children and families lived life while getting through all the rough spots of the cancer-symptom trajectory.	•ranged along a continuum from barely surviving cancer, to surviving, to moving beyond surviving, to living, and lastly to celebrating life •it was important for children and families to have a life not totally dominated by the cancer •the bonds/connectedness that existed between children and families helped to determine how they lived life •during the more difficult times, the focus was on surviving the cancer - living in the cancer world was more dominant
	ii. A sense of self or the changing self -referred to the self and how it changed in response to the changing cancer-symptom trajectory.	•ranged along a continuum from feeling least like oneself to feeling more like oneself •Experiences changes in self throughout the cancer especially during the most intense periods
	iii. A sense of well-being - referred to the degree of comfort or psychological ease that one could feel; it involved achieving some sense of solace and inner peace.	•developing a sense of belonging to others and feeling connected was significant to a sense of well-being especially during the times of increased distress

CHAPTER V: PRESENTATION OF THE FINDINGS

Children's and Families' Lived Experience of Childhood Cancer-Symptoms: An Introduction to the Theory

The second substantive theory that evolved from the findings is entitled: "Children's and Families' Lived Experience of Childhood Cancer-Symptoms." This theory was nested within the first substantive theory, Keeping the Spirit Alive, and reflects how getting through the cancer and maintaining a spirit was so much influenced by and tied to the cancer-symptoms. A second theory was substantiated when it became evident there were two more core categories emerging from the data. Although these categories could be explained to some extent by the first theory, they nonetheless warranted a theory of their own. The two core categories identified are as follows: (1) Personal meanings of the cancer-symptom experiences; and (2) Passage through the transition periods. The first core category represents the basic psychosocial phenomenon of the theory and refers to the phenomenon of children and families giving meaning to the cancer-symptom experiences. Symptoms were experienced not only as physical entities but were lived by the children and their families through the meanings that they gave them. The personal meanings affected how children and families viewed the overall cancer experience and could increase or decrease the hardness of cancer. The second core category represents the basic psychosocial process of how children and families moved through the cancer-symptom trajectory. "Passage through the transition periods" involved experiencing change in the "keeping the spirit alive" strategies. The process of "passage through the transition periods" helped the children and their families deal with the

personal meanings of the cancer-symptom experiences. It helped children and families to integrate the personal meanings into their daily lives so that they could survive and live through the cancer-symptom experiences.

In this chapter, the first core category, "personal meanings," is the focus of discussion with attention to the changing sense of self and changing body. The second core category, "passage through the transition periods," is discussed in the next chapter and completes discussion of the second theory. Consideration of how the cancer-symptom experiences relate to the phenomenon of getting through all the rough spots and the process of keeping the spirit alive is also discussed in the next chapter.

Introduction to the Basic Psychosocial Phenomenon: Personal Meanings of the Cancer-Symptoms

Although children and their families consistently emphasized that cancer involved many aspects, events, elements, and rough spots, the cancer-symptoms as represented by personal meanings especially were significant to how cancer was experienced by children and their families. Even during those periods when the children were symptom-free, the living through the overall cancer experiences and the meanings assigned to it were still determined by the symptoms or the lack there of. The presence or absence of symptoms also helped to determine the children's and their families' degree of uncertainty, feelings, restrictions, extra work, and loss experienced. Ultimately this had an effect on their quality of life, and their need to keep their spirits alive as is evident by the following:

> *Mother: Unpredicted symptoms are big things cause I don't know where the Hell they are coming from, like what is this (long pause). Symptoms are important...Yeah! To me symptoms are like signs of trouble. I mean something is happening and...*

The symptoms served as a source of knowledge as well as concern for children and their families as is evident by the following:

> *Mother: Well his body is telling us something, so, like the signs are there, it is just a matter of figuring it out!*
>
> *Father: She was complaining of stomach-aches (pause) and she vomited, she would get tired, and sometimes she had fever problems. We would bring her to Emergency. You know, once again you start worrying more.*

Moreover, the symptoms helped to shape how the children defined their worlds and their changing self as well as changes within the family unit. While the identification of specific symptoms such as nausea or fatigue in and of themselves added to an understanding of how the children were medically progressing from a disease perspective, they provided little understanding as to how the children and families were affected personally. It was only when children and families talked about how the symptoms made them feel within the context of the whole cancer-symptom experience that one could get a sense of how the symptoms affected them and their quality of life. Considering specific symptoms solely in and of themselves provided little insight into what the children and families were thinking and feeling, or what they were going through. Understanding could only be achieved by considering symptoms and their effects within the whole cancer-symptom trajectory because individual symptoms took on different meanings depending on the context within which the symptoms occurred.

For example, one mother expressed no problems in caring for her child's mouth sores and the resulting mouth pain that was caused by the chemotherapy. Although feeling bad for her child's pain and suffering, she expected the mouth sores and pain, and

referred to them more like side effects of the chemotherapy treatment. In contrast, the child's mouth sores and pain took on a whole different meaning when they occurred after a bone marrow transplant. To this mother, the mouth sores although expected and still a major concern, were now viewed to be more serious. Although she would do his mouth care during the chemotherapy, she felt the nurses should be the ones doing the mouth care after the bone marrow as the mother noted "*they knew what to look for.*" The mouth sores after the bone marrow transplant now became something "*repulsive*" to her because of how they looked, how they made the child feel, and the fact nothing helped to make her child carry on with some normal activities:

> *Mother: This is worse...How he feels, the mouth sores are* ***GROSS*** *!(pause) Like when he was in with the sores down his throat and stuff, he wasn't spitting up all that stuff. I was able to do the mouth care and he was able to take Nystatin (medicine) and he was able to...You know a warm blanket and some morphine calmed him enough to breathe and it cleared up. But now he is throwing up stuff I have never seen, throwing up like that bile stuff, it is just gross and the glut that collects in his mouth is just gross. Yeah, like horrible, horrible mouth sores cause I can see them all over him.*

The symptoms were not so much mere side effects or single states that resulted from a particular cause that led to specific effects or outcomes. Rather they represented multiple levels of meanings that were connected to the changing context of the children's and families' experiences. This led to the development of the second substantive theory which was guided by the core category: Personal meanings of the cancer-symptom experiences (see Figure 2, p. 177). This core category referred to the meanings children and families assigned to the cancer-symptoms as they were experienced within a particular context. In Figure 2, the personal meanings are situated within the spirit. The

"keeping the spirit alive" process extends from the spirit and varies in response to the personal meanings that children and families assigned to the symptom experiences. Eight personal meanings emerged as follows: (1) I have a sick stomach...I feel sick, I feel bad; (2) I feel yucky, crappy, shitty...I feel really sick, I feel really bad; (3) I am sore...boy, my body hurts; (4) I am cranky...I am not myself; (5) I am just experiencing an everyday thing...I am just a little sick; (6) I feel wiped out...my body is just too tired for me to care; (7) I am scared...I don't know what is going to happen to me; and (8) I am hurting...my heart is sad. Although each symptom experience was unique they did share the quality of being "hard" on the child and family. Overall, the cancer-symptom experience was best summed by families as a "*bittersweet experience*" and is depicted in Figure 2 as a curved line situated directly above the eight personal meanings.

"My changing self" and "my changing body," subcategories of the core category, personal meanings, are also depicted in Figure 2 as curved lines directly below the categories of the personal meanings and "keeping the spirit alive" strategies. These subcategories represent how the sense of self of the individual and family as well as the children's sense of their bodies change throughout the cancer experience. The changes discussed in this chapter are interpreted within the changing personal meanings of the cancer-symptom experiences.

The next sections of this chapter first describes the eight personal meanings of the cancer-symptom experiences. Following this discussion, "my changing self" and "my changing body" are elaborated on. The complete theory is depicted in Figure 3 in Chapter VI (p. 257). A summary of the findings presented in Chapter V has been provided in

Table 5 at the end of this chapter (p. 251).

Key:

My Changing Self

My Changing Body

All The Rough Spots

Figure 2 Personal Meanings: The Basic Psychosocial Phenomenon of Children's and Families' Lived Experience of Childhood Cancer-Symptoms

Personal Meanings of the Cancer-Symptom Experiences

(1) I Have a Sick Stomach, Sick Head...I Feel Sick, I Feel Bad

The phenomenon of "feeling sick" involved those experiences when children were not only sick with cancer, but because of the cancer, felt sick physically. Although by the very virtue of being diagnosed with cancer, children were labeled as being "sick," the children did not necessarily have to feel sick. They could be sick with cancer and yet feel well:

> *Child with cancer (7 ½-year-old male): I was not that sick...*
> *Interviewer/Researcher: What does "not that sick" mean? What does that mean?*
> *Child with cancer (7 ½-year-old male): Um...I was feeling good.*

> *Child with cancer (11-year-old male): I feel like I don't even have cancer sometimes.*
> *Interviewer/Researcher: Well do you feel like that right now?*
> *Child with cancer (11-year-old male): Yes (during this time the child had minimal symptom distress)...Because it's never on my mind.*

> *Interviewer/Researcher: Do you feel like you are sick?*
> *Child with cancer (9-year-old male): Yes, because (pause) my tummy feels sick.*

Children described themselves as being healthy when they experienced few symptoms:

> *Interviewer/Researcher: What does it mean to be healthy?*
> *Child with cancer (7-year-old female): No runny nose, no cough, nothing...*

However when symptom distress or discomfort was experienced by the children, it was then that they felt sick and associated feeling sick with being sick and being part of the "sick world." It was the experience of feeling sick that made the cancer seem real and more difficult to bear. As was noted by one child "*feeling sick is worse than being sick!*"

Usually the discomfort associated with "feeling sick" was experienced in one or two areas of the children's bodies. With this symptom experience children often were able to express how and why they were feeling the way they were; they had less difficulty in both pinpointing the source of their distress and describing how they felt:

> *Child with cancer (15-year-old female): You feel bad, but you know in what way. When you are feeling like vomiting or nausea, I guess the word for feeling bad is nausea or you have a headache like those are the words to describe it (feeling bad) because you know exactly what is wrong with you.*

"*Feeling bad*" most often was linked to the side effects of the cancer treatment. Accordingly, although "*feeling bad*" was an unpleasant, undesirable, and a hard state to experience, it nonetheless was perceived as something to be expected. However, while it was to be expected or even if children and their families knew it would be temporary and would eventually resolve, it did not make it easier for the children to experience:

> *Child with cancer (15-year-old female): It is not so bad getting the medication, because once you have your I.V. (intravenous) started it is just another liquid dripping into you. But you know that later it is going to make you so sick and that is what is so hard about getting it because you don't want to get sick later.*

Although children could feel bad, this did not necessarily mean that they were perceived by others to be "*really sick.*" In other words, the children could feel sick, but the families did not necessarily view the children to be really sick in the sense that the cancer was no longer under control:

> *Mother: Nothing has changed....he still has the migraines...but at least his cancer is under control.*
>
> *Mother: Things are O.K., but he is nauseated and tired...this is to be expected.*

Moreover, while the "feeling sick" experience was taken seriously by children and

their families in relation to the distress and suffering that resulted from it, it was never associated with the children not be able to get through the cancer experience. It was part of the rough spots of cancer.

When children and their families were asked to describe signs and symptoms that were associated with feeling bad or sick most, including the siblings, associated "feeling bad" or "feeling sick" with nausea and vomiting or as the children would say "*a sick stomach or sickness or pain in the stomach*":

> *Mother: It is tough, there were times when she could hardly keep anything down for about four days. I think it might have has something to do with the anesthetic but I am not sure. Yeah so we told the doctor how sick she was after...*
>
> *Interviewer/Researcher: So do you remember what that was like starting your medicine for the first time?*
> *Child with cancer (11-year-old female): Well, I felt sick ...I think a little bit nauseous and a little bit dizzy...and then school started and I missed almost the first day of school.*

The symptom of nausea and the vomiting associated with it, was very visible to children and their families, and therefore, legitimized the children's feelings of sickness. In fact, how sick the children were judged to be, was in part based on the severity of the children's experience with nausea and vomiting. Symptoms that were less graphic, especially fatigue, although contributing to the children's sickness, were in fact not always associated with the "feeling bad" experience. Some parents and the children did not even identify fatigue as a "feeling sick" symptom experience:

> *Mother: He was just tired. Not so much sick, not throwing up and not wanting to eat and stuff. This time he was just plain tired and he would eat half asleep but he was still eating.*

However, not all children experienced nausea and vomiting as the main symptom

of the "feeling sick" experience. Instead of feeling bad or sick in their stomachs, some felt sick more often in another part of the body such as in their heads in the form of a headache.

In addition to experiencing "feeling sick" from symptoms such as nausea, the children and their families also had to experience changes in their daily routines in order to truly qualify for the "I am feeling sick" status. That is, the children and their families were no longer able to carry out all of their normal routines or day-to-day activities. However, it did not mean that everything in their lives was put on hold. The children's spirits were temporarily challenged or weakened, but the children were still able to continue to some extent in their day-to-day living. Although the children concentrated more on their physical bodies during the "I feel sick" periods and did not feel completely whole, their sense of selves were still not totally overcome by the symptoms. The children were described as "*more or less like their old self*"; that is, they still exhibited a part of their physical, emotional, social, and mental self even though the total self was not as strong. As well, the children's bodies were much more sensitive; that is, they sensed every feeling and change that was brought upon their bodies. The children, however, still tried to remain connected to their old way of life:

> *Interviewer/Researcher: How different was that day compared to the other days of the week?*
> *Child with cancer (7-year-old female): Just that I threw up Monday.*
> *Interviewer/Researcher: Were you still able to play and do everything that you normally did?*
> *C: Yeah.*

When children had to give up some of their favorite things such as missing some school days or not being able to go over to play with their friends, they would try to

compensate for such losses. Alternatives were put into place such as inviting one good or special friend over to their home to play with them:

> *Child with cancer (11-year-old male): He was just my one special friend who would always come over. He even sent me a letter.*

Likewise family members tried to remain connected to some of their old ways of life in order to maintain the family's sense of self and keep the family unit together. Keeping things "normal" was also viewed as one way to make things a little better for the ill children:

> *Sibling (14-year-old): I just tried to keep doing like the regular stuff I was always doing like...Our house was pretty normal but she had her central line and that is really weird to see something sticking out of her...Well I don't know if you could really say "normal." Things did change obviously but it wasn't like it was a whole lot different. We had to do all the things...and then she just looked bad too like because she was so skinny and everything. I think we tried to keep everything normal probably for her too, just...*
>
> *Father: If she eats a little bit, she may want to throw up and that's probably you know (pause) any of those symptoms are showing the sickness. But if she can keep up on the bike, let her do it.*

However, the "feeling bad" cancer-symptom experience made life harder for families with respect to the extra restrictions, work, uncertainty, loss, and so on, that resulted from the children "feeling sick" and the families struggling to maintain some unique family and individual functions and roles:

> *Mother: It was hard...Trying to get a family routine again, be a family. But still running back and forth to the clinic... And then he picked up things and had to come back to clinic.*
>
> *Father: Sometimes you can't, sometimes you can (in relation to maintaining a "normal" life), I mean. And certainly in terms of my job there has been you know a lot of days where I haven't been there and you know I think it puts stress on other people in the office and you know I can't say it hasn't affected my work, it still obviously has affected my work during those times.*

Family members could not always be together and like their children, parents had to make changes in their lives:

> *Father: Well we (parents) said "well we have three kids at home, we can't just (snaps his fingers) up and leave"(in reference to taking their ill child to a hospital in Saskatoon)...But what we did, we found a babysitter, packed our bags and went to Saskatoon. We had made arrangements that I would stay and I had taken time off work...*

Time and experience affected whether or not children experienced the "I feel bad" experience. The more frequently children experienced a certain symptom coupled with the children's and families' ability to manage them helped to decrease the children's "I feel bad" experiences. Children and their families had at least some idea how to make such experiences not as bad or they knew how to make one feel better to some degree:

> *Child with cancer (15-year-old female): Like I can remember if I was sick to my stomach and was going to throw-up, I usually feel better right after I threw-up you know, because it, I don't know, it just makes you feel better right afterwards. I don't know if it makes you feel better in the long run (laughs), long term.*

However, there were times where even the most experienced child or family had problems reducing the symptom distress. As was the case for all of the symptoms experienced by the children, total relief was not always reached. Key phrases such as "*sort of,*" "*a little less,*" "*a little,*" and "*I guess*" were often frequented in the children's, parents', and siblings' talk of symptom management and were indicative of the fact that many of the children's symptoms were not completely eliminated:

> *Mother: He still had a headache but it lessened a degree.*

> *Child with cancer (7-year-old female): Well it (medicine for nausea and vomiting) took away most of it, but I still threw up a little bit.*
> *Interviewer/Researcher: Did you still feel sick in your tummy too?*
> *Child with cancer (7-year-old female): A bit.*

For some children, rest or sleep was the their only option in dealing with their symptoms. Sleep was valued by the children not because it helped to relieve specific symptoms, but because it took the children out of the realm of the world of feeling anything, even if it was just temporary:

> *Child with cancer (9-year-old male): Sleeping that's because my mind was totally off things right!*
>
> *Interviewer/Researcher: Anything that you could do to make yourself feel better?*
> *Child with cancer (7-year-old female): No, I just laid in bed...Just lay in bed.*
>
> *Interviewer/Researcher: What things helped you the most when you had cancer?*
> *Child with cancer (7 ½-year-old male): Mm...having sleep.*
>
> *Child (5-year-old female): My sore tummy, I just could not get to my bed fast enough!*

At times the treatment undertaken to relieve the children's symptoms made the children feel even worse:

> *Child with cancer (14-year-old male): I was kind of almost ticked off cause they were using Maxeran and Benedryl (drugs to treat nausea) and then finally after I refused to take it cause, it would be like I would take it and then my parents would either have to scrape me off the ceiling or scrape me off the floor. And then my last treatment, they found out that what was easier and worked better was Gravol.*
>
> *Child with cancer (4 ½-year-old female): I was feeling good. They give me special stuff that makes me gooey in the head. I hate that stuff.*

Arriving at some degree of symptom relief often involved a "trial and error" approach by children and their families, and the children discovering and trying out self-initiated strategies:

> *Child with cancer (16-year-old female): They just told me to take Tylenol (for headaches). They told me to take two extra strength and I was taking three extra strength. And it didn't really, it just kinda made it a little bit less... Yeah, I even tried having morphine for...Like I had mouth sores, so I had morphine right? But when I was done with my mouth sores I still had some morphine left so I even*

tried taking that with my headaches and that didn't work. And so I just laid down a lot and put pressure on my head. That sounds kind of weird, but it felt good to like kind of push on my head.... I just figured it out (laughs)....

Interviewer/Researcher: Did anything help to take away the headache?
Child with cancer (7 ½ -year-old male): Calming down...I just talked...I used to do that all the time.

Child with cancer (4 ½-year-old female): My brain just kept on thinking...Just to get rid of this pain. And it helped me not think about dying.

Although many children in this study engaged in self-initiated strategies that helped to relieve some of the symptom distress, such strategies were not always recognized or known by the professional care givers, nor were children encouraged to use these strategies.

The difficulty in managing and controlling symptoms accordingly resulted in the children and their parents believing or accepting that some sort of unresolved symptom distress was to be expected, that it came along with the territory. An unfortunate consequence of symptoms that were treated but unrelieved was that some children and their parents gave up on managing subsequent symptom experiences. In fact there were times that when the "I feel sick, I feel bad" experiences could evolve into "I am feeling crappy" experiences (refer to personal meaning #2) if children and their families had problems managing the symptoms. However, there were also the times when the "I feel sick, I feel bad" experiences evolved into "I am just experiencing an everyday thing" experiences (refer to personal meaning #5) . In such instances it was not always that the suffering and hardness associated with such experiences became less, but that the children and their families were now accepting them as part of their daily routine within the context of the cancer-symptom trajectory.

(2) I Feel Yucky, Crappy, Shitty...I Feel Really Sick, I Feel Really Bad

Symptom experiences identified or referred to as "*yucky,*" "*crappy,*" or "*shitty...*" involved those experiences in which children not only felt "*really sick*" but were viewed by themselves and others to be "*really sick*":

> *Child with cancer (11-year-old female): Like it (the chemotherapy) makes you really sick and yucky!*
>
> *Child with cancer (16-year-old female): When I feel crappy, I feel like a cancer patient!*

Not only did such experiences result in the children feeling "*yucky*" or "*crappy*" or "*shitty,*" at times parents would themselves feel "*shitty*" having to watch their children suffer so much. Likewise the siblings also experienced feeling yucky in response to seeing their siblings' suffering:

> *Sibling (8-year-old female) And sometimes his eyes would be like more shut or because probably because most of the time when you have cancer you get really tired. You need to take all sorts of needles and stuff. Yeah most of the time when I visited him in the hospital, um, he would be asleep. I felt kind of like yucky because I wouldn't be able to see him. Like he wouldn't pay very much attention to me.*
>
> *Sibling (12-year-old male): Seeing her sick is hard...Like eating and (pause) throwing up, her eyes slightly closed (pause) walking slowly, throwing up when she eats stuff.*

"*Feeling yucky*" experiences were perceived to be more than the children's "*regular*" or "*normal*" symptoms that would resolve once the children completed a specific phase of the treatment course. Instead, the symptoms were no longer viewed as "*normal*" because they were experienced more intensely and for the most part, took longer to resolve. "*Feeling yucky*" was associated not only with the cancer treatment but

also with the cancer itself. Whereas with the "*I am feeling sick*" experience there was always the expectation that children would get over the physical sickness, children and families did not immediately assume this with the "*feeling yucky*" experiences. Families experienced much more uncertainty with the "*feeling yucky*" experiences. The children and their parents and siblings all feared that the symptoms would not resolve or that they would not being able to control the symptoms. It was the "I feel really sick" symptom experiences in which parents viewed their children to be really sick. Moreover, the parents feared such experiences could result in the children's death. Interestingly, as much as the children did not like being hospitalized, it was when they felt "*yucky*" that they did not mind being hospitalized. Sometimes they even requested to go hospital which not only supported how sick they must have felt, but also suggested that the children felt that they needed more protecting and comforting. In effect, they were "taking care" of themselves by realizing they needed to go to the hospital:

> *Child with cancer (11-year-old male): Yeah, cramps here and headaches there, my arms were really weak, my legs were really weak I could barely walk...Well I was thinking about having to go to the hospital.*

Another difference between "I feel bad" and "I feel yucky" cancer-symptom experiences was that for the latter the feeling sick was more intense for the children. There was "*feeling sick*" and then there was the experience of feeling "*really, really, sick.*" The intense feeling associated with "*feeling yucky*" was often in relation to the children feeling terrible all over their bodies. In contrast to the "I feel bad" experiences, the "feeling yucky" experiences involved more than one part of the children's bodies; every inch of the children's bodies became extremely sensitive:

Child with cancer (9-year-old female): It is worse, it is like a shark biting me all over!

At times, the "*feeling yucky*" was so intense for the children that they had a hard time describing how they felt as reinforced by one of the children: "*When you feel yucky all over there are no words to describe it except that you just feel bad all over.*"

"*Feeling yucky*" all over the body could be the result of many symptoms affecting many different parts of the body or in fact just one symptom affecting only one part of the body. However, in comparison to the "feeling sick" experience, the one symptom became so intense that it made the children feel really bad all over their bodies. For example, one mother noted that the mouth pain her child was experiencing from treatment-related mouth ulcers at one point became so severe, that her child refused to move because it would only cause the pain to radiate all over his body as indeed it did sometimes:

Mother: Mouth pain is his major problem. First it was his teeth and now it is his whole mouth and he ate little...He is also having stomach pain, he is not talking, he is tired...

The intense feelings that could also be experienced because of one symptom was reinforced by the following:

Child with cancer (15-year-old female): Ah, I did have the headache for about, from like May twelfth when I first started treatment. I got a headache and I had it until like the longest, for the longest time. I had it for like a month! ***I COULDN'T STAND IT!***

Child with cancer (16 year old female): Yeah because sometimes you have headaches and they don't hurt as much and sometimes they are really bad and sometimes you just want to go to bed and leave me alone.

Interviewer/Researcher: Like do you remember how you were feeling the last time we talked?
Child with cancer (11-year-old male): Pretty sick! I had bad cramps. It felt like

somebody pinching my stomach really hard, really hard, like somebody pinching your stomach really hard. I had to lay in bed a lot.

Although nausea and vomiting were often associated with the "I feel sick" symptom experience, they also were equated with the "I feel really sick" experience when they became constant or increased in intensity:

Child with cancer (14-year-old male): I'm handling the nausea, sort of but sometimes it gets so bad that I get to the point of crying...Well, this month has been quite horrible. I've been feeling really bad...Well, my stomach basically...It feels really gross...

Interviewer/Researcher: When would you say you were the sickest? Do you remember a day when you really felt sick?
Child with cancer (7-year-old female): When I first started chemotherapy. I just kept on throwing up...I kept on throwing up and throwing up and throwing up. ***Yuck!****...It was* ***really*** *bad. I kept on throwing up, I didn't want to do anything (pause) and stuff like that.*

Child with cancer (9-year-old male): Kind of puked a lot and it hurt.

Father: Her first set of chemotherapy, she was really, really sick like nauseated and didn't want to get out of bed and she kept throwing up.

Father: These things she was throwing up, she was throwing up blood and big chunks of black stuff and oh it was horrible.

"Feeling really sick" could also be the result of the children experiencing multiple symptoms:

Child with cancer (16-year-old female): Sore stomachs, headaches, weakness, blacking out. Like I'd turn my head and I'd black out.

Child with cancer (7-year-old female): Mm...I can't remember when it was (when she was feeling really sick) but when my throat was really sore and I couldn't eat or drink anything and I kept on throwing up.

Child with cancer (4 ½-year-old female): I hate mouth sores...I hate diarrhea. It (the chemotherapy) made my bum hurt. It made my...

Sibling (8-year-old female): But then when you're really sick it's like you have

like quite a few things at once like maybe a headache and dizzy and stomachache. Lots of things.

As well, children could not always identify which of the multiple symptoms made them feel worse or "*really sick.*" Instead, children would state that "*all of the above*" (in reference to their multiple symptoms) made them feel "*really sick.*"

When children felt sick all over only their bodies, this only made them more sensitive which in turn compounded their suffering. Children also experienced few reprieves from their source of distress. Besides feeling sick all over, the "feeling yucky" experiences were more difficult to relieve. Children and their families did not always know how to relieve or fix these symptom experiences. There was an uncertainty about what was happening and also how to make the children feel better:

Child with cancer (15-year-old female): But you know when you are feeling really sick and there is just no way of fixing, you just feel absolutely terrible. I mean at least with throwing up you know you are going to throw up and you go and vomit and you feel better. Like you just do it and get it over with. Feeling really sick, you just feel terrible all over, your body is weak, your head hurts, and you feel yucky and you don't know how you are going to fix it and you don't know what is going to happen. It is like the anticipation, you don't know what is going to happen.

For many, sleep was the only option and even then children still felt crappy to some degree:

Child with cancer (14-year-old female): Plus sleep for everything as you don't feel it any more! Sleep doesn't take away the crappy feeling, it is just that the time you sleep, you don't feel crappy or don't feel anything. Sleep is good because even though you miss out on things, if you were awake you still would miss out on things because you feel so crappy!

When "*feeling yucky*," the children experienced their sense of self mainly within the context of their physical sense of self or through their physical bodies. Mainly

experiencing life through their physical bodies was seen by the children and their parents to be necessary. The children needed to direct all their energy at maintaining their weak, yet very sensitive bodies as one mother reinforced:

> *Mother: When I looked at him I could see, I didn't see Jeff, I saw a fight for life...no his mind would just go somewhere else, I think...it is a survival thing.*

Understandably, it was during the times when children were feeling "*yucky*" that parents and siblings described the children to be least like themselves; certain attributes that made the children unique were missing or changed:

> *Mother: He was sick, he was really sick, he'd cry he'd have a stomach ache, a headache and it's you know (pause) he was not the same Daniel for how long? For one month.*
>
> *Father: You don't recognize him when he is sick, you know?*
>
> *Sibling (7-year-old male): She's not fun anymore.*
>
> *Sibling (14-year-old female): Okay so I went in there (the hospital) and she still had her hair but she looked really pale and like thin and then I went and I sat beside her and she was just watching TV and like she never said anything. It was so weird. It didn't even seem like her...just the way the look...She just looked really sick.*
>
> *Sibling (16-year-old female): I found Jane to be the most sick right after her surgery because she looked so frail and weak, and because she wasn't talking and smiling. She was very unlike herself, it seemed to me at that point that she was very ill.*

Parental statements such as "*he wasn't Bruce, he was a sick child,*" reinforced the affect that the symptoms had on the parents' perspectives of their children. They often described the children as "*being in their own world.*"

Feeling so yucky meant that the children could rarely do or partake of things that they normally would do. The symptoms were so hard on their bodies, and more to the

point on their spirits, that children at times did not care about anything and sometimes felt like giving up. For example, one adolescent who had experiences with severe headaches and fatigue expressed the following:

> *Child with cancer (16-year-old female): I just didn't care really how I got to wherever I got to. Like, I mean I wanted my mom to like carry me because I couldn't walk and I just kind of gave up. I was like "I don't care I just want to go home and lay down" you know? There are sometimes when I just feel like crap, and, you know, I just sometimes feel like I wish it was all over you know? But not very often.*

The children's spirits had been weakened or were fading and therefore, they not only were less likely to act like themselves, but also interacted less with others in their world when feeling "*really sick.*" Indeed, it was during such times that the children were quick to inform the researcher verbally and/or nonverbally that they wanted to remain quiet and be left alone. Lack of direct eye contact or comments such as "*Not today Bobby,*" was their way of telling the researcher that they did not want to be bothered. It was as if they were slowly disconnecting with their world. They became very quiet and still. It was their quietness and stillness that really scared parents because it represented to them that the children were giving up; that they were losing their spirit to fight. To parents and siblings, the children's subdued manner meant to them that the children were "*really sick*":

> *Mother: I know when he is not talking a lot, he is not feeling well.*
>
> *Sibling (13-year-old male): Connor isn't interacting with me as much as he usually does, he does not want to participate in any games. To me this is a sign that he is not feeling well.*
>
> *Sibling (14-year-old female): But just to see her lying there...it was just hard but...I just couldn't believe that she was in this position (having cancer)...*

Although the children did not want to interact with others during the "yucky" times they nonetheless wanted to be near their families or have their families "be there" for them. However, it was important that their family members not touch them physically or talk too much to them:

> *Child with cancer (7-year-old female): Well not to sleep with me but just sleep near me (in reference to having her family near her).*

Their bodies were so sensitive that any additional movement, touch, sound or any other action that aroused them, only made the "*yuckiness*" worse, that is, it just made them feel sicker.

Parents also felt a need to be near their children during the "yucky" times, be it at the hospital or in their homes. While feeling helpless in resolving the children's symptoms, parents nonetheless felt they needed to be there in order to take care of them by watching over them and protecting them from any other intrusion that would make them feel worse. It was if they were "standing on guard" for their children. They became very vigilant in watching over their children and making sure that their children were cared for in an appropriate manner:

> *Father: We keep an eye on her (child with cancer).*

Some times this involved parents not waiting for care to be delivered:

> *Father: Don't sit back and wait for the others to do it because it won't get done..*

The very fact that the parents' physical and mental presence was constant during the "yucky" symptom experience resulted in the parents' sense of self merging with their children's sense of self. For the parents and children, the voice of "I" became the voice of "we." It was during these times that the children and their parents existed within their

own world. The only outsiders let into their world consisted of those individuals who would be involved in the children's care.

Just as it was the case for their parents, the siblings' worlds were especially defined or determined and controlled by their ill brothers' or sisters' "I feel yucky" experiences. "Feeling yucky" symptom experiences made the siblings' worlds harder to live in, that is, they had to put up with more work, restrictions, and uncertainty. Their emotions were more intense especially with respect to feeling sad and their sadness was best described as an "unspeakable sadness"; that is, they were silent about their sadness. Most parents never realized just how sad they were. The siblings' sadness for most part was associated with the real and potential losses. This included losses related to activities of daily living such as going out with their friends. More importantly was their loss of their family. Whereas the parents especially the mothers, were given the opportunity to be with their ill children, this was usually not the case for the siblings. The siblings felt isolated being away from their ill brother or sibling:

> *Sibling (12-year-old male): The house is usually quiet and like it gets quieter and quieter and then I kind of miss her because she isn't here. Normally she is always talking a lot and then it gets annoying, but when she isn't here the house is quiet.*

Not only were siblings more often separated from their ill siblings during such times, but they were also separated from their parents. Their parents were less able to "be there" for them. Yet in spite of this, most siblings although missing their parents, never resented the special attention that their ill brothers or sisters received:

> *Sibling (8-year-old female): I was treated like less "carely" by my parents but I didn't mind because my brother needs lots of care.*
>
> *Sibling (12-year-old male): ...but I understand that because she needs more*

attention.

Sibling (14-year-old female): I know people had asked me when it was going on, "was I ignored or whatever." But I didn't really feel I was ignored because I knew they (her parents) were, it was just to help her get better so it didn't really bother me...but then I guess now if you think about it I was left at home alone...

The siblings were only concerned about their ill brothers' or sisters' needs; their own needs did not matter. In fact through out the complete cancer-symptom trajectory, siblings for the most part would put their ill siblings' needs before their own needs. They never "wished" for anything for themselves. Moreover, it was like their sense of self did not matter or exist. Whereas parents often talked in the voice of "we," siblings talked in the voice of "he" or "she" and not "I" or even "we." The voice of the "other" was how siblings lived life, especially when the brothers or sisters were feeling yucky. The siblings acted like they were outsiders. Compounding such feelings was that they wanted to help their brothers and sisters feel better, but often were not given the opportunity to do so. Although support from the family unit was recognized as the most valued form of support in helping children and families get through the cancer-symptom trajectory, it was apparent that the direct physical care of the children's symptoms experiences was mainly the responsibility of the mothers. This was of course to be expected considering it was the mothers who had the most opportunity to spend time with the children. However, both siblings as well as fathers expressed a sense of loss about not being more involved in the children's symptom care. They really downplayed their contribution in helping the children deal with the symptoms. It was hard for them to be on the outside with respect to the direct care:

Sibling (19-year-old male): Um (pause) I wish I could have been there, more for

her like when she was in clinic going through her treatments, in a way I feel bad that I wasn't there more.

Father: Joyce (wife) was looking after the actual treatments and stuff like that and I would be on the road. I found it very difficult to deal with being on the road.

Father: But like I told her, I says I know I can't fix nothing, I know I can't do nothing about it and I don't want you to think that I can and I said I might say that I can, but I can't fix everything but I ***need*** *you to talk to me...*

Father: No, I didn't even know (in reference to his child receiving oxygen)...That's what I mean, like she hadn't told me everything. Like I wasn't there!.

Even when fathers and siblings were involved in the direct care they, like the mothers, felt that they could not provide complete relief for their children. The care they provided only "*sort of helped*" the children. They felt that they could not fix everything or make everything better which only made the symptom experiences harder to get through:

Father: Because as a parent you feel that you can do everything for your child and not being able to fix something that your child is going through is very, very difficult. I mean they break something, you'll find a way of fixing it...They cut their self and you fix it. You run against something like this and you can't fix it. You have to, you originally walk in to a building of total strangers and say "Here. I'm putting my child in your hands. Fix it." And it's a different view for a parent to go through that. Its, "you can't do it for your child." You have to rely on other people's knowledge and other people's experience and you're so unprepared for it. It scares you to a point that, oh I hope they didn't fall asleep in this class or that class, you know, if it was something a parent could fix...

Father: You didn't like seeing her laying there sick, in pain. It was hard too and not being able to do nothing about it. Yeah that's the hard part, is not being able to do nothing about it.

Keeping the spirit alive was especially important for children and their families during the "I feel yucky" symptom experiences. However, it was during such times that maintaining a sense of spirit was also most difficult. Their need for support became

extremely important during such experiences. The support helped them to survive the "yucky" cancer-symptom experiences.

(3) <u>I am Sore...Boy, My Body Hurts!</u>

Symptom experiences identified as "I am sore" were viewed by the children and their families as those experiences that resulted in the children feeling and being in physical pain; that is, those experiences that made the children hurt physically. However, unlike the pain that could be experienced during the "I feel bad" or "I feeling yucky" experiences, the physical pain during the "I am sore" experiences was not constant; the pain was briefer. Moreover, the pain was not experienced all over the children's bodies. Nonetheless, the physical pain experienced was equated with life being hard or unfair.

The pain experienced during the "I am sore" experiences was usually the result of some type of procedure such as a bone marrow aspiration or intravenous insertion. Procedural pain, even though temporary made, the children feel especially sore and scared; regardless of age, all the children dreaded procedural pain:

> *Child with cancer (7-year-old male): The bone marrows, I hate those!*
>
> *Child with cancer (16-year-old female): Bone marrows I can't stand! I have ask to get put out (anesthetized) for them now. I told the doctor that I should get put out for now because there was too many painful ones.*

The pain experienced during the "I feel sore" experiences could also result from the cancer treatment such as in post-therapy headaches that would come and go. In such instances, the children may be hurting physically, but were not necessarily feeling sick. That is, children and families did not view the pain as a sign of being sick; the children could experience "*feeling sore*" but still be viewed to be healthy. However, children

could also experience brief episodes of pain while at the same time feeling sick due to some other reason and therefore, experience both "feeling sore" and "feeling sick" experiences. Additionally, when the physical pain became more constant and ongoing, children were labeled as sick. Such painful experiences then became "I feel sick" or "I feel yucky" experiences:

> *Child with cancer (16-year-old female): Yeah. It was it was a really **HARD** headache. Before I got diagnosed I was having like headaches all the time, that's why they said it was migraines. And I could hear, I could hear like thumping sounds and stuff like that. It was really weird. And like sometimes waterfalls and stuff like that. It was so weird!*
>
> *Child with cancer (4 ½-year old female): I went to the hospital...Because I had pains, pains, pains, bad pains.*

Even though the pain experienced by the children during the "I feel sore" symptom experiences was brief, it nonetheless resulted in the children mainly existing within or focusing on their physical self. They felt "less" like themselves, although they felt like this for a much shorter period in contrast to symptom experiences such as "I feel sick" or "yucky" symptom experiences. Parents' and siblings' sense of self remained fairly intact during the "I feel sore" experiences, although during such times all their attention was directed at the children. Their lives were temporarily on hold.

Associated with the "I feel sore" experiences resulting from cancer-related procedures were feelings of being afraid or symptom experiences labeled as "I am scared" experiences. In fact, sometimes the feelings of being afraid would outweigh the feelings of being sore. Overcoming the fear during painful procedures really required a lot of strength and concentration from the children and often would vary from procedure to procedure for each child. Although the children were often able to carry on after the

procedures were completed, this did not lessen the difficulty of dealing with such symptom experiences. The anticipation of future procedures affected their way of being in the world in that some of the children would experience feelings of anguish and distress; their emotional sense of self became the focus.

The pain experienced during the "I feel sore" experiences, although brief, was not something taken lightly by the children. And contrary to what may be expected, the older children just as much as the younger children had a hard time dealing with their pain. Of all symptom experiences, "I am sore" was one that children in retrospect would describe more vividly than the other experiences. What was common to all their descriptions was the hardness of the pain. Moreover, for some children there was nothing that could reduce the hardness. Basically, the only way the hardness of the pain could be relieved was by removing the source causing the pain. For example when asking one four year old child what helped her to feel better during a bone marrow aspiration, she responded by stating "*nothing*" and that she only felt better "*after its done.*"

The sensation resulting from the pain was never forgotten by the children. This was because the children viewed their "I feel sore" pain to be an experience and not a single physical state. Although never forgotten, children did try to deal with the "I feel sore" experiences by reducing the stature of such events within the total cancer experience:

> *Child with cancer (15-year-old female): You don't remember it feeling it as bad (in reference to a painful procedure). I mean you know that at the time you would have rather just died than have to do it for another second (pause) and then you know, like even though it was completely terrible, thinking back you know you are not in that moment so you don't know how bad it was and you think "Oh, that wasn't that bad." But if you had to do it again you know you would still die to*

have to do it again.

The "I feel sore" symptom experiences like all the other symptom experiences, resulted mainly in feelings of sadness as opposed to other feelings:

> *Interviewer/Researcher: O.K. show me how you feel when you get your IV in?*
> *Child with cancer (4 year old female): (points to the sad face on faces diagram)*
> *Interviewer/Researcher: Sad?*
> *Child: Yeah.*
> *Interviewer/Researcher: Do you ever feel angry or get mad?*
> *Child: **NO!***

For the parents and siblings, the physical pain that children experienced was understandably hard on them. Moreover they experienced the children's physical pain more as a "I am hurting" symptom experience (refer to personal meaning #8). That is, they experienced a lot of mental distress or suffering because of the children's pain. The mental distress was in relation to seeing the children suffering, as well as not always being able to take away the physical pain. For the children and families, " the "I am sore" symptom experiences reinforced to them how unfair life could be; such experiences were equated with life being unfair. However, although the children's physical pain experiences caused a lot of distress for families, parents nonetheless found some of the other symptom experiences such as "I feel yucky" more difficult to accept. Accepting the children's pain was seen by the parents as part of the normal cancer trajectory. As well, although they did feel helpless to some extent in dealing with the pain, they nonetheless felt that they had more options and control in dealing with the "feeling sore" experiences compared to the "feeling yucky" experience.

(4) <u>I am Cranky...I am not Myself</u>

Symptom experiences identified as "I feel cranky" were viewed by the children

and families as those experiences that resulted in the children experiencing changes in their moods and behaviors, from being depressed to becoming turbulent and agitated:

> *Father: He cried for no reason...You didn't know why, or knew what was going through his mind but I mean they told us when they started the Prednisone, one of the side effects is emotional ups and downs kind of thing so we just attributed to that and you know you get over it. He had bad days and good days...But I don't think he ever got (pause) like, I mean he never got violently angry. If anything he got depressed and cried for no reason, more that way than the other way so he never got violently angry and started throwing things like that, never!*

> *Father: You look across the table the wrong way at her and look out...She (child with cancer) has gotten to the point now where a mood swing will hit her and quite often she will just walk away, she'll go to her room, it will pass eventually.*

> *Child with cancer (11-year-old female): It changed me a little because when I had my treatments, I would be grumpy, usually. I became more grumpy than normal.*

Although reasons contributing to the state of "feeling cranky" varied, this symptom experience resulted in all the children and families feeling out of control to varying degrees. Most found the changes in behaviors and mood not a pleasant experience:

> *Child with cancer (11-year-old male): Mood swings, I would like say on Nintendo 64, if I like lose, I would get mad and go, yell at Karl or something. And if I can't have that then I would go like "mom, I want this!" Um me and my brother would have a lot of fights (previously he rarely fought with his brother).*

> *Child with cancer (9-year-old male): Physically I felt like shit. I was "cryish" (crying easily). I was depressed. I was a total son of a bitch...I could kick anybody's ass kind of stuff.*

The children's sense of being were viewed to be different and the changes that occurred were perceived as negative changes, something not desired by their parents and siblings. Like their siblings and parents, the children did not like the changes that made them cranky and unpleasant to be with. It was difficult for the children because they had

no control over their sense of self or how they acted. They often realized they were acting differently, but could not change their behavior and hence, became frustrated:

> *Child with cancer (16-year-old female): These days when I'm feeling cranky I hate it, because I am sometimes mean to my family and I don't want to be, I love them way too much!...I don't like how this changes everything...*

Because the changes in the children were changes that often were not desired or welcomed by the children and their families, each family member and the family unit as a whole were affected. When the children were "feeling cranky," the children and their families did not want to be around and close to each other. They experienced fewer social interactions; their social sense of self was affected. Accordingly the dynamics of the family unit changed during such symptom experiences. Even the siblings who so much needed and wanted to be near their ill siblings, did not want to be around their ill brothers or sisters when they became cranky.

The "feeling cranky" symptom experience could result from the very fact of being diagnosed with cancer. Or it could also result from the physical and mental distress caused by the other symptom experiences such as experiencing a bad back ache that caused the children to "*feel sick*" as well as "*sore*." Of particular importance was the effect that certain medications, most notably steroids, had on the children. Often the steroids' effects on the children's personality was what families and children found the most difficult to control. Children were often described as hysterical, anxious, and having a low frustration level. When taking steroids, many children were described as having totally different personalities especially affecting their social sense of self:

> *Mother: When she is on steroids, a lot of times when she gets the obsessive thoughts, it carries over to times when it is completely out of her system. It has*

really affected her socialization, it hugely has affected her socialization and not only when she is not on it. Just the whole, you know kids get used to reacting in a certain way and that has become a big part of her. Father: Oh yeah, yeah her reaction, a behavioral pattern that she learned when she was on steroids, she'll continue to use it .

Although families were made aware of the effects of the steroids, for most the experience was something that no matter how much they was warned about, it was much worse in reality. The moodiness and frustration experienced by the children were hard for parents to deal with because their children were not the "kid" that they were used to or the child that they found to be unique and special. Parents found their anxious, cranky behavior hard to manage. For the most part, they found that the only way to deal with it was by letting it run its course. Additionally, parents felt that they had no control in parenting when the children became cranky. They felt guilty not being able to control their children's behavior:

Mother: You start doubting your parenting skills. "May be I am creating a monster?" You don't, like I don't know what it is going to be, cause you really feel at the time that you may be creating a monster.

Associated with the change in the children's moods and behaviors were changes in the children's appetites and the subsequent feelings and sensations experienced by most of the children because of the changes. Specifically because of the cancer and its cancer symptoms and treatments, especially steroids, children's appetites would change from a complete loss of appetite to appetites that were described as insatiable:

Child with cancer (4 ½-year-old): I feel hungry from my medicine (prednisone). I eat lots! I'm hungry, I'm hungry... I asked Daddy "do you eat all of that pizza pop?"
Interviewer/Researcher: You asked Daddy if he was going to eat all of his pizza pop and what did he say?
Child with cancer (4 ½-year-old): No.
Interviewer/Researcher: So you ate yours and you ate his?

Child with cancer (4 ½-year-old): (laughs) Yes!
Interviewer/Researcher: When you're not that hungry how many pizza pops would you eat?
Child with cancer (4 ½-year-old): Uh, usually I have three.
Interviewer/Researcher: Three but when you're really hungry how many do you have?
Child with cancer (4 ½-year-old): A little bit more, like three more and that would make five.

The changes in their appetite warrant discussion under this subcategory because both children and their families viewed these changes as changes in how the children acted and behaved. Changes in the children's appetites were associated with a lack of control. To some extent parents and siblings measured or evaluated the children's sense of self or how much children changed according to their eating patterns or appetites; that is, seeing the children overeat or not eat brought on feelings that their children had changed and were not themselves.

Of all appetite changes, the children found a ravenous or insatiable appetite to be the one that affected their life the most, as well as the one most difficult to deal with. Experiences related to having an increased appetite to the point where most over-ate, were viewed by the children as something really unusual and strange. Phrases such as "*just a pig*" were used by the children in describing how they changed with respect to eating. Whereas they associated a lack of appetite with being sick, they never associated an insatiable appetite with illness. Perhaps this is why the children were much more animated in their telling of their experiences related to having an insatiable appetites. Such experiences were unexpected and it is was like in the telling of these experiences, the children were saying "you will not believe this, but..." There was a tone of astonishment in their voices and often they eyes were wide-eyed in their recollections of

such experiences.

In addition to experiencing an increased appetite, children also developed strange and unusual cravings:

> *Father: For a while it was every night at 10 o'clock that she wanted garlic sausage. So we gave it to her and she ate it.*
>
> *Mother: Like she craves particular things and only that.*
>
> *Mother: He craves things too...I cooked constantly. I'd be cooking lasagna in the middle of the night. Homemade spaghetti. Like the kid craved. We had stacks of bags of McDonald's in the fridge, day and night.*
>
> *Child with cancer (11-year-old female): Um (pause) when I first started going on Prednisone, the steroids, I didn't really care for pickles but I ate* ***tons*** *of them!*

Although each child developed different patterns of eating, a shared element of such experiences was eating a specific food(s) frequently and/or at odd hours for a certain period of time such as the need to eat cabbage at three o'clock in the morning. The children would often go through periods of craving a certain fast-food chain specialty. One 13-year-old adolescent boy first started off craving one fast-food chain's fried chicken, then another's hamburgers, then another's Chinese food, and finally another's submarine sandwiches. Each craving lasted approximately three to four months and in fact could be used as categories in defining the very phases of cancer. Another 11-year-old boy would move back and forth from a fast-food chain that specialized in pizza to another chain that specialized in seafood.

While at times children enjoyed the food they ate, for some it got to the point that they also did not enjoy what they were eating. For some, the over-eating became a chore; eating constantly became physically exhausting especially when they were fatigued to begin with:

Child with cancer (14-year-old female): And then I was still on this medicine that made me hungry and I was so tired and I just wanted to lay down and rest but then I had to keep on eating. I had to keep on getting up and thinking of things that I had to eat and I wasn't getting enough sleep because I was up every three hours during the night to get something to eat.

Yet, they could not stop themselves from eating and as noted by one 18-year-old adolescent male, "*there was not much others can do, except for having the child's parents not always giving into their child's craving.*" The children accordingly experienced feelings of frustration. Over-eating represented to the children a lack of control over their bodies and their sense of self. They perceived their bodies to be distorted.

Whereas the children found over-eating distressing, parents found a lack of appetite more difficult to deal with. Even though the children still may have had strange cravings and ate at odd hours, this was preferable to seeing their children not being able to eat and/or keep any food down. Whereas "eating more" represented a sign of health to the parents, the image of an emaciated child getting sick at the sight of food only reinforced to parents and siblings that the child was sick and that death was near. While parents often were unsuccessful in getting their child to eat during periods when the child had no appetite, they were successful in getting food down them during periods when their child had an insatiable appetite. In effect the parents felt they were "doing something" that really helped their child; they were taking care of their child. Not only were they feeding the child, they were feeding their child's spirit.

Because of the need to focus on the children's diet during periods of under-eating, the families experienced changes in how they lived life. Just as an insatiable appetite meant more work, restrictions, and disruptions in their normal mealtime and lifestyle for

children and families, so too was this the case when the children had no appetite. The act of eating when they had no appetite was perceived as a chore by the children; children had to work hard at it:

> *Child with cancer (4 ½-year-old female): You try to eat. While you eat you should watch TV. Keep your brain supervised. It helps you not think about food.*

Although the children knew that eating would help them to heal, they frequently could not make themselves eat no matter how hard they worked at it. Moreover because a lack of appetite was associated with "*feeling yucky*," at times eating became just too "*hard*" or difficult to do.

Disruptions with respect to normal eating patterns had resulted. However, whereas dealing with an insatiable appetite involved more work for the parents with respect to purchasing and preparing the food, it was still not as taxing as caring for children with no appetite:

> *Mother: Everything that she has been eating has to taste just right or if you put too much spices or not enough spices or something in or something that is too tomatoey or whatever, she doesn't like it...If anything doesn't taste you know just perfectly then she'll eat may be just a few spoonfuls of it. Everything has to be just so.*

Although the child's ravenous appetite meant more work and disruptions in parents' lives, it nonetheless was a welcomed sign for parents as most of the time throughout the cancer-symptom trajectory, getting their children to eat usually was a constant struggle. Parents really felt out of control during periods when their children refused or could not eat. The siblings' also experienced negative consequences because of changes in the children's eating habits and included such things as the break-up of the family unit during mealtime, eating at odd hours, and not going out for dinner with the

"whole" family.

(5) I am Just Experiencing an Everyday Thing...I am Just a Little Sick

Symptom experiences identified by the children as "*everyday things*" were viewed by the children and their families as those experiences that became a part of their everyday life. Although most symptoms were accepted and viewed as part of getting through the cancer-symptom trajectory, symptom experiences labeled as "everyday" were distinguished from the other symptom experiences by children and their families as being not as severe even if they did occur on a daily basis or even if health professionals viewed them with more concern:

> *Child with cancer (11-year-old female): I think I got headaches from the...I don't think they were that bad though.*
>
> *Child with cancer (16-year-old female): I still have, I have a headache right now kind of but it's not a bad one...*
>
> *Child with cancer (17-year-old female): I don't know like some days you are having a good day and so you have a headache but you still able to manage it.*
>
> *Child with cancer (17-year-old male): No, no sometimes they're really bad and sometimes they're just light headaches.*

Additionally, children were more adjusted living with "everyday" symptom experiences:

> *Child with cancer (15-year-old female): It is only because you become accustomed to it, like it is something that is not going away so you stop noticing...*

Defining symptoms as "everyday" symptoms was one way for children to convince themselves that they were not too sick:

> *Child with cancer (16-year-old female): I feel a lot healthier right now. But I still like can like have headaches and I still feel nauseated like all the time...*

To some extent labeling symptoms as "everyday" experiences became one way to normalize life; it became one way for children and the families to be not so consumed with cancer. It was their way of spending less time being associated with and in the world of cancer. Understandably during the researcher's informal and formal conversations with the children and their families, discussion of "everyday" symptoms were never brought up by them even when the researcher specifically asked if they were experiencing any symptoms. Often in conversations with them, they would talk about how "*good*" things were and that they were feeling fine or alright:

> *Child with cancer (11-year-old male): Yeah, I am feeling good right now, almost back to normal (the child was in between treatments).*

In fact, except for perhaps some signs suggesting that the children were not completely right such as thinning hair, most of the children did appear completely well. At times, it was difficult to distinguish them from their "healthy" siblings in clinic especially if their hair remained intact. An awareness of any symptoms only became evident when children or their parents would by coincidence or accident weave the experience of "everyday" symptoms into discussion of other situations or events or if the researcher directly asked them about a distinct symptom. It was as if both parents and children, regardless of age, assumed that the researcher was already aware of the "everyday" symptoms. These symptom experiences had become so much a part of the children's and families' lives that they were in fact taken for granted, not warranting discussion even between the parents and children themselves. Even siblings viewed these symptoms as a matter of fact and referred to them in a nonchalant manner.

And when children and their parents talked about these symptoms, there was an

ordinariness assigned to "everyday" symptoms or a tendency for them to downplay the quality of the symptoms. Words or phrases such as "*not too bad*" and "*tolerable*" were referenced to when they talked about them. This language contributed to them trying to achieve a sense of a normal life or more to the point a life in which it was cancer did not dominate. Downplaying the cancer-symptom experiences was one way families could gain control over their day-to-day living. For example, one school-age child's and his family's symptom talk was limited and downplayed despite the fact that he had experienced headaches, some pain from mouth sores, and an increased appetite. Interestingly, experiencing the cancer-symptom trajectory did not disrupt the family's day-to-day activities. His mother had trouble identifying changes in her child and family.

In experiencing "everyday" symptoms or perceiving symptoms as everyday events, the children's and their families' sense of self did not appear to be challenged or threatened as much in comparison to the other symptom states. This was not to say that they did not need to apply or use the "keeping the spirit alive" strategies. They still had to work at maintaining their spirits, and in fact viewing symptoms as "everyday" things was an example of believing they could get through the rough times and showed the faith that the children and families had. The strategies were also necessary, especially if other symptom experiences were occurring concurrently.

Although the children experienced bodies that felt somewhat renewed in the sense that the symptom experiences were not overwhelming, the children nonetheless did not experience complete renewal. They still experienced some lack of control over their bodies. As well, even though children believed that the "everyday" symptom experiences

had not changed them much, they experienced life differently and still could not participate in all of their favorite activities as they did before the cancer experience. No matter how hard they tried, the children and families could not live a life completely free of cancer. The very nature or fact that there was work involved in disregarding or downplaying the "everyday" symptoms, was itself a reminder of the cancer-symptom trajectory.

A consequence of labeling some symptom experiences as "everyday" was that for those experiences children and their parents did not always talk of such symptoms during interactions with the nurses and doctors at clinic visits:

> *Child with cancer (16-year-old female): Like I mean things are bothering me but stomachaches and headaches, I usually don't say anything because that's normal for me now.*

Children at times also did not seek out their parents in relief of these symptoms. Instead, the children would go about their day-to-day activities incorporating their own interventions that helped to bring some relief. Most children would ask for or accept symptom relief in the form of a medication only when the "everyday" symptom got "*really bad*" and was no longer viewed as "everyday." For the most part, the "everyday" symptom experiences were taken for granted by those involved in the lives of the children. However, the longer the children experienced the "everyday" symptoms, the less tolerant they became of them or the cancer-symptom trajectory.

While "everyday" experiences were usually noted during the time when the children were still undergoing treatment, most of the children also had experiences with "everyday" symptoms years after completing their treatment; that is, most never became

totally symptom-free. True the "everyday" symptoms were often minimal, the children nonetheless experienced symptoms that they referred to as "*everyday*" such as having as an occasional headache or sore body joint or feeling slightly more tired on occasion.

(6) <u>I am Wiped Out...My Body is Just Too Tired for Me to Care</u>

The symptom experience identified or referred to as "wiped out" was viewed by the children and their families as an experience that resulted in the children feeling totally exhausted:

> *Child with cancer (14-year-old male): There are days when I wake up when I feel like I've been hit by a truck.*
>
> *Mother: You know she's very, very tired. She doesn't have the same energy at all like there's such a huge difference in her, she doesn't want to go anywhere, she doesn't want to do anything. And a lot of that its not just emotional. She's literally very tired. She just can't do it. She can't sit in the car for half an hour till we get somewhere.*
>
> *Child with cancer (4 ½-year-old): I sleep lots some days.*

The exhaustion resulted from a variety of factors including the cancer itself and all the rough times associated with it, as well as having to maintain a sense of spirit. The feeling of exhaustion was not to be confused with feeling sleepy. Although there was a range in feeling exhausted from extremely tired to totally wiped out, feeling exhausted involved much more than feeling sleepy or being just tired. When the researcher referred to the children's exhaustion as just being tired, she would often be corrected by the children as evidenced by one young child's response:

> *Interviewer/Researcher: Because you were just so tired?*
> *Child with cancer: Because I was too exhausted and stuff and I didn't have enough muscle or stuff like that.*

Indeed, feeling exhausted was beyond a normal "*sleepy tired*" feeling and

involved so much more of the children feeling bad:

> *Child with cancer (15-year-old female): The difference between like "tired-out your body" and sleepy tired (pause) is like your whole body is just being really tired, like exhausted.*

Whereas feeling "*just tired*" or "*sleepy*" did not affect one's sense of self, "*feeling wiped out*" did affect one's sense of self and challenged one's spirit. When the children felt wiped out they experienced life in a state of limbo; they felt like they not in the living world, yet not also in the world of the dying. At best, children could be described as "*zombies*" when feeling "*wiped out.*" It was like they were sleep walking through the cancer-symptom trajectory while feeling "*wiped out*" or as one mother stated the children looked "*zonked out.*" With the exhaustion, the children really could not do much, nor did they care to do anything. For many of the children, the couch in their living room became their best friend:

> *Child with cancer (16-year-old female): I just lie on the couch mainly (laughs). I didn't move much. I just...I...I...yeah, I didn't do much.*

> *Sibling (7-year-old female): Um...sometimes when he comes home he's really, really tired and he just watches a movie and sleeps on the couch.*

In fact, instead of the "sick bed" it was more appropriate to refer to the "sick couch" as an appropriate symbol of the sick role in children. The tiredness the children experienced not only prevented the children from carrying on with simple day-to-day activities like even stepping outside to sit in their backyards or being with their friends or peers, but virtually at times prevented them from feeling and thinking. Every activity or response became harder to do. It was as if the tiredness put them in a state of suspended animation. Moreover, feeling "*wiped out*" made it difficult for the children to feel

connected in their worlds:

> *Child with cancer (15-year-old female): It is usually that (fatigue) that prevents you from going out unless you are really sick and vomiting and can't stop throwing up. But it is usually that, that prevents you from going out and going to school...I mean lots of people sit through school if they have a headache or the flu or something...But when you are wiped out, it takes too much energy to get up, get showered, or get dressed and by the time you are ready to go you just want to pass out and die and sleep for another 12 hours. I used to be very excited about going to school but by the time that I got ready, I used to be so tired, so out of breath that I would fall back to sleep and sleep for about eight hours straight.*

However, while the children hated feeling "*wiped out*," many of the children and parents did not always see the extreme or constant fatigue as a cancer-symptom. To some extent the feelings of total exhaustion were viewed as a normal part of the cancer-symptom trajectory that could not be changed or treated. While children and their parents at times found the "wiped out" symptom experience difficult or even unbearable, they rarely sought out help or relief for the exhaustion. It was almost as if they had given into the exhaustion. Even those who did identify the exhaustion as a symptom, often had the view that there was nothing or "*no particular medication that could fix it.*" The only thing parents recommended for the children was that they rest for their exhaustion. Although families felt that it was good for the children to rest, they expressed concerns about the children's lack of energy or motivation to do anything. At times parents and siblings viewed the children in such as state as almost being dead.

Children also felt that sleep was about the only thing one could do when feeling exhausted. The children expressed that the only thing that one could do for the exhaustion was "*to go with it and not fight it.*" That is, it was important to try to sleep or rest:

> *Interviewer/Researcher: When you are tired do you play as much or what do you do differently when you are tired?*
> *Child with cancer (4 ½-year-old female): Go to sleep.*

However, sleeping provided only short reprieves from their exhaustion because when the children would awaken from their sleep, their exhaustion was still evident. In fact, some children felt so exhausted that they did not even have the energy to fall asleep:

> *Child with cancer (11-year-old male): Well (pause) I just relax and then shut my eyes and go to sleep.*
> *Interviewer/Researcher: Anything else that helps you being tired, when you are tired?*
> *Child with cancer (11-year-old male): My pills. Um (pause) well, I can't sleep sometimes so I have to take these pills that help me go to sleep.*

Just as feeling "*wiped out*" affected the children's sense of self, so too it affected the family unit's sense of self. When the children were wiped out they did not interact much with their family which was difficult for family members, especially the siblings. In a way it put the family in a state of limbo as they waited for the children to regain their strength and become once again a "whole" family unit.

Interestingly, although children hated feeling dragged out or having less energy, the feeling "*wiped out*" experience gave them a reason or permission not to partake in their world. It was a legitimate and temporary way to take a rest from all their worries and pain caused by the cancer symptom trajectory.

For most of the children, feelings of exhaustion to some degree continued even when they had completed treatment or were near completion of their cancer treatment. This was the case for the following child who was near completion of her treatment:

> *Mother: She has a teacher's aide for two and half hours in the morning because I think she'll frizzle out by the afternoon...if she went to play in somebody's at 1030 AM and then I took her to school (kindergarten), she would be miserable and by three o'clock she be exhausted. You know it is a loss for her, it is very hard for her.*

Although the lack of energy that children experienced at the end of treatment was

not as severe as that experienced during treatment, it nonetheless was present. The length of time that it took for this symptom experience to resolve was what made it even more "hard" and difficult to get through it. Most of the children who had been in remission for many years felt they never regained back all their strength. Children would describe their energy levels as being around "*80 to 90 percent*," but rarely "*100 percent*." Interestingly too, lack of energy in their children prior to the cancer diagnosis, was one of the first signs that triggered parents to think the children had more than just flu:

> *Father: Her energy loss. Aahh, I mean she, she had already was unable to complete the track and field activities because she just had no energy and for Beth that was a 180 degree turn. So that combined with when we were at the lake and the kids were taking turns running down the hill and races and she didn't participate and spent most of the time laying down and wrapped in a blanket and so on. And so it was all those things.*

Interestingly, Beth (child in previous quote) to this day, many years after completion of the cancer treatment, never did regain all her energy back; she never went back to participating in any track and field events.

(7) I am Scared...I Don't Know What is Going to Happen to Me

This category referred to symptom experiences that brought on fear and a feeling of trepidation to children and their families. At times the "I am scared" symptom experiences were the most difficult ones to live and deal with by the children and their families. Families experienced a lot of uncertainty:

> *Sibling (8-year-old female): Yeah, I worried when Tina first got sick and then she was really sick but now I'm not as worried (not "feeling" sick presently).*
> *Interviewer/Researcher: And when she first got sick what was it that made you worry?*
>
> *Sibling (7-year-old female): Well I didn't know what was gonna happen to her so I was scared.*

Sibling (10-year-old male): Like when I first saw his leg amputated when he first came back from Vancouver um I hadn't seen his leg for about three weeks because he had jeans over it and he was using crutches and when I finally seen it I was scared to death. I was scared of how it felt to him. I did not know.

It was the "I am scared" symptom experiences that most threatened the individual's and family's sense of self as it represented to them the possibility of the recurrence of something they feared very much such as painful treatments or procedures (e.g., bone marrow aspirations):

Interviewer/Researcher: Tell me about the needle in your back? (Pertains to the bone marrow aspiration which the child referred to as "the needle in the back.") Child with cancer (4 ½-year old female): ***SCARED!***

While the children feared the physical pain of the treatments, the parents and siblings feared that the children would not be able to handle the treatments or procedures or that they would be too much for the children to endure. Children and their parents also experienced fear in relation to potential side effects of treatment that would lead to temporary changes in the children such as hair loss. However, of all events that led children and their families to be overwhelmed with feelings of fear and anxiousness were those symptom experiences that could lead to the potential of relapse or even worse, death:

Child with cancer (17-year-old male): Yeah, yeah, like that was the scariest part cause like one day I'm driving home and the next thing I know I'm in the intensive care unit with a bunch of people on top of me (laughs).

Father: I do. I fear at any moment that her blood counts are gonna go down unnaturally and we're gonna take her in and they're gonna say "Oh it looks like the medication isn't working...The fevers and infections...She's out of remission."

Sibling (10-year-old male): Then I thought that he would die. And until he went to his operation I was crying lots of times when he was gone to Vancouver and I stayed here with my aunty and uncle for three and half weeks. And I was afraid

that he was going to die but ...

This included symptom experiences that were related to potential side effects or complications of the children's treatments:

> *Father: Heart damage. All major organs, like your main organs could have damage to them. Or the onslaught of leukemia. Or another type of leukemia could start. Then there's that one that you have to wear gloves that you inject into her and its highly toxic. And yet you're putting that into your kid.*

The fear of relapse or death sometimes resulted from the children experiencing new symptoms; symptoms that neither the children nor families knew how to respond to. This included unexpected symptoms that were not emphasized or recognized as common side effects of the chemotherapy or radiotherapy treatment regime. While the symptoms may not necessarily have been serious, parents experienced fear and increased anxiety because their children were not responding like the majority of children did to treatment or according to the treatment protocol. For example, some children never got too sick during the more intense phase of chemotherapy regime, yet became sick during the less severe chemotherapy phase. This resulted in the children and their families developing an even greater feeling of uncertainty with respect to the overall outcome. If the children did not respond typically to the chemotherapy with respect to side effects, the parents sometimes felt or reasoned that there was always the possibility of the children not responding typically to cancers that had high rates of survival. A sense that something bad was going to eventually happen prevailed in their minds. It was like "*waiting for the other shoe to drop*" as so many parents often expressed.

Likewise, children and their families experienced fear of relapse or death in relation to children experiencing symptoms and signs from treatment that were identified

as more serious in nature such as side effects that were life threatening:

> *Child with cancer (5-year-old female): I didn't eat when I fainted (fainting was this child's definition of being really sick). It was scary because I was fast asleep.*

Another example involved a school-age child who required medication for high blood pressure caused by the cancer treatment. The drug that the child was put on, was a very strong drug. While it helped to relieve the child's blood pressure, the child developed breathing problems and became incoherent to the point of becoming delirious when he initially was put on the medication. His mother had emphasized that this was a "*very scary time*" for the child and the family:

> *Mother: It scared the heebie-jeebies out of us! It was Hellish on Friday...We even thought he could die! The physicians were really worried.*

The child's side effects were treated and the child was temporarily taken off the medication. However, in order to maintain his blood pressure at the proper level, he still needed the medication, although at a lower dose to prevent the serious side effects from recurring. When it was time for the child to resume the medication, the child became very apprehensive and fearful. On observing the interaction between the nurse who was trying to get the child to swallow the medication, a look of terror covered the child's face. He refused to take it initially which was atypical behavior for him in relation to him taking his medication. He had expressed:

> *Child with cancer (9-year-old male): Is that the medication...I am afraid I won't wake up...Last time I didn't wake up!*

Eventually after much discussion, reasoning, and reassurance by his mother that things would not be like last time due to a different dosage of the medication, he did resume taking the medication. Nonetheless both the child and family were very fearful

about what did happen and what could have happened. His siblings who also witnessed his severe reaction and expressed how frightening the experience was to them.

Although the fear resulting from treatment-related symptoms was difficult for children and their families, cancer-related symptoms were even more terrifying as the children and families felt they had less control over fighting the cancer as opposed to fighting the treatment. For many of the families, the fear that the cancer had returned did not always pertain to a specific symptom state. Rather it related to the child generally not feeling well:

> *Mother: So like for the first, for four years since Peter was diagnosed he never had the flu or nothing, never. So anyway last year he complained he doesn't feel well and it lasted a few days so you know everyday I would give him a physical and he was okay and then Saturday morning, you know my heart sank. I thought oh no, perhaps the cancer had returned.*

The symptom experiences that triggered the most fear in relation to relapse or death were the reappearance of symptoms that were initially experienced during the onset and diagnosis of the cancer:

> *Father: No. No, it was one of the worst times because of the fact that we were seeing the symptoms coming back that actually got us to the doctors in the first place.*

Children and their parents feared both the relapse and the threat of having to once again get through all the rough times and the hardness of the cancer-symptom experiences. They feared losing control of their bodies. For some, the fear of having to experience all the rough times was more prominent than the fear of dying. Such symptoms produced so much fear, that they often paralyzed children and families from participating in life. Their spirit was overtaken by fear which in turn affected their sense

of self.

Uneasy feelings occurred any time the children became sick. The uneasy feelings were especially experienced by the parents, perhaps because the parents more so than the children were always waiting for the cancer to return. Common acute illnesses like the flu forever took on a totally different meaning for parents:

> *Mother: Anyway I seen Dr. B you know and each time he gets the flu or whatever but I always think you know that direction (referring to a return of the cancer).*

For some parents the fear of symptoms never subsided, no matter how long the children's cancer remained in remission:

> *Interviewer/Researcher: Do you think now too because it has been five years, do you still feel when he gets sick that it could be the cancer?*
> *Mother: Oh yes (immediately responded). Like last week he was feeling sick. I mean I know it's just, it's just ...But I think it will be like this.*

The symptoms children experienced did not always have to be perceived or classified as intense to be "*scary*" to parents. At times the symptoms could be subdued, yet parents could still be afraid:

> *Mother: Well he looks, acts, and feels well,* ***but****...*

The "but" was in reference to this mother fearing that while her child may have looked better, there was something to suggest that he was still really sick. Often the parents' fear occurred during the times when the children were going through a particularly critical phase of treatment. Even though the children appeared to be stable, parents experienced feelings that something was "*not quite right*" which in turn provoked feelings of fear. Past negative symptom and treatment experiences contributed to the parents' fear and feeling that something bad was going to happen.

Children, like their parents, associated specific and non-specific symptoms with a the fear that the cancer might be recurring. Sometimes the fear would be so great in the children that they would not talk about the specific symptom(s) or would downplay how they were feeling. For example, one adolescent girl who was on maintenance treatment for high risk leukemia had experienced a five week episode where she was not feeling well which corresponded with abnormal blood counts. As the weeks progressed she experienced more fatigue, headaches, and stomachaches, to the point where she was just dragging herself into the cancer clinic for her scheduled appointments. In addition to feeling scared, she also felt "*yucky*." However, it was not until she started feeling better and her blood counts were improving that she shared with the researcher that she was afraid her cancer had returned because the way she felt in the past weeks was how she felt prior to being diagnosed with leukemia.

Families especially experienced feeling scared when their children expressed feeling "*yucky*." For the siblings and parents, it was during these times that they felt that the children were very close to dying. Although siblings and parents worried about the ill children dying throughout the cancer-symptom experiences, the fear of death was even more prominent to them when the children were feeling really sick. It was during such times that symptoms were no longer just viewed as symptoms but instead viewed as signs of impending death. Such feelings were further compounded by how the children looked, that is, if they physically looked like they were dying. For most siblings and parents, the dying child was perceived to be a child who was very pale and scrawny with sunken eyes. A sense of emptiness and stillness were associated this look of death:

Father: It was scarier...Because I mean he was sitting there and (pause) slumped over and wouldn't say anything, nothing, he would just, there was nothing there at all.

This "death look" when combined with such symptom responses of pain or lethargy, only led to more feelings of fear and at times were too overwhelming for the siblings and parents. The fear at times got to the point that they could not focus their thoughts on anything but the cancer. Their sense of self was being consumed by the fear generated from the symptom responses that signified death. Their overwhelming feelings of fear revealed just how much they loved and cared for each other:

Sibling (10-year-old male): I would tell them (other siblings) that it is good that you are afraid because that just means that you are concerned for your brother or sister and that you really care for them.

(8) I am Hurting...My Heart is Sad

Symptom experiences identified or referred to as "hurting" were those viewed by the children and their families as experiences that caused them mental distress and heartache or suffering and varied depending on the context of the cancer-symptom trajectory. In addition to the physical pain, children and families experienced emotional pain:

Child with cancer (4 ½-year-old female): Anytime my head hurts he (brother) laughs at me...And he hurt my feelings. He laughs at me when I get hurt.

Sibling (10-year-old male): It is mostly painful inside where it hurts and it basically acts like if you have leg cancer it acts like if you have a big bruise and you all know how bruises hurt.

The suffering experienced in fact resulted directly or indirectly from all the symptom experiences previously discussed, from feeling sick to being scared. In the recounting of "I am hurting" experiences, families described feelings of their "*hearts*

breaking"; it was like their sense of self was wounded:

> *Mother: I remember thinking of Karen (child with cancer), it's like you poor soul how could you go through this time after time. It's painful.*
>
> *Mother: It hurt. It hurt so much...I know he doesn't complain but you know I guess it just hurts and hurts me too when I see him cry, when I see him you know.*

Watching and knowing the children were experiencing physical pain from intravenous insertions, bone marrow aspirations (BMA), and lumber punctures (LP) were especially hurtful for parents and caused them a lot of distress. Children experiencing physical distress in relation to other symptom states such as nausea also caused much mental distress for the parents. The heartache and mental distress experienced by parents also resulted from seeing their child hurting not so much in a physical sense but more in a mental or psychological sense such as the psychological distress children suffered in relation to hair loss.

Having the children do or go through things that made the children sad was hard for parents to deal with as this one mother acknowledged:

> *Mother: Oh I hate that, like I mean today when she went in (to the operating room) she had tears in her eyes and she just hates to go.*

Realizing their children were not able to partake in daily childhood activities of living due to an increased degree of symptom distress, was especially hurtful to the parents. Not only did it represent to the parents that their child's condition could be worsening, but it reinforced to them that their child was not allowed to "*just be a kid!*":

> *Father: Oh yeah, yeah, it brings tears to my eyes you know. You can see she wants to go but she can't (in reference to going on a bike ride).*

Any additional illness setbacks experienced by the ill children only made the

children's suffering more difficult for parents to endure. Their suffering was tied to many emotions. In addition to the sadness felt, parents experienced some anger and resentment:

> *Mother: She is taking a step backward...she CAN'T EVEN WALK!.That's great...it is not fair!*

Parents' suffering was also in relation to not being able to take away their children's physical and mental pain. Not only did this make them feel like they failed as parents, but simply put, it hurt parents that they could not make things all better. It was not uncommon for parents to suggest that they would in a moment not hesitate to trade places with their ill children. The physical and mental pain of the ill children caused so much hurt and suffering in the parents it was like they themselves were experiencing the pain. Moreover, it reinforced how much their sense of self was interconnected or tied to their children's sense of self.

The parents also experienced increased suffering in relation to their healthy children missing out on things or having to sacrifice a lot because of the cancer-symptom trajectory. Part of their suffering was related to the guilt they felt because they were not able to be there or present for all their children. Parents suffered in relation to the possible damage their lack of presence may have or will cause.

Siblings also experienced increased suffering in relation to their ill siblings' experiences with physical and psychological pain and distress. Like their parents, the sadness experienced by the siblings was very evident in their narratives and stories:

> *Sibling (6-year-old female): I was sad when Cory was sick...I was sad that he might die!*

> *Sibling (19-year-old male): I remember the first day of her treatment, we walked into the treatment room and there is all these people sitting in chairs with I.V.'s*

(intravenous) and you got people with no hair or people on the brink of death and like they all have different types of cancer but to us, cancer we think it's all one thing. When she sat down to get her I.V., we were looking around in this room and there are old people, young people, middle-age, getting treatments you know and they have all these ***sad faces.*** *I will never forget that look because it's (pause) you look at it and they are suffering and when I look at that and I think of her and just, you know, I think about her getting treatments*

Sometimes the siblings' sadness was attributed to losses that their ill brothers or sisters had to experience:

Sister (6-year-old female): It made me kind of worried because there's this T.V. show, a guy has cancer and he's bald. He lost his hair and it seems like he's not going to grow it back because he's like he says that he won't grow his hair back because he had it since he was a little kid and he starts to cry and tell his dad and he told his dad that he doesn't want to be bald.

Sister (5 ½-year-old female): Like he (her brother with cancer) felt sad, very sad because he had nothing to play with in the hospital, just color and bingo...Oh, that made me really sad.

Sister (5 ½-year-old female): Sad sometimes because I have nobody to play then.

Often a profound sense of sadness would overcome siblings when they talked about having to see or just being aware or knowing that their ill siblings had to endure painful procedures. Like their parents, siblings felt helpless in not being able to take away the pain. In fact sometimes when siblings tried to relieve the children's pain, it only led to more physical pain. For example, one mother recalled how her seven-year-old daughter while visiting her hospitalized brother one weekend had tried so hard to make her brother feel better from pain caused by his mouth sores. She knew he was hurting a lot so she tried such things as making a spaceship for him from his Leggo collection as he was too weak to do so. However, nothing helped and in fact she only made the pain worse when she kissed her brother on his cheek. This mother recalled: *"Linda (sibling) felt so bad for*

seeing him the way he was, for hurting him...it was important for her to see him the following weekend when he was feeling better."

Perhaps even more telling was the suffering expressed on the siblings' faces in relation to seeing their ill siblings being hurt physically and mentally. As previously identified, the siblings experienced much sadness, but often their sadness was unspoken. However, their sadness could not always be hidden in their facial expressions. They gave the impression of being like wounded animals.

The ill children themselves, experienced hurt and suffering in relation to the physical effects of the cancer on their body and included everything from experiencing procedural pain to feeling nauseated to just feeling really sick:

> *Interviewer/Researcher: Okay can you show me here how do you feel when you get your IV in?*
> *Child with cancer (4 ½-year-old female): Sad!*
>
> *Interviewer/Researcher: Can you tell me some of those times when you got sad?*
> *Child with cancer (5-year-old female): When I was very, very sick.*
>
> *Interviewer/Researcher: What has made you most sad since you've had cancer?*
> *Child with cancer (11-year-old male): Cramps, headaches, taking a lot of medicine!*
>
> Children also experienced sadness knowing other children were hurting:
>
> *Child with cancer (11-year-old female): What made me sad? The cry of listening to little kids going through treatments and getting a needle and screaming.*
>
> The fear of death resulted in the children feeling sad for themselves:
>
> *Interviewer/Researcher: What made you most sad about being sick?*
> *Child with cancer (4 ½-year-old female): That I was going to die!*

The hardness in relation to the cancer symptom trajectory such as all the uncertainty or restrictions caused increased psychological distress and suffering for the

children just as it did for their parents and siblings. This included such rough times as thinking about and waiting for painful procedures, having to miss out on certain events because they were deemed to sick, and missing school. All the rough times including all the losses experienced by the children resulted in them feeling sad for themselves:

Child with cancer (5-year-old female): I was sad because I couldn't climb the tree.

Interviewer/Researcher: Like when you were getting your cancer treatment, your chemotherapy, what made you sad?
Child with cancer (7-year-old child): I didn't have any hair.

Interviewer/Researcher: What made you the most sad?
Child with cancer (7 ½-year-old): When Laurie (another child with cancer) died.

Child with cancer (8-year-old male): Sad, I felt sad because I'm tired and I can't play and I can't go to school. Once I could go to school and play outside but now I can't.

Child with cancer (10-year-old female): Oh, it was sad because I wanted to see those fireworks that I missed.

Interviewer/Researcher: What's the thing that's made you sad the most about having cancer?
Child with cancer (11-year-old male): You lose your friends and you have to go back to a different school.

Child with cancer (11-year-old male): Sad...Can't play football, can't play soccer, can't play basketball, can't play Kings Court.

Being separated from one's family especially resulted in the children feeling sad:

Interviewer/Researcher: Was there anything that made you really sad when you were in the hospital?
Child with cancer (7-year-old child): Yeah (pause), um my family wasn't there.
Interviewer/Researcher: Tell me some of the happy days that you had while having the bone marrow transplant?
Child with cancer (7-year-old child): Um (pause), when my family came to visit me and "grammy" too.

The ill children also experienced hurt in relation to seeing their parents and siblings suffer because of the cancer experience. They felt at times that they were a burden to their parents and siblings because of the cancer-symptom trajectory and felt bad that their families had to make so many changes:

> *Child with cancer (16-year-old female): It was my mom's and dad's first night ever going out since I got sick. Like ever really going out! They went, they went gambling to the casino and ah, it was, it was Father's Day you know and I ruined my dad's Father's Day because they had to come home because I got sick...*

> *Child with cancer (16-year-old female): I feel bad because P (brother) is really jealous now and he is upsetting us all...*

To say that having cancer in one's family, was complex and caused a great deal of suffering for all involved would be understatement. The children's and families' experiences and stories reinforced that the cancer-symptom trajectory resulted in more sadness in the hearts of the children and their families than they had been accustomed to in the past. In addition to all the added pressures, there was now as many of the families expressed: *"the sadness."* When children were asked what it was like to have cancer, many responded like this one young child did by simply stating:

> *Child with cancer (7 ½-year-old male): Um (pause), it was sad.*

Just as there was more than just one specific event that contributed to the hardness or roughness of the cancer-symptom trajectory, so too were there many reasons that caused the children and families to feel hurt and feelings of sadness. From dealing with the loss of the children's hair, physical pain and exhaustion, loss of friends and families and so on, children and their families had many sad days and nights. Children and their families did not become numb to the sadness. In fact with each subsequent experience the

sadness was felt even deeper or as expressed by one mother:

> ***There are many layers of sadness!*** *...It is like peeling an onion! The layers, as you peel the layers off, the layers have gotten deeper now, now it has gone right to the core of you. Before it was getting used to it, just surviving. Now it is part of you, it has taken a year to become that sadness, now it is part of us . It (sadness) will always be there. It changes your whole life. I can't even explain it. I don't look at anything like I have before.*

The sadness and the suffering associated with it, became even deeper was they got through the cancer experience; the sadness was felt more, to the point that it helped to define who they were. It became a part of them; yet the sadness was not *"worn on their sleeves"* or out there for others to see:

> *Father: No, it is a different degree of difficulty.*
> *Mother: It is a deeper sadness, I think. It is not on the surface any more. It is where nobody can see it, it has become inward now, don't you think Bill?*
> *Father: Yeah...*
> *Mother: It is not something you talk about to people. Before people would say "how are you?" But everything seems normal now, nobody says that anymore, and nobody gives you that understanding anymore, that leeway. It is more of a deeper sadness, it is a deeper sadness, it is more inward.*
> *Father You get less leeway for that than when you are actually in the middle of a crisis.*
> *Mother: Because you don't, people were understanding, it is not there anymore.*

And only by sharing their suffering and sadness with others, did the hurt and sadness become evident. Fortunately, the families in this study wanted to share their sadness with the researcher who felt very privileged to be a part of their worlds even for a brief moment in time.

While children and their families experienced a lot of mental suffering, this did not stop them from getting through the cancer-symptom trajectory. Nor did it take away their hope. They continued on, despite experiencing less understanding from others:

> *Father: The bombs have finished dropping and now we have to rebuild over*

again, at least we hope they have finished dropping!
Mother: You never know.

Summary of the Eight Personal Meanings of the Cancer-Symptom Experiences: A Bittersweet Experience

Although each cancer-symptom experience was discussed separately, the children could experience more than one symptom experience at the same time. Moreover, the children could not really separate one symptom experience from another symptom experience without affecting the overall cancer experience. Thus the meanings in Figure 2 are depicted as overlapping circles in which each symptom experience is connected and related to one another. The circle demonstrates that each experience contributed to the hardness of the children's cancer experience. That is, all symptoms experiences were considered by the children to be difficult. They all brought with them varying degrees and types of extra effort, restrictions, pain, and additional worries. Just as children and families had a difficult time articulating what the defining event of the cancer-symptom trajectory that had the greatest effect on their lives was, so too they had a hard time deciding what symptom experience was the most difficult:

> *Child (17-year-old male): You couldn't go out and play and nausea. Its not fun at all and you'd like to take that away and then there's the headaches which you can live with but some were so great that I just kind of said I don't want to live anymore. You kind of look at them and try and stage them but they're all pretty bad cause if you look at tiredness you're laying around and wasting your day...kind of not fun with those either so...they're all kind of intertwined and you kind of have to really, really...Yeah it would depend on the day and situation and how bad they were.*
>
> *Child with cancer (7-year-old female): They were both about the same (referring to how she felt from the chemotherapy and bone marrow transplant).*
>
> In hindsight children and their families would often imply that while a particular

symptom experience may have been truly "*bad*" at the time they were having to get through it, the experience in the end was no worse than other symptom experiences. All symptoms were experienced as rough spots:

> *Interviewer/Researcher: Of all those things (symptoms) I mentioned, being tired and everything, what is the worst part for you?*
> *Child with cancer (11-year-old male):(pause) C: All of them yeah, yup.!Mostly just (pause) all of them.*

> *Interviewer/Researcher: But there is not one symptom worse than another, like her throwing up?*
> *Father: (pause) It's all together.*
> *Child with cancer (14-year-old female): I don't know because for me it is so weird because while it is happening I could just tell this is the worse I ever experienced but then afterwards, "so I guess it wasn't that bad!" I guess thinking back you would ask me then I would have said* ***"I FEEL SO HORRIBLE*** *" but now I am saying I guess compared to other things it wasn't that bad.*

> *Child with cancer (17-year-old male): Nausea, headaches, um....I don't know. I don't know if there was one worse than another one. Um,...Well the headaches at times were like really, really bad like the whole head hurt. The nausea was...(pause) I don't remember what the drug was but when they hospitalize you for it you start to throw up in the middle of the night. I started to throw up when they started the drug and I would thrown up constantly from then until when I got out and...*

Symptoms identified as the most difficult or hard, were those experiences that were occurring in the moment; the symptom experiences that the children were presently going through:

> *Child with cancer (15-year-old female): Well when you are going through it, it is the worse symptom in the world. But then when you are going through something else it is the worse thing.*

The children's difficulty in separating or dividing up the overall symptom experience was also reflected in their inability or their lack of desire to rate specific symptoms such as pain on a rating scale or measurement tool. Initially the children,

regardless of age, cooperated and responded to the researcher's request to rate the intensity of their symptoms either on the VAS (refer to Appendix F). However, it did not take long before they became easily tired and frustrated with such requests. Even when the children did rate the symptoms, they indicated by what they said as well as by their tone of voice a degree of uncertainty to their ratings. They were never totally definite or absolute about their ratings:

> *Child with cancer (16-year-old female): Um (pause) when I was in the hospital before with my bone marrow transplant, they were always asking me to rate my pain and you can't really measure pain. So if you are feeling bad then it doesn't really matter how intense it hurts or whatever, it feels bad and (pause) when you are feeling the pain, you don't really want to have people asking you "how are you feeling?" (mocking tone - laughs) "I feel like, I don't feel good thank you very much!"*

This lack of desire to assign a specific rating was also observed when nurses or doctors would ask children to rate the intensity of their symptoms. For example, when a nurse asked one hospitalized nine-year-old boy to rate "how bad the mouth sores were," he hesitated and then responded by stating "*I can't use that (the scale)...do that.*" The nurse interpreted this to mean that he did not understand although in the past the researcher had witnessed him having the ability to use the scale. Accordingly the nurse then asked him to rate his pain on a different scale. This time the child said nothing and just stared at the nurse. He seemed to become increasingly frustrated and angry as indicated by his facial expression. The nurse responded by stating that the child would need time to learn how to use the scale. Later the child confided to the researcher that he did understand how to use the scale, but that he just did not want to because it could not describe how he really was feeling. To the children, assigning a number or level to a

particular symptom could not capture how they truly felt. Although each symptom resulted in unique or different sensations and emotions, in the end each symptom experience was described as being "*bad*":

> *Child with cancer (14-year-old male): They were all bad (laughs)...Cause they all sucked! (Laughter) I don't know.*

It was perhaps for this reason the children and their families never really got used to the symptom experiences even though they often would talk about the need to "get used" to the symptom experiences. For the children and families, "getting used" to the symptoms really meant learning "*to live with the symptom experiences, but never really liking them.*" Although part of keeping the spirit alive involved parents and children accepting that symptom experiences, at the same time this did not mean that they got completely used to them in a true sense:

> *Child with cancer (16-year-old male): You don't really get used to it (cancer and its symptoms). You really don't get used to it, you adapt to it. You don't really get used to it. I mean you have to adapt because if you don't you're going to die...And I don't think there's any way that you can totally prepare because there are no actual guarantees.*
>
> *Child with cancer (17-year-old male): I think you learn to adjust to it. I don't think you ever get used to it really. You learn to adjust to it but get used to it is kind of like you sort of do but its kind of like I felt that we got used to it sort of and then, we stopped and then started all over again.*
>
> *Child with cancer (9-year-old male): I got used to it I guess (not definite).*
>
> *Father: I think you never get used to it. You can get into the routine and know what to anticipate so that it lessens some of the fear and the unknown, but it still hurts and it still breaks up your routine and you still know two days later "I am going to be sick," you know?*
>
> *Sibling (8-year-old female): Like you adjust to it but you're not really used to it and you don't really feel like doing it (things cancer-related) but you know you*

have to.

It was important that the children and families never became totally used to the symptom experiences, as there would be no need for them to apply the strategies of keeping the spirit alive. It was the personal meanings that triggered the keeping the spirit alive strategies as depicted in Figure 2. While they adapted to cancer and its symptoms as well as a new routine to life, the families still experienced pain and suffering. Moreover, the new routine unlike their old routine was not carried out unconsciously:

> *Father: You do the things that you have to do but it is still a pain every time! It is still a conscious thing, it. It is not like you slip unconsciously like going to work everyday! It is a very different kind of routine.*

Even children who had relapsed and undergone numerous treatment courses never totally got used to the cancer-symptom trajectory and all its treatment. This was because there was always the hardness that came with each cancer-symptom experience:

> *Child with cancer (17-year-old male): Well every time like after I had about three remissions and they were short. So after each one it kind of changed a different treatment protocol and stuff but as it got to the end it sort of was the same. You would go in every Friday and get this done and that done. Every week or every second week or something we'd have a or every month you'd have a bone marrow or spinal tap or something like that. It got sort of predictable but it was **STILL HARD**.*

The hardness of the cancer-symptom experiences was something the children and families never got used to. Children and their families described their experiences with the cancer-symptoms as bitter in nature with many layers of suffering. To hear parents refer to cancer as "*horrendous*" or "*hell on earth*" reinforced their suffering and underscored their feelings of bitterness. Likewise, children of all ages experienced the bitterness and suffering as evident by the following statements:

Child with cancer (16-year-old male): It is not a pleasant or fun experience!

Child with cancer (5-year-old female): ***THE HORROR OF IT ALL!***

Sibling (10-year-old male): Cancer is very painful inside...Lonely..Very sad...Is symptoms...

However, while suffering was unpleasant, painful or almost unbearable at times, it could not be avoided. One needed to confront the suffering related to the cancer and its cancer-symptom experiences. Just as one adolescent explained it was important to rip down the barricade piece by piece in order to get through the cancer-symptom trajectory, children and their families had to get through each layer of suffering and bitter feelings in order to survive.

Perhaps even more difficult to bear than one's own suffering was the suffering experienced by others. The children especially shared the feeling that they caused their families to suffer which in turn caused them deeper sadness and anguish:

Child with cancer (15-year-old female): It is terrible going through it, but I can see it being more terrible, not more terrible, but really terrible to be part of the family who has to watch somebody go through it cause like you know you feel so bad, like there is just no way you can help them...It just that you feel really helpless not being able to do anything as a family member...

Yet despite their suffering and bitter feelings, children and families were able to appreciate that there were some good things about cancer as was evident in the children's narratives. Amongst the layers of suffering and bitterness, were layers of joy that were important to the children and families:

Child with cancer (4 ½-year-old female): You don't get to have fun cause you're not feeling well...But I had lots of fun...

Interviewer/Researcher: Okay if someone said to you what is it like having

cancer, what would you say to them?
Child with cancer (11-year-old male): (pause) Some of it is pretty cool (in reference to getting things and people being kinder when he felt sick) and some of it is pretty bad (in reference to feeling sick)!

Child with cancer (18-year-old male): Yeah. Well, well a lot of bad things were happening and a lot of good things happened in those years. I'm working on my 4th year of remission.

Mother: It is just finding some joy in the middle of it and may be some boredom or some (pause) routine or control of your day.

Mother: And aahh we were certainly disheartened after the results (results after the first surgery). We were overjoyed by the end of the second sets (second surgery), there was a big improvement!

Sibling (7-year-old female): When I'm not happy I'm usually like...umm...I don't know kind of in between, lonely and sad.

In addition to learning how to experience the bitter times, families had to come to accept the "good" associated with cancer and the cancer-symptom experiences:

Mother: I mean you have to live...You know I cherish every moment with those kids now. And like we joke around a lot when we're home together and they (her children) don't want to get up and go to school. Like I just make my rounds jumping from bed to bed to get in with them and they just love it and we sit and talk for hours you know. I don't know, I think we're closer. And before when John (child with cancer) was younger we never had the talks. Like he was too young he didn't really...he just wanted to play with you and my girls were very, "come lay with us, let's talk, let's talk girl talk." But now, just before I went to Toronto, he called me into his room and said "Mom come lay with me and let's have a talk." And so I did and we were there for half an hour and had our little mother-son talk and it was quite good.

As many of the children and families noted, the experience of cancer involved the good and bad times. It was important for them to "*take the good with the bad!*" Even is instances when children did not survive the cancer, it was important to find the "good":

Interviewer/Researcher: So you think cancer has two sides? There is a dark side and what would you call the other side?

Sibling (13-year-old male): Joyful.
Interviewer/Researcher: Joyful okay. So what's the dark side?
Sibling (13-year-old male): Having some, having the person that has cancer suffer and having pains and aches and having to go through it 24 hours a day, 7 days a week.
Interviewer/Researcher: And what's the joyful side?
Sibling (13-year-old male): Either having them die or survive.
Interviewer/Researcher: And when you say die, what's joyful about that?
Sibling (13-year-old male): Like it's, like a reward. That, cause if you're really suffer a lot...

Mother: Experience that we wouldn't want anybody else to go through (pause) but with the son that we had that went through his cancer, it was a good experience.
Father: You wouldn't wish that on anybody but the point is that our (pause) experience was good you know, the whole thing is I mean you can't even say it is finished because he is only in remission...I would say it was a positive experience in the way for only in the way that everything went well for us. Everything turned out right from bad at the start to good at the end and even if everything in between was not always good, we had (pause) because you had to do it anyways. We had fun, we had a good time, we made friends and everything was good that way.

Interviewer/Researcher: Okay if one of your friends got diagnosed with cancer, what would you tell them?
Child with cancer (11-year-old female): That you are going to be okay and (pause) don't think of the bad things, think of the good.

Accordingly, "*bittersweet feelings*" emerged as the overall cancer-symptom experience. Bittersweet feelings is depicted in Figure 2 as a curved circle directly above the "personal meanings" phenomenon.

Subcategories of the Core Category

Although the previous sections described how the self and body changed in relation to the changing personal meanings, this section further clarifies the relationship of the core category to its two subcategories: (1) my changing self; and (2) my changing body. Because of the cancer-symptom experiences, children in this study became more

aware of who they were and how they felt. They reflected more on what made them unique. As well, they became more aware of their bodies. Although the self and body are discussed in two separate sections, in reality they did not exist as distinct entities but instead were interrelated and reciprocal. How the children felt in their bodies in response to the cancer-symptom experiences, affected how the children felt about themselves. Likewise their sense of self determined to some degree how their bodies responded to the cancer-symptom experiences.

"My changing self" and " my changing body" are depicted in Figure 2 as two curved lines. These two curved lines are closely situated to each other to reflect their interdependency.

(1) My Changing Self

As was noted in the discussion of the eight personal cancer-symptom meanings, the children's and families' sense of self was greatly influenced by the meanings assigned to the symptom experiences. When children experienced any of the symptom experiences it resulted in them feeling different; they did not feel like their "old selves" which in turn affected how the family felt.

As is depicted in Figure 2, "feeling different" could range from "I feel least like myself" to "I feel most like myself." The degree of feeling different was determined by the type and number of symptoms experienced by the children. Understandably the children felt least like themselves when they experienced symptom experiences such as "I feel yucky" or "I am cranky" symptom experiences. When experiencing "everyday" symptom experiences, the children felt more like themselves. However, the ability to

keep the spirit alive also influenced how the children felt as is depicted in Figure 2 in which the process of keeping the spirit alive extends from the personal meanings and changing sense of self.

The very nature of cancer resulted in most children and families having to experience suffering at a level that was never quite experienced before, so it would be unrealistic not to expect changes. However, the changes were characterized in terms of the children and families growing. Most children and their family members described themselves as developing as individuals, becoming more mature or being more sensitive to the needs of others. While for some, the changes were viewed to be overwhelming; others did not describe the changes in such a grand way:

> *Child with cancer (15-year-old female): You know those people who go and say they are going "I am going to dedicate my life to good things, life has So much meaning to me now!"...A lot of people end up with those different perspectives like people say things like "this has made me realize you only have so much time to live and things can happen at any time." I never ended up with a perspective like that. I ended up just like I was before... I think you realize how important family are to you. Like I guess before it was like the sister I was stuck with having, but now I realize they are really, really, important to me and you know when I need them they are there for me and when I am going for something, they'll always be there...that did change. You also realize how important your friends are...you it is not like one of those eye opening life changing experiences, not for me it wasn't.*

> *Sibling (10-year-old male): I changed because I have heard more about him (older brother with cancer) since he got cancer. Before he got cancer he used to defend me and I just let him do all the work and I would do nothing and I would sit back and now I defend him. I used to never defend him. Now if kids make fun of him because he has cancer I'll defend him...*

It also must be noted that while the children and their families expressed that at times they "*felt different*" or "*not themselves*" or "*not normal,*" they nonetheless reinforced that the basic core of what made them unique had not changed. In effect,

although children and their families experienced a changing sense of self throughout the cancer-symptom trajectory, their inner core or their spirit remained intact:

> *Child with cancer (16-year-old female): Mmmm, I don't think I changed much as a person and who I am, I may be have some different opinions on some things, and for all I know my opinions may have changed like that anyway, but no, I don't think it completely changes who you are. Well it didn't for me any ways...*
>
> *Interviewer/Researcher: Okay tell me if you had to describe who "Chris" is what would you say?*
> *Child with cancer (11-year-old male): I would say my name is "Chris" and "I'm still an 11 year old. I still have to do my chores and I can still go sliding. I can still go snowmobiling. I still can go ice fishing."*
>
> *Sibling (10-year-old male): He (brother with cancer) was the same person just a lot more tired and just because he looked different. I thought he was the same person, but I knew that his hair would grow back and he would eventually get a prosthetic leg...I was looking, I was seeing if he would be a different person but he didn't. I wasn't looking at looks or sleepiness or grouchiness. I was looking at his actual personality if it was changing him.*
>
> *Mother: Oh, there's the self that's who he is and there's the self what he does. And he wasn't the "doing" Brad, but he was certainly the Brad!*

Even with the changing attitudes or perspectives and even though their lives had changed forever because of the cancer-symptom trajectory, most felt that they nonetheless maintained their sense of spirit. Comments such as "*at least he maintained his sense of spirit*" supported this.

Likewise even though the family unit changed, the basic core of what made the families unique, remained the same. That is, those families who were strong to begin with, only became stronger; and those families who were not too united to begin with, only weakened and eventually fell apart.

(2) My Changing Body

In addition to experiencing changes in their sense of self, the children also

experienced changes in their bodies as is depicted in Figure 2 as a circular line directly below the changing sense of self. Because of the symptom experiences children also became more aware of their bodies. Prior to experiencing cancer, the children may have lived through their bodies, but they did not really pay much attention to what their bodies felt like to them or reflect on what their bodies meant to them. That is, prior to the cancer experience they really did not know their bodies and in fact, took their bodies for granted. It was not until the children experienced the symptom experiences that they became experts in relation to knowing their bodies:

> *Child with cancer (15-year-old female): I don't know I guess for example each time you throw up you notice each time before you throw up you know you maybe get a funny feeling right here (points to an area on her stomach) and it is a funny stinging feeling or a funny piercing feeling. Whatever it is that your body does or you know you get a funny taste in your mouth, whatever it is.* ***AND*** *you start to* ***notice*** *those things. So you know when you get the funny taste you say "O.K. this means I am going to throw up" and you can go running to the bathroom. Whereas someone who has never gone through cancer, if they are feeling sick to their stomach and they are about to throw up. You know they get a funny taste in their mouth, they don't know why. They just for some reason have a funny taste in their mouth...*

Having to get through the varying symptom experiences resulted in the children becoming focused on their bodies because of what the symptoms meant to them as well as how the symptoms made their bodies feel. The attention they afforded their bodies varied according to the degree of suffering they experienced because of the symptoms. This ranged from the children almost forgetting about their bodies, to becoming completely fixated on their bodies. Not thinking about their bodies occurred during times when symptoms were minimal. Awareness of their bodies did not mean that their bodies were becoming separated from their overall sense of self. However, because of an

increased awareness of their bodies in relation to the symptom experiences, children experienced their sense of self differently. For example, when children defined their symptom experiences as "*nasty*" they lived mainly in their physical sense of self. Increase symptom severity resulted in the children's bodies feeling totally different to them. In contrast, children experienced a healthy, "normal" body when they experienced minimal or no symptoms.

Understandably, the children's changing bodies affected how they lived life and interacted with others important to them. In the end, having to get through all the rough times of the symptom experiences resulted in the children never again taking their bodies or life, for granted. They had developed respect for their body, especially a healthy body that was free of symptoms. Developing a respect for their body involved the children becoming more attentive to subsequent symptom experiences and taking better care of their bodies.The children as well as the families became experts with respect to the children's changing bodies. And indeed, most children experienced bodies that changed throughout the cancer-symptom trajectory. Moreover, families wanted others to be aware that the children experienced changes. It was not uncommon for the families to want to show the researcher pictures of the children as they changed. The family picture album would often be pulled out and for some children, it was like the researcher was viewing pictures of multiple individuals, and not just one child.

Throughout the cancer symptom trajectories, the children experienced many different types of bodies including: (i) the unruly and failed body; (ii) the sensitive body; (iii) the distorted body; (iv) the regulated or engineered body; and (v) the renewed body.

(i) The unruly and failed body referred to the children's experiences of a body that were uncontrollable. Instead of the children having control over their bodies, the symptoms took control over their bodies in two ways. First, children could no longer make their bodies do certain things that they wanted to do and normally were able to do such as run in gym class or walk up a flight of stairs:

> *Child with cancer (7-year-old female): Before I could run longer and I wouldn't get so tired!*

The children's bodies rebelled against the children by not allowing the child to participate in certain activities including activities of daily living:

> *Child with cancer (16-year-old female): Because I couldn't do anything by myself. I had to learn like I didn't have to learn, but I mean, like I had to get help off the couch, and if everyone is sleeping, how am I supposed to go to the bathroom, you know. It was really, it was a big chore to try and get off the couch.*

The second way that the body became the unruly body was that it would do things that the children could not stop it from doing. They had no control over their bodies. Sometimes this involved the physical body such as trembling fingers; sometimes it involved their mental or psychological body such as when they became cranky or "*out of control*" with respect to their personality. Because of the symptoms, the children's bodies were no longer dependable, trustworthy, or predictable to the children. Instead of the children having power over their bodies, the bodies now had a will of their own. This had an effect on how children participated daily in life and interacted with others.

Having unruly bodies also led to children feeling confined or restricted in what they could and could not do on a daily basis. Moreover, "others" now were having to do things for the children that the children could no longer do themselves. Hence, the

children needed to rely on more help and support from others such as requiring assistance in walking and going up the stairs. The children's bodies became dependent bodies. Although children were dependent on others prior to the cancer-symptom trajectory, this dependency was a normal dependency that all children experience growing up. Hence children became aware of having a body that was dependent on others. The unruly and failed body resulted in a loss of some freedom.

(ii) The distorted body was the body that children viewed as different from their normal physical self. Hair loss, round and puffy faces, weight loss or weight gain, slow moving bodies or bodies with limited movement, tired bodies and so on, contributed to feelings of a distorted body:

> *Child with cancer (11-year-old male): It (the medicine) makes my cheeks and my body really huge!*

Any devices to assist the failing body such as a wheelchair further provoked feelings that their bodies were distorted and that their distorted bodies were more observable or prominent to others:

> *Child with cancer (14-year-old male): It is a little embarrassing (having to use a wheelchair). They automatically think I'm crippled, I can't walk or something. And then all of a sudden I get up and start walking. And then they think that I'm faking it or something, I don't need the wheelchair or something.*

All the children would talk about their experiences of other people staring at them, especially as they all agreed "*when they had no hair!*" Moreover, the ill children perceived that others looked at their bodies, or more appropriately, the ill children as different even though inside the ill children may have felt the same inside:

> *Child with cancer (16-year-old female): Like some people think I'm a boy (with hair loss) and... just I don't know... people don't recognize me and stuff like*

that...people don't usually recognize me. Unless they know who I am...

Child with cancer (9-year-old male): Okay well it (the medicine) makes me fat as a hog. Everybody makes fun of me. I felt like anybody picked on me.

Families often confirmed that their children at times did not look like themselves:

Father: Oh they don't look the same, I mean especially with no hair and with the Prednisone, his fat little face that you don't even recognize...

The ill children believed others misunderstood them or misinterpreted who they were because their physical body had changed. At times, even the children themselves did not understand what was happening:

Child with cancer (16-year-old female): Right now it is hard to understand what is going through this crazy, chubby, watermelon face of mine...God knows I sometimes can't understand myself.

The distorted body as the children perceived it, was noticeable to others in an unpleasant way. The children felt others saw them as deformed or distorted or as complete strangers. One adolescent said she was often mistaken for a "*punker*" when she had her hair loss:

A lot of people are like kinda different, like people that I just meet and stuff like that. People that know don't mean to, they're just kind of you know...A lot of people thought I was into punk, like I was a punker you know but uh...

Like having a balding head, the children felt at times bald or naked in a general sense because of their obvious body. At times children sensed that their appearance caused others to be afraid of them. Even after treatment completion, children for the most part still felt their bodies showed signs of their cancer-symptom experience. On one hand, the distorted body made the children feel that their true self was hidden, like they were wearing a mask and costume, and on the other hand, the distorted body made them feel

like they were naked to the world.

But perhaps what was most telling was how children themselves were obsessed with their bodily changes. Although they really believed they were the same deep inside, they nonetheless did not like how cancer changed them physically or outwardly. This was never so evident in one five-year-old girl who while attending the cancer clinic throughout her treatment course would not play much with the other children in the clinic. It was not until the end of her treatment course when she was beginning to look like her old self that she began to interact more with others. During one visit her mother and the researcher caught her staring in one of the clinic's mirrors. When the researcher said how nice her hair looked she responded by saying "*I am still not Carrie!*" She had said this because although her hair was growing out it was still not the same as it was before the cancer experience. Her mother also noted that when she had no hair she avoided dressing like a girl even though she realized she was a girl and would start fights with anyone who would call her a boy. This child felt her body was so distorted that although feeling the same, she avoided the world. Likewise, the older children would at times avoid seeing their friends because of their body appearance:

> *Child with cancer (15-year-old female): I loved WK (shopping mall) but I wouldn't go there because I know I would see somebody I knew.*

(iii) The sensitive body referred to a body that lived in a world of physical and psychological pain. Although children had experienced pain and suffering to the cancer-symptom experience, the pain and suffering were for the most part, not as intense or constant as it could be because of the cancer. Pain resulting from symptoms such as nausea or back pain, from being isolated from others, from seeing other children die were

just some of experiences that resulted in the children becoming more sensitive. Even after treatment was completed, children defined their bodies as sensitive bodies in that they remained perceptive to any physical changes in their bodies and were more sensitive to how they responded to others and how others responded to them. Because the children experienced a sensitive body, the children seemed to have developed a sense of self that was much more sensitive to the world around them. In a way, this was a positive outcome because they felt they became more understanding of others. For some of the children their sensitivity was so intense it was like they existed in another world or state from others. They had their own culture in which most were outsiders looking in. In interacting with some of the children it felt like they were scrutinizing everything that the researcher was doing. For all the children, the sensitivity was reflected in their ability to judge who was truly sincere to them. Their increase sensitivity was understandable considering they had endured things that many adults had not experienced.

(iv) The regulated and engineered body referred to a body that was managed and administered to. Although children and their bodies prior to the cancer experience were regulated by their families and other significant adults in their lives, the regulation and administration of their bodies became even more pronounced once the cancer was diagnosed. The children and their bodies became like machines or computers requiring updating and maintenance on a constant and fairly strict basis. Moreover, the greater the symptom distress experienced by children then the greater need for regulation.

Viewing their bodies like machines was even more appropriate considering the children's lives evolved around and relied on the treatment regimen that kept them

running and on track. Just as eating was a necessity, so too was having treatment. However, whereas such activities as eating could be more flexible, with treatment there was less room for flexibility. To some extent, children defined themselves in relation to their treatment regimen:

> *Child with cancer (16-year-old female): Well, at first I was on Monday Tuesday...every Monday Tuesday and Friday I think it was? Or Monday Wednesday and Friday? Pardon me. But then every now it's basically like every once a week type of thing or sometimes a couple times a week but it's not as heavy as it was before?*

Their lives were planned around the treatment regime, from the day-to-day activities to future activities. For example, in deciding where to go on a holiday one of the adolescents noted that she would have preferred to go to Hawaii, but realized that it was too far away and so she settled for Florida. Part of her decision was based on the timing of her treatment schedule and how having treatment prior to going on the trip would make her feel. However, sometimes the regulating of their bodies became too much for the children and their families which led to them rebel against the treatment regimen by delaying or postponing some of their treatments.

(v) The renewed body referred to a body that enabled the children to carry on in life and enabled them to do things that they wanted to do; it was a body that made the children feel alive, energized, and spirited. It was a body that made them feel like a kid again. Understandably children's bodies most often felt renewed once treatment had stopped, and when the symptom experiences had resolved or were minimal. Their bodies were not failing them like they used to. It during such times that children once again realized how good their bodies could feel.

The renewed body could also be experienced while the children were still in treatment and often was the result of some type of treatment intervention that helped to boost their spirit even if it was for a short time. For example, one child who received blood on a regular basis expressed the following:

> *Child with cancer (12-year-old female): Yeah, I feel more energized and stuff like that...like I got a new battery or whatever so...(laughs)....I had two units of blood on Friday before I went to the mall and I'm still feeling pretty good. Usually it lasts at least a week or two.*

It was the renewed body that helped to revitalized the children's and families' sense of spirit. It gave children and families hope to continue on.

Conclusion

This chapter demonstrated the significance that the cancer-symptom experiences and their assigned meanings had to shaping the children's and families' cancer experiences. The personal meaning affected the children's sense of self and how they experienced their bodies. In turn, the changes experienced by the children affected other individual family members and the family unit's sense of self. The next chapter further completes explanation of the second substantive theory by focusing on the theory's second core category: Passage through the transition periods.

TABLE 5: PERSONAL MEANINGS OF THE CANCER-SYMPTOM EXPERIENCES

CANCER-SYMPTOM	MEANING AND CHARACTERISTICS	THE CHANGING SELF AND BODY
I have a sick stomach, sick head...I feel sick, I feel bad	•experiences where children feel physically sick; unpleasant, hard, and undesirable state •feeling sick is different from being sick •feeling sick made the cancer more real; however, feeling sick was not necessarily equated with being "really" sick •although an undesirable state, feeling sick was accepted as part of the cancer experience; regular or "normal" cancer-symptoms and provided evidence that the cancer is being beaten •usually involves one or two areas of the body and associated with treatment •nausea and vomiting especially associated with it	•experiences some changes in daily routines •more concentration on the physical self but other dimensions of the self are present •body more sensitive; experiencing more restrictions •sense of self viewed to be "more or less" like the old self; however, child did not feel completely whole •although the family experiences changes, it remains intact
I feel yucky, crappy, shitty...I feel really sick, I feel really bad	•experiences where children feel "really sick" •children are considered "really sick" •associated with death •equated with "something else is going on" or that things are "not quite right" •treatment- and cancer-related •every inch of the body feels "shitty" •children are very sensitive to the outside world •much harder to manage	•especially "hard" on the children and family unit •carrying out daily activities becomes extremely difficult •children described as not acting like their "old selves" •physical self dominates; failed, distorted body •parents and siblings also feel yucky •parents' self is merged with the children's self •siblings' self remains on the "outside" of the family unit **Table 5 continued➡**

TABLE 5: PERSONAL MEANINGS OF THE CANCER-SYMPTOM EXPERIENCES

CANCER-SYMPTOM	MEANING AND CHARACTERISTICS	THE CHANGING SELF AND BODY
I am sore...boy, my body hurts	•because of this symptom experience, life was perceived as unfair, something hard, and rough; like life "sucks" type of thing •experiences where children feel physical pain •usually not as long lasting •usually procedural-related •not always associated with "being sick"	•physical self dominates but is limited compared to "I feel yucky" experience; body sensitive during the hurt •family unit remains intact •parents and siblings experience a lot of mental distress because of the children's physical pain; children experience mental distress when their pain is not taken seriously
I am cranky...I am not myself	•experiences where children undergo changes in their moods and behaviors - out of control, anxious, low frustration level; in turn parents and siblings become anxious and frustrated •life is something where the individual has no control •experiences changes in appetite •children described as being unpleasant •associated with many aspects of the cancer experience, but especially associated with the steroids •there is "no medicine" or nothing specific that can help to make it better	•children described as not acting like their "old selves"; body out of control •affects social sense of self/ fewer social interaction •family finds it is not pleasant to be around the children •family spends less time together •disruptions in family's activities
I am just experiencing an everyday thing...I am just a little sick	•symptoms that become a part of everyday life •symptoms perceived not to be too severe •symptoms identified as "not too bad" •labeling symptoms as "everyday" helped children to maintain some normalcy •associated with viewing life as "more normal" •frequently do not seek help for these experiences	•children's and family's way of life more similar to the way it was like before the cancer diagnosis •sense of self different, but not to any great extreme •some sense of a renewed body **Table 5 continued➡**

TABLE 5: PERSONAL MEANINGS OF THE CANCER-SYMPTOM EXPERIENCES

CANCER-SYMPTOM	MEANING AND CHARACTERISTICS	THE CHANGING SELF AND BODY
I am wiped out...My body is just too tired for me to care	•life was equated with exhaustion •experiences where children feel totally exhausted •different from feeling tired; instead children feel "really" tired •no energy •not much helps to relieve the exhaustion except sleep •sometimes so exhausted that even falling asleep is a chore •usually longer lasting	•children's self is in limbo - not in the world of the living but also not in the world of the dead •children spend most of time on the "sick couch" •family carries on but extra work related to caring for the "exhausted" child •body has failed
I am scared...I don't know what is going to happen to me	•associated with viewing life as the "unknown"; life is the unknown •experiences that brought on feelings of fear and trepidation; feelings that "something bad is going to take place" or "waiting for the other shoe to drop" •associated with painful treatments, the possibility of relapse, the possibility of death •uneasy feeling state •some degree of fear remains forever in children and families	•threatened the children's and family's sense of self •family unit tries to stick together and become closer - to protect themselves from the dangers of the outside world •uncertainty of what is happening to the body
I am hurting...my heart is sad	•experiences where children and families experience mental distress and heartache •feels like the heart is breaking •associated with all the cancer events that cause children and families to suffer	•fragile sense of self especially for parents and siblings -related to seeing the ill children's pain and distress; sensitive body •sadness dominates self - especially for siblings •family members "take care" of each other - not to hurt one another

CHAPTER VI

PASSAGE THROUGH THE TRANSITION PERIODS OF THE THEORY "CHILDREN'S AND FAMILIES' LIVED EXPERIENCE OF CHILDHOOD CANCER-SYMPTOMS"

From one transition point to another; So many difficult roads ahead...

Introduction to the Basic Psychosocial Process: Passage though the Transition Periods

The cancer experience for the children and families in this study was a dynamic one greatly affected by the personal meanings that they assigned to the cancer-symptoms. Children and families experienced many changes with respect to their experiences of getting through all the rough spots associated with the cancer-symptom trajectory. These changes are represented by the second core category of the theory, Families' Lived Experience of the Childhood Cancer-Symptoms (see Figure 3, p. 257). The second core category, the basic psychosocial process, is identified as "passage through the transition periods."

"Passage through the transition periods" as a core category represented the changing nature of the children's and families' use of the "keeping the spirit alive strategies" and their way of being in the world as represented by transition periods. Critical to the process of passage was how the cancer-symptom experiences and the meanings assigned to them affected children's and families' way of being in the world; the children and families approached the "getting through" differently as the meanings changed. The "keeping the spirit alive" process was experienced as a change or movement over time when the meanings of the cancer-symptom experiences became part of the cancer experience.Transition periods truly reflected the diverse journeys children

and families embarked on with the changing symptom trajectory serving a the head guide for them.

Overall, the core category, "transition periods" constitutes seven transition periods or changing states. The changing states that could be experienced by the children and their families are: (1) It is just the flu; (2) It is a blur; (3) It hits home; (4) It is not so bad, it is pretty good; (5) It is nasty; (6) It is "dragsville"; and (7) It is comeback time.

In the discussion of the varying transition periods it is important to note that children and families did not necessarily experience passage through the "transition periods" in a relatively systematic and progressive manner. In fact some did not go through every period or changing state. For example, one family whose school-age child had been diagnosed with low risk leukemia, never had to get through the "*nasty*" or "*dragsville*" transition periods. As well, it was also possible for children and their families to experience two transition periods concurrently, to experience one transition period more than once, or for members of the same family to experience different periods. The cancer-symptom trajectory was an "*up and down*" experience for many families:

> *Mother: The first three months of chemotherapy was the worse...but her body adjusted to chemotherapy, and things got better....but then she would get another new set of chemotherapy that resulted in us adjusting to a whole new set of symptoms!"*
>
> *Father: I go on an up and down roller coaster. Well it is, it is just a big roller coaster.*

Although there were similarities that families shared in experiencing a specific transition period, they also experienced differences related to the surrounding context and

conditions, and the meanings they assigned to each phase. Thus while the transition periods are presented here in an organized and sequential manner, they were not experienced as such. They were not experienced like stages in which one stage gives way neatly to the other until resolution is declared. Instead children and families experienced the cancer-symptoms in a more fluid-like type of movement; movement that was not fixed in one direction which explains why "passage through the transition periods" in the model's diagram (Figure 3, p. 257) is depicted as an outer circle with bi-directional arrows. It was more likely for families to experience the periods as transitions coming and going. Discussion in this chapter is directed at how this core category relates to the phenomenon of getting through all the rough spots and the process of keeping the spirit alive. This discussion is summarized in Table 6 (p. 304).

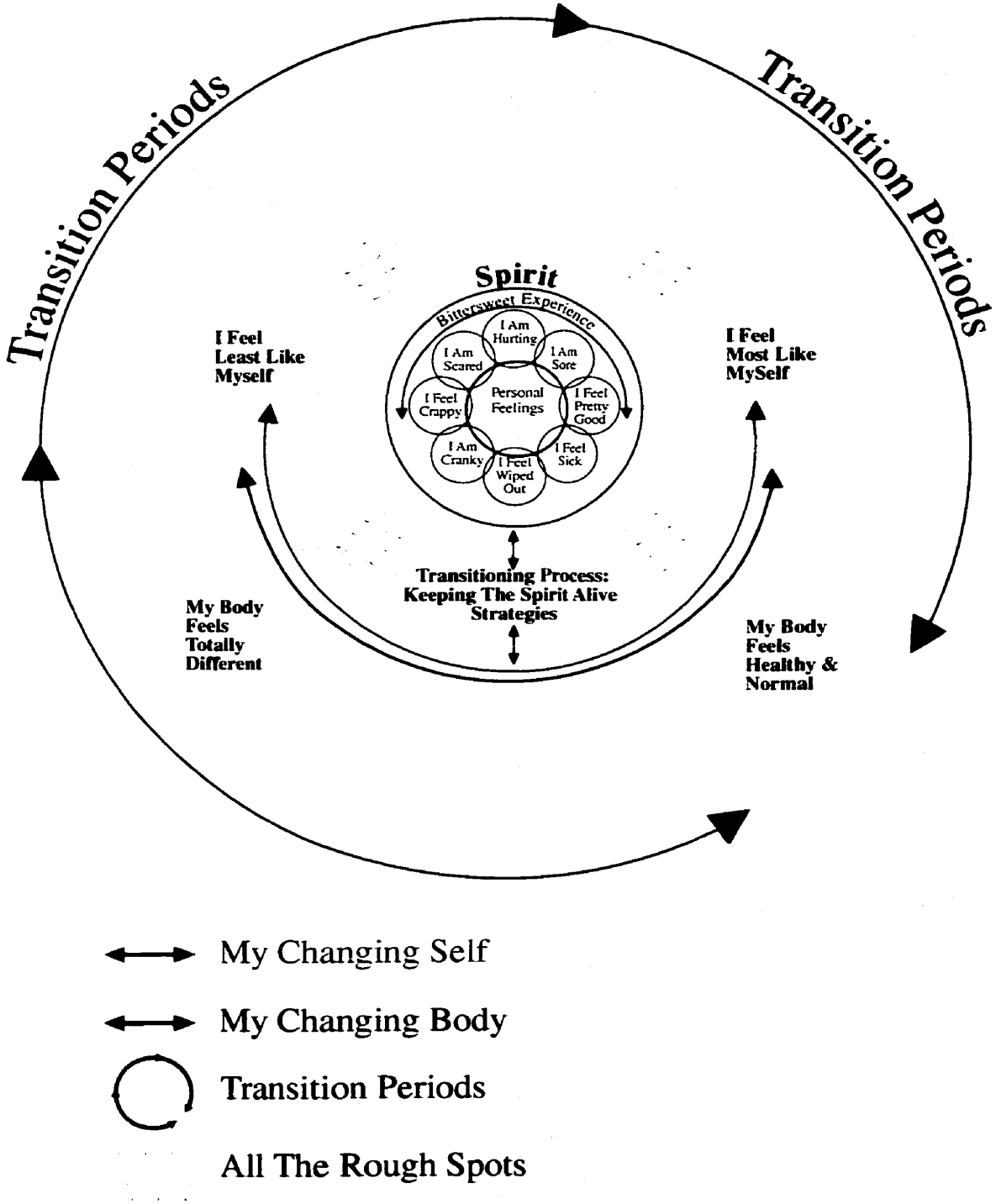


Figure 3 **Passage Through The Transition Periods: The Basic Psychosocial Process of Children's and Families' Lived Experience of Childhood Cancer-Symptoms**

Transition Periods

(1) It is Just the Flu...Anything but Cancer

"It is just the flu" period usually for most families marked the beginning of the cancer-symptom journey in which parents felt and expressed that "*something was not quite right*" in relation to how their children were feeling. Although this transition period occurred during the pre-diagnosis time frame, it could also occur anytime during the cancer treatment and post-cancer periods. The children's symptoms triggered the parents' thoughts or feelings that something was wrong with their children, were the children's symptoms. Although at this point the symptom(s) demanded attention, they were not considered to be of great concern. That is, the symptom(s) at this point represented to the families nothing more than a sign that the child might be temporarily ill, experiencing something minor or something not too serious:

> *Mother: When he was going to school and we realized that he was coming home and sometimes having to go to the bathroom more often than normal, we didn't chalk it up to anything. But maybe I said to him one day, "Maybe you're overeating. Like two sandwiches at lunch maybe is making your bowels loose." That's sort of the start but nothing kind of rang that anything was really bad.*

As was the case for most, the thought was that the children were experiencing a bad case of the flu that the children could not shake. In most of the families' stories, both the children and parents made statements such as "*we thought it was just the flu*" or "*we thought it was just the flu hanging on...*"

Children themselves did not always complain about how they felt and if they did, they usually described themselves as "*feeling sick*" or "*feeling bad.*" Siblings often thought the ill children were "*putting on an act*" in order to get some extra attention:

Sibling (10-year-old male): Actually as soon as he was whining about his knee was hurting, I would start bugging him about it. I thought he was faking.

Sometimes too, families associated the symptoms with "*growing pains*" or some type of injury like falling off the monkey bars. Parents usually viewed the symptom(s) as a normal part of childhood:

Mother: Nothing really kind of clicked and then one of his friends at school had mentioned to him that he looked like he had put on maybe a little bit of weight here because his t-shirts weren't fitting the right way. Then again kind of we listened and we thought the kid is growing...I mean everything was going great and he was eating in his teenager thing. He was eating a lot... And I chalked it up to his having his dad's metabolism...

The families' views were reinforced by the children's family physicians. Many of the families were told the following by their physicians:

Father: Like her cold sort of disappeared but she still had pain and the doctors kept telling us well it's growing pains, it's growing pains...

Child with cancer (16-year-old female): I was really sick since December and the hospital and my doctor kept sending me home telling me I had the flu. Yeah, I went to the hospital even and the hospital told me it was the flu.

Child with cancer (7-year-old): Well, mom took me to a doctor and they said it was probably just that I got a cold or flu in my bones...

The belief held by most physicians that nothing was wrong was evident by the fact that for at least half of the families it took months before the diagnosis of cancer was made. And even when physicians suspected that the children had something more than the flu, cancer was often not considered:

Child with cancer (16-year-old female): Well they (physicians) said the reason that I either had epilepsy or migraines because of my headaches and because I was blacking out. So I was supposed to see a neurologist, but I didn't...it didn't end up happening because they finally took blood from me...

Hence for most families, their first encounters in dealing with the symptom(s) was

to be concerned, yet to continue on as usual such as planning for family outings or vacations, going to work, or going to school. The individuals' and families' sense of self had not really altered that much. Families did experience uncertainty and worry as many of the children were never were given a definite diagnosis during the initial period. However, for the most part families initially did not view or describe this period as "*really hard.*" They did not have to get through anything too difficult so carrying out the process of keeping the spirit alive was not given as much consideration as it would be later on.

Part of this lack of taking the symptoms too seriously could be due to the fact that for most children, the symptoms were in fact nothing out of the unusual or were not different from what the children had experienced with past illnesses. A sore back, tiredness, lack of energy, and no appetite and so on, were some of the common symptoms that first called attention to the cancer experience, and without situating the children's symptoms within the context of cancer, families understandably would not be too concerned.

However, as time went on and the children's symptoms had not resolved and in fact got worse:

> *Child with cancer (7-year-old female): First it hurt in my back, well actually my neck...And then my back hurt and my legs, then my arms and then everything started to hurt and I just didn't want to move.*
>
> *Child with cancer (11-year-old female): It hurt so much that my mom took me to the Emergency room and then they prescribed inflammation pills and then the doctor sent me to the hospital to see if it was arthritis because they thought it was arthritis so the pills seemed to help and then finally around July it started getting* ***really bad!***

The increasing severity of the cancer-symptoms caused the children and their parents to worry more:

> *Child with cancer (16-year-old female): I was like "Oh cool I have the flu no more school for a while" and then I went back to school for about a month out of the whole second term and then spring break came along and I got sick again. So then I was in the hospital and then came home and...I was feeling fine for a little while and then all of a sudden I just started feeling really dizzy and I felt like I was going to like get sick all the time and I couldn't walk a lot. Like when the day I went into the hospital I couldn't even walk...I didn't know, I was like really scared because I didn't know what was happening to me.*

Symptoms became to be viewed as something more serious, something to be feared. Instead of just feeling sick, children started to feel "*scared*" or "*nasty*" or "*feeling really sick*":

> *Child with cancer (16-year-old female): I couldn't even move. I was like bent over and everything. I was just...and walking to the car and stuff like that I was too sick to do.*

The "hardness" of the cancer-symptom trajectory was beginning to creep in and affect the families' sense of self. Families were now making changes in their lifestyle like not going out as a whole family and the ill children were missing more and more school or not being able to participate in their regular or favorite activities like gym. The children were now starting to focus on their bodies. More restrictions and losses were being experienced. Most telling of all though was that the ill children were changing; that is, they were described as not acting or looking like their usual self:

> *Mother: About a week before, we were at the lake for about ten days and for about a week he just wasn't himself... Yeah he would wake up every morning saying that he is nauseous and he was sleeping an awful lot and he wouldn't go into the water and that's not like Ken. Ken lived in the water when we were at the lake and so we took him home, took him to the doctor with his bumps and he sent us to Children's right away and they diagnosed him the same day.*

Father: Well the way Sara (child with cancer) was acting...we know our daughter, it's not just growing pains. Well she didn't like school no more. She didn't want to go to school. It was hard to get her on the bus because it hurt. She could barely walk. She wouldn't hold her head straight, you know, she would hold her head sort of kinked to the side, when you asked her to hold it straight, "I can't it hurts".

It was during this time that parents and the children were becoming discouraged or in fact, their sense of spirit was weakening. The ill children became especially discouraged as they not only could do the things they really liked doing, but they did not feel like themselves. Feelings such as frustration, anxiety, and anger were becoming more evident during this period. Hence the need to really start to work at keeping the spirit alive. Although all the strategies were used, most important to families during this transition period was the strategy of "coming to know." Both children and parents needed to find out what was really wrong. In fact, some of the parents and siblings acted like they were detectives on a fact finding mission:

Father: Well we were going to push...like we kept pushing the doctor, like there has got to be something, you've got to be able to find something!

Child with cancer (11-year-old female): And my dad goes "we really want to know what is going on here!"

Children and families were no longer accepting the physician's evaluation that their children were fine and that there was nothing seriously wrong with the children. Often a specific episode or some unique, sometimes subtle symptom or sign triggered parents into thinking that their child was really sick; that something was really wrong:

Mother: Basically I just said to him "you know Bob's eyes are not as white as they should be. They just don't look right to me and something is off.

Parents needed to become more demanding in order to protect or take care of their children. They became more vigilant in watching over and protecting their children.

Although children and their families needed to find out what was happening and now worried that it could be something more serious than the flu, they still never expected cancer or any other life threatening condition that was associated with dying. Suspecting cancer especially was not common because as most children and their families believed that only older people got sick as a young child was too young or simply put by some families "*they had not lived life as yet.*" The only families who did suspect cancer, either had a child who previously was treated for a life threatening illness or had someone extremely close to them such as a husband or father experiencing cancer. However, most children and their families did not suspect or even consider cancer and were in fact quite surprised when the diagnosis of cancer was made:

> *Child with cancer (16-year-old female): I didn't even think it was cancer. Like I didn't even think about it. Well they took blood just to see what it was. We thought I was anemic. My grandma was like so maybe "you're anemic" or, you know, because you're really white and stuff.*
>
> *Father: Well we never even thought of cancer. Like cancer had crossed my mind at the time but (pause) I never even, I never even gave it a second thought like it sort of went in one ear and out the other sort of thing.*
>
> *Interviewer/Researcher: You were saying you didn't think it was that life-threatening...but what was in your mind?*
> *Father: I don't know, something like appendix, some infection inside her body or something.*
> *Interviewer/Researcher: So when they told you it was cancer, what did you think?*
> *Father: Well it's a shock you know. My wife cried right away. I didn't cry until a couple hours later.*

It was important for the children and families to believe that the children were not experiencing anything that could lead to death. Believing that the children had a serious condition but not too serious, was another important strategy used during this period to help maintain their spirits or their will to fight. The need to believe was so necessary and

prevailing that upon reflection, parents questioned themselves with respect to how they could have not have thought otherwise as all the signs were there. The very fact that children and their families were not expecting cancer made the diagnosis even harder to deal with. It was at this point that they now moved into the period referred to as "It is a Blur."

(2) It is a Blur

Unlike the "it is the flu" period which for most families took time before the roughness or hardness could be really felt, the "it is a blur" period began abruptly or commenced in a rough manner for the children and their families. It was like being "*kicked in the face*" as many expressed. To say that the children and families were in shock during the transition period of "It is a blur" would be an understatement; it was like being in a "*haze*" or "*fog*" or "*in the dark*" or "*in a blur.*"All the children and families were still so surprised to hear that it was cancer and accordingly were in a state of shock. They really did not know what to expect. As one adolescent noted when she was asked to recall what she expected or thought when she was told she had cancer:

> *Child with cancer (14-year-old female): I had no idea, no idea. I was out shopping with my friend and as her mom was driving us back to her house, I noticed my dad was waiting there, sitting in his car in my friend's driveway. He said he had been sitting there for 20 minutes. He told me to get into the car, that we had to go somewhere and I thought what did I do...and I thought something happened to my grandma, that she had passed away. I knew something was not right and then he said Dr. G had called and she wants us to come in and talk to her. And then what I thought it might be anemia because anemia makes you really tired, you know, pale, and it would make me sick all the time. That's basically what I though it was.* ***AND THEN WHEN WE WENT TO HER, IT WAS SO NOT WHAT I EXPECTED AT ALL!***

Children and families all expressed disbelief. They could no longer feel

completely secure in the world. Their worlds had been shaken:

> *Father: Well I think (pause) it was very traumatic experience. We went from having a child who kind of had the flu and take her to the doctor and (pause) all of a sudden she's got this. You have to deal with it all of a sudden...it felt like road wreck!*
>
> *Sibling (16-year-old female): When my parents would feel sad, that is when I would kind of feel insecure. Because you know you're usually the one that depends on the parents and then you see the parents crying and you'll usually be "okay who do I go to now?" You know, I just sat there.*

This transition period could last anywhere from one day to approximately a month. For a few, it was very brief lasting only during the first few hours after hearing the diagnosis. During this period, the rough spots became "*harder*" with more intense uncertainty and more loss. Although children and families were finally told what was going on, therefore gaining some certainty in one way, they now had another type of uncertainty to deal with. For the children and families, the feeling of a world as a totally safe, secure place was lost. The uncertainty concerned what would happen to the children and the family as a whole. The uncertainty of death now hung over them. Parents could no longer claim that all their children would definitely outlive them:

> *Mother: Anyways then (sigh) its just a blur, I think you're just numb and you know it just becomes timeless and (long pause)...I thought he was going to die... I don't know, I just really lost track and sort of you become automatic. You just go where you're told and do what you're told.*

While the children and families had not yet experienced much of the cancer-symptom trajectory, they all realized that life as they knew was "*going to change forever,*" and that they would have to change with it. They would now have new roles and responsibilities. Just exactly how things would change for them, however, was not clear

to them. Even after being told by their health care team what to expect over the next few months, most did not really comprehend what this would all mean or imply.

The shock and uncertainty experienced by children and families resulted partly from the fact that the pre-diagnosis cancer symptom course resulted in a different and unexpected outcome. It was as if the symptoms had betrayed them in that they indeed were an indication of something more serious. From the moment of being told the diagnosis, the children's symptoms now took on a whole different meaning as the possibility of death now entered the picture. The symptoms were no longer considered or looked upon as a normal part of childhood or of growing up. A headache, upset stomach, and so on could no longer be viewed as something small or minor.

The symptoms demanded more attention, and were viewed to be nasty and something to be feared. Most parents feared that the children were going to experience or go through something very painful where they would suffer a lot. The symptoms that were a concern to them at this point of the cancer-symptom trajectory were not only the symptoms that the children were presently experiencing, but also potential symptoms that they could experience in the future. Siblings no longer thought the ill children were "*putting on an act*" in order to get some extra attention, and they also feared that their ill siblings would suffer. The families' views of the children having to experience suffering were reinforced by the children's oncology physicians when they talked about some of side effects the children would experience.

It was during this period that families really started to change how they normally functioned. However, the changes at times were experienced as a blur. Some described it

as time when they were just "*going through the motions of life*" or as an "*out of body experience.*" Family members had difficulty concentrating because of all the worry and sadness that succumbed them:

> *Sibling (14-year-old female): Tuesday we found out and Friday it was surgery already. So then she got home and I actually figured out what it probably was and that got me more worried and then I had to go to school the next day and I really couldn't do anything...Yeah, I couldn't really do anything in class. Like I couldn't think and then...I think I made it through the first class and then I think I started crying after like the first class and the principal took me and I was just in her office for the rest of the day.*
>
> *Father: The first thing I thought of was that I looked at Ann and thought I'm going to lose her, you know. The first two weeks were the hardest on me because I did not want to accept that fact that she had cancer...*
> *Interviewer/Researcher: So you found that the first two weeks that was the hardest?*
> *Father: Well for me it was and any ways (pause) my mind was not working...My little girl is going to die, that's all I could think of was my little girl is going to die, I'm losing her, I don't want to lose her...It's a death sentence.*

It was during this period that things such as siblings going over to the friends or parents going to work were abruptly put on hold. Everything evolved around the news of the diagnosis. Because everything was so new, all they could do was not only take one day at a time, but more to the point take one hour or minutes at a time.

All energy was directed toward taking care of the ill child as well as the family. The strategy of putting cancer in its place, was not too helpful at this point. Instead, the strategy of taking care by the means of protecting each other from falling apart was especially focused on. This included the parents finding a safe place for their healthy children to stay, while the parents remained with the ill children who were hospitalized. It was important for the parents to be there with the ill children in order to watch over them and to make sure that they were not experiencing unnecessary pain. While it was

important for parents to come to know what would happen in the future, all that parents truly wanted to know was whether or not the children were going to live.

Siblings too at this time wanted to "be there" for their ill siblings, but unfortunately were not always allowed to be with them during the initial diagnostic period. The siblings also wanted their parents to be with them, again something that was not possible. For the siblings this was a very uncertain time and they experienced lots of worrying. While it was important for them to know if their ill sibling was going to live or die, they also needed to know what exactly was going to happen to their ill siblings as well as what would happen to themselves. The "not knowing," just made life more of a blur for them.

The family's sense of who they were was beginning to be defined according to the ill children's sense of self. The children's symptoms now determined the way of living for both the ill children and also all members of the family. The symptoms were no longer a separate entity but instead, were being weaved into the very fabric of the families' world. Family life from this moment on would evolve around the ill children and how they were feeling.

Although many things occurred during the diagnosis period, in retrospect parents and children had a hard time in providing the details for many of the events which further emphasized the cloudiness and darkness of this phase. Some children noted that they did not remember much during this period because they basically slept through. These children felt so sick that sleep was the only way to deal with their feelings. However, one aspect of the whole diagnosis period that stood out for children and their families was the

date of the diagnosis day:

> *Mother: He was diagnosed October 3rd, I cannot forget that, October 3rd.*
>
> *Child with cancer (11-year-old female): When I got sick? Um, it was (pause) July 30th of 1996.*

Although "it is a blur" occurred around the diagnostic period, for some families it also occurred during times when the children's symptoms were uncontrollable and especially difficult to manage. As well, "it is a blur" could result when the children were having to undergo a new type of treatment that was considered especially physically and mentally challenging for children and their families, such as a bone marrow transplant. For example, one mother noted during the early phase of her son's bone marrow transplant that she felt she was on "*automatic pilot.*"

"It is a blur" characterized by an overwhelming sense of disbelief could also occur when children relapsed. Relapse was a surprise and especially difficult to accept in those families where children did not seem to experience a lot of symptoms during their first round with cancer. In such instances it was not uncommon for parents to wonder what went wrong as evidenced by the following statement expressed by a father whose child had relapsed: "*He was doing so well...never got sick like....what happened?*"

(3) <u>It Hits Home</u>

This transition period was characterized by three main events. First, it was marked by the families recognizing what getting through the cancer-symptom trajectory really was going to entail for them. Although they were uncertain about the details, they knew one thing for sure: that they were going to experience a lot rough times and suffering over the next few years. There was no way to avoid the suffering especially in relation to the

cancer-symptom experiences. Often their realization of future rough times was brought on by the children undergoing their first or second cancer treatment, and was further reinforced by seeing other children and their families in the clinic or hospital experience difficult events:

> *Mother: I mean it doesn't really hit home until you are there, when she is there and you hear of stories and everybody's horror stories and it is very difficult and it really hits home but it is just something that isn't just going to go away.*
>
> *Father: I think it was just a case of coming to grips with reality that I had to deal with it, not that it was the material itself you know, it was just (pause) it was making things hit home and (long pause) becoming aware, so many statistics and some of the risks.*

Secondly, the "it hits home" period also marked the time when the children and the family declared war on the cancer and the cancer treatment and the children's symptoms. This period was identified as the real learning period for children and their families. Children and their families sought to discover all the ins and outs of the practical aspects of cancer treatment such as what clinic days would involve the children getting blood tests. Coming to learn about the cancer itself such as prevalence rates and treatment approaches was a concern for families. Some families also found it necessary to review research-related cancer information:

> *Father: And I think at the time, I went looking for research on the internet and (pause) I think what she was going through and the proposed course of treatment, well it was fairly well studied and so everything was agreed on what the doctors were saying. So we went along with that, the process.*

"It hits home" occurred during the initial period of cancer, but also occurred every time the children received a new course of treatment. To some extent, "it hits home" was ongoing as the fight and the learning never ended:

Father: I think it was just a case of coming to grips with reality that I had to deal with it...it was making things hit home and (long pause) becoming aware, so...

Thirdly, "it hits home" was also a period when most children and their families, finally realized or experienced the effects of treatment. They now got a taste of what they were previously told may occur, and for most this meant symptoms that really did not make the children feel too well. Hence, the label "it hits home!" For most, the children first experiences with treatment were not very pleasant. Words such as "*scary*" or "*crappy*" or "*nasty*" were more and more frequently used to express how they felt.

As well, the degree of the severity of the children's symptom experiences or the children's symptom distress, helped to determine how hard the hit was. Understandably when the distress was more severe, children had a "*harder*" time dealing with the symptoms and had to work a lot harder in maintaining a sense of spirit in order to get through the cancer-symptom trajectory. Increased symptom distress also resulted in the children and families experiencing a harder life because increased symptom distress resulted in more disruptions and restrictions in their daily living. It was during this period that parents realized the danger of making too many plans in life and living solely for future goals. Instead, parents had to learn to accept that not all plans would transpire:

Mother: If you have a butterfly in your hand and if you grab it and hold on to it too tightly, you'll crush it. And so life is like that when you come up to a situation and you think this is going to be normal, if you hang on to it too tight and if it doesn't happen like that, then it devastates you! But if you hold on lightly then...

Father: We said "well we can't make any plans." For two years we made no plans. You don't plan even for tomorrow because you don't know what tomorrow is going to bring so you don't plan anything. Anybody phones you up and says "well do you want to go to a movie, you want to do this, you want to get together." I said, "Call us that day, we will see what Tom is like."

Considering the children and their families not only had to adjust to the side effects of the treatments, keeping the spirit alive was most necessary. Strategies used included need to believe that they could beat the cancer, to take one day at a time, and to take care of each other especially in response to the distress resulting from the symptoms. It was important for parents to spend time and be involved with their children in a way that would help reduce their symptom distress:

> *Father: There was always one of us there every night (in the hospital) and (pause) we spent time over there. And we would get to the Nintendo games and we spent a lot of time playing Nintendo and cards and going to play pac man and stuff like that. And that passed the time and it makes a big difference then just sitting there doing nothing and feeling sorry for yourself or whatever. I mean we were always doing something. He never sat there and just groaned about things because we were always busy doing something and (pause) you know, if your mind is busy you think of other things...*

Additionally, it was during this time that family members needed to take some time for themselves:

> *Father: I had to get out, get out in the bush where it's quiet and I could think about it (the cancer)...It's hard, so I just jumped on my horse and I went riding. I told them (his family) don't expect me back. I don't know when I'm going to be back and it might be tomorrow, it might be the day after, it might be today. So I just went riding, the horse is walking and a lot of thoughts went through my mind. Like I was only gone for that day and I came back that evening.*

> *Father: Debbie goes out, Debbie has a really close circle of friends, I have some hobbies, we try to make an effort to go out together at least once a week.*

For children experiencing symptoms on a fairly consistent basis, it was especially important for them to do things that they liked as well as have some fun or pleasure even if it was only for brief periods. Like their parents, children needed to take some time for themselves and start learning how to cherish the good moments. Any break from the symptom distress was an added bonus for the children and families and afforded them

more time for themselves.

A most important strategy for this period was coming to know what to expect. This included figuring out when the children were getting sick either in response to the treatment or to the cancer itself. Being able to differentiate between symptoms seen by families as normal or typical and those viewed to be abnormal or atypical, was one the most important "*knowing what to expect*" source of knowledge for families. No longer were families going to be left in the dark about the children's symptoms. Knowing what to expect in relation to the symptom experiences was critical in helping children and families deal with the associated distress:

> *Mother: The doctors told me all hell will break loose in about three weeks, that is when he'll get sick!"*
>
> *Mother: You knew that this (symptom) is expected, it was expected.*
>
> *Mother: Because you have to be reminded again that's normal (symptoms) to be going on right now.*

The children were becoming more aware to how their bodies were feeling. When the children, parents or siblings perceived something was not quite right, they took action to find out why things were the way they were. It was almost as if that they were fighting the symptoms and not so much the cancer. The families wanted to always be one step ahead of the symptom course. Parents especially saw this as a way to take care of their children.

Although symptoms were perceived to be the enemy, they were also to some extent viewed as a friend because symptoms served as a very valuable source of knowledge for children and families with respect to how the children were doing

physically and mentally from the cancer and cancer treatment. Parents and the children took pride in their knowledge of the children's symptom course. In comparison to the "I think it is the flu" period where children and their families lacked confidence in talking about the symptom course, they now exhibited more confidence in their knowledge about the symptoms. Families' talk soon became the talk of experts such that they would assign special labels to certain symptom experiences and were able to identify what was considered "*normal*" or "*abnormal*." Children and families would share their knowledge about the children's symptom experiences with other children and families. But they were always cautious to reinforce to others that each child responds in their own unique way. It was important to expect the unexpected and to be prepared for some uncertainty:

> *Father: It depends on what you are going through. I mean (long pause) if you go through two or three courses of the same thing, you can start to predict a little bit of what's going to happen. Um (pause) and you can start to see if you had the med once and there is that side effect and you have the med again and you get that side effect again, well you kind of expected it and not panic about it, um (pause) and deal with it as a side effect and sort of move on...But you get a list of things that could happen and the reality is that sometimes all those things will happen and the sometimes none of them will happen...and you know you have new combinations of the medicine or whatever, so you don't really know what to expect...But I also learned that statistics don't mean a hill of beans because (laughs) if they meant anything right now well 95% of them haven't gone down the course that we've gone down, so.*

It was during the "hits home" period that children and their families also started to put the cancer in its place. They had to make some sense of all the suffering that was caused by the cancer and its symptoms. This included making sense of why they had to enter the world of cancer as well as why their families were the ones having to experience cancer:

> *Father: What made me finally accept it is like I'm not a religious man, never have*

been. I believe in God but I'm not religious, so what made me accept it is I said "God you give her to me, if you are going to take her away from me, there is nothing I can do about it."

Child with cancer (11-year-old female): Well the reason why we got, I got cancer was because we are very strong and we are good people.

Mother: I think it made me more aware that there is a lot of cancer out there. It's funny, I think I'm paranoid because it's like it can hit you any time, you can have a healthy child, and when Mary was diagnosed, um (pause). I bought baby food for Bob (mother's oldest child) for example and because I didn't have a blender, I was younger. I blended Mary's food because now I am older, I wanted everything to be fresh. But it doesn't matter how you eat, what you eat, if you are going to get it, you are going to get it, that's my opinion now.

Father: In many ways, if God forbid that to happen to anyone, I think in a lot of ways we are the ideal couple for it to happen to, however crazy that sounds.

For most, making sense involved accepting that in order to get better, one had to feel worse as evident by the following most parents expressing: *short-term pain, for long-term gain.* Some parents even saw the symptoms as an indication of hope. It was as if their child was experiencing side effects or symptoms, this meant the medications were working on destroying the cancer and that their child had a greater chance of making it:

Mother: You can't breeze through it. If you breeze through it they say, other families say, if you breeze through it, you're more likely to relapse. The sicker you are, the better chances of getting better...Like if he had gone through it and never thrown up, I would think something was wrong...You expect him to be sick. Like if he had went through it and just sat there and like looked normal, felt normal, I would have wonder. It (the chemotherapy) wouldn't be working. That's what I would have thought.

Father: Yes, she is going to be sick but if we want her to get better, we have to do it (put her through treatment that makes his child sick).

Sibling (8-year-old female): Well when like your brother or sister takes some medicine they might throw up cause it might go down the wrong way or it doesn't agree with them. And that they might just not feel good after, sometimes...Well it actually makes you better but it makes you feel worse at first and then you feel better...I thought medicine was like you're supposed to take it and right away you

feel better but it takes a while to work.

Despite experiencing treatment-related symptoms, children too viewed the medications as necessary. They also were a little anxious when they no longer were receiving the medications that fought the cancer cells:

> *Child with cancer (11-year-old female): When I was on treatment it was killing all the cancer cells.*
> *Interviewer/Researcher: Now are you going to be okay now, like when you are not on treatments, are you going to be nervous at all or scared?*
> *Child with cancer (11-year-old female): I think a little bit I'll be nervous and then in a way I'll be glad.*

It was important for children and their parents to clarify that the territory they were referring to was the direct result of the cancer treatment and not the cancer itself. That is, treatment-related symptoms were expected, but cancer-related symptoms were not expected especially once treatment had commenced. Focusing on the treatment side effects as opposed to the cancer symptoms was easier for the children and families because treatment-related symptoms were seen to be necessary in order to rid the body of cancer even though treatment-related symptoms caused changes in their lifestyles. Parents the treatment-related symptoms as a sign that the children and their bodies were still fighting as is evident by the following:

> *Mother: We were scared...People said he looked good because he no longer had the rash. He was no longer itchy. But this was because he has more leukemia cells. His leukemia was taking over...his body was not fighting as much...the leukemia was taking over.*

Fighting the treatment-related symptoms as opposed to the cancer was more tangible and less frightening to the children:

> *Child with cancer(14-year-old male): I had to fight how bad it felt, but I didn't have to fight the cancer. I had to fight the pain. Mother: He was only fighting the*

chemotherapy...

It was important for the children to fight with help from the medicine that they received as well as self-initiated strategies:

> *Child with cancer (4 ½-year-old female): Yeah, but the bug (cancer) hated that so it tried to get rid of the medicine.*
> *Interviewer/Researcher: So the bug was fighting the medicine, but who won?*
> *Child: The medicine..And also my brain. It sends it's own medicine down.*
> *Yeah. It helped that other medicine.*

Parents especially had to rationalize that the side effects and symptoms resulting from treatment were to be expected and justified especially considering some of the potential side effects that could occur. This enabled them to deal with letting their children go through treatment that could be more potentially damaging than the cancer itself:

> *Mother: And that drug is another one that makes it really difficult for a mom because it's highly toxic. It is highly corrosive to your skin. Drop it on the floor, it will burn a hole in it. I am supposed to inject this into my daughter. This makes me feel comfortable? You have a hard time with it, but if I don't she will die!*
>
> *Father: Like one of the doctors said "You're going to feel like we're killing her. And we basically are knocking her down to bring her back up." That's a scary time for a parent. Are we doing the right thing? Is this going to work? Yes its tough to see your child get knocked down but you have to be there to pick her up and help her through it.*
>
> *Father: Nausea, oh now I didn't rationalize that as being sick with cancer. But that it was the cancer drugs that were killing the cancer. Like we were told that she might get diarrhea but not to stop it because it was something it did to pass the cancer out of her body and this kind of thing. If she was nauseous with chemotherapy I didn't have a problem with that.*

In fact, experiencing increased symptom distress in some instances was a sign that the cancer was being destroyed as was the case with children feeling more pressure and pain on bone marrow aspirations. The increased pain signified that the children's own

blood cells were slowly replacing the cancer cells. Children were also aware of this, although they were not as positive about feeling the pain as others may have been for them:

> *Child with cancer (16-year-old female): But supposedly they (bone marrow aspirations) hurt after you get, like after the cancer starts to go away they hurt more?*

Children and their families found it necessary to believe that one had "*to feel worse in order to get better.*" The very notion that one could die from cancer justified the suffering that resulted from the treatment-related symptom experiences, as it was a way to avoid the ultimate suffering experience: the death of a child. For this reason, children and their families returned dutifully to clinic to receive their treatments. There was an acceptance of the treatment and its side effects by parents, but also by the children. However, the children did have a harder time accepting the symptoms in comparison to their parents. Their talk that centred around the symptom experiences was more expressive in tone and they expressed more anger than their parents. Nonetheless, the children accepted that they would have to experience pain in order to rid them of the suffering resulting from the cancer. They viewed the treatment-related pain as necessary and never resented those carrying out the treatments:

> *Interviewer/Researcher: Did the nurses and doctors do anything to help you feel better?*
> *Child with cancer (5-year-old female): Yes. They gave me a needle.*
> *Interviewer/Researcher: But if a nurse or doctor gave me a needle that would make me feel worse cause it would hurt me. Why did they make you feel better?*
> *Child: Because they are trying to take care of me.*

Asking children and their families questions such as "most medications are supposed to make you feel better, yet with chemotherapy it makes you feel worse...how

do you deal with that?" or to parents "how do you explain it to your children?", seemed irrelevant and even irrational to them. Upon asking such questions, most including the children would look at the researcher strangely and express that taking the medications were necessary to survive. It was not uncommon to hear the children, regardless of age, "be*cause you have no choice!*" or "*well if you're not going to take it then you won't get better!*" Contrast cancer to illnesses where the possibility of death is much less, and perhaps parents and children may have been less faithful to treatment.

Acceptance of symptoms experiences, however, was dependent on the type of experience. Children and families had less difficulty accepting symptoms viewed as relatively short-term or those side effects that were temporary and did not cause permanent damage. In contrast, symptoms or side effects viewed to be long-term and causing permanent damage or disability were not as easily accepted as part of the cancer symptom territory. Parents were more likely to question if suffering was justified if it meant that treatment would result in permanent or long-term disabling symptoms:

> *Mother: I don't know, I worry about his organs and stuff because of all the chemo and stuff. You never know. Sally's (another child with cancer) liver really kind of...I mean its hereditary but what went on with her but still...its...*
>
> *Interviewer/Researcher: So it's not one particular symptom, it's just the whole thing?*
> *Father: The whole thing, yeah, the whole thing and then we don't know what she is going to be like with the cancer. She is going to beat the cancer for sure but because of the chemotherapy, "what is going to happen to her, is she going to recover good, her body, are things going to be okay?"*...maybe she will have some problems later.We have to cure the cancer that's the biggest problem, (pause) but we are going to hurt other things?

Especially hard to accept were any long-term changes related to the children's mental abilities or any changes that prevented the children from functioning as

"complete" human beings were difficult for parents:

> *Mother: He couldn't talk, couldn't move, couldn't do nothing and they couldn't understand what had happened... It wasn't very good. And then so he couldn't even squeeze our hands or nothing for a whole week and then finally they kept him an extra week in ICU. Then they moved him up to the ward, and we were in the hospital 14 weeks straight. Bruce couldn't move his legs, couldn't move nothing and couldn't eat... they thought there must have been something when they removed the tumor because if you touch something or whatever...So at the beginning he would squeeze my hand or something and then after awhile it was a thumb, and after awhile that got better then it was nodding, and then after awhile he finally could yes nod and then finally every stage and like now he's talking a little bit. But he has lost, he couldn't eat. He was tube fed and didn't know how to eat. He couldn't open his mouth or nothing for weeks, and weeks, and weeks. He just laid there for weeks doing nothing.*
>
> *Father: Just when they found that spot on his brain, (pause) I mean the seizures were bad enough and then they found that spot and we thought that was the end.*
>
> *Father: I think the biggest thing I can say is her motor skills, she was a very active child and now she is only able to just sit up. Quite often, her and her sister were mistaken for twins and you can't, there is no resemblance now...So like pictures on the piano, if you would look at them, you could see there is a resemblance between the two and they are quite often mistaken for twins, I think the hardest part now is seeing the difference in the change with her motor skills.*

Likewise, children also feared that the cancer treatment with respect to the affect it had on their mental abilities. For example, one childhood cancer survivor (11-year-old) talked with regret and sadness of the affect that extensive treatments including cranial radiation treatment had on her mental abilities. She blamed the treatment for her inability to do math in school. It was hard for her to accept because it made her feel different from her peers. Even though she talked about her many experiences with cancer including the nausea and pain and all the losses, it was her conversations relating to her decreased mental abilities that revealed the greatest pain. Problems that were not related to mental functioning but nonetheless caused permanent physical damage such a limb amputation

also were not welcomed.

However, even long-term problems were accepted if it meant that children would survive. Part of this had to do with the immediacy of the long-term problem. That is, if the problem would not occur till years long after the cancer was over it, then the problem was not feared as much or was not that great a concern:

> *Mother: I do know one thing, if he makes, he will not be able to have kids, he is for sure infertile!*

The immediacy of death and preventing it, took precedence over everything else. For example, one mother whose son was not responding to chemotherapy was willing to risk the possibility of her son developing long term problems if this meant his survival:

> *Mother: Everything is happening so fast. It was last November where they were not even going to do a bone marrow transplantation...now they are...I don't know what problems he'll have, if his liver, spleen or whatever will be a problem..not sure.*

Understandably because the children and their families had to do a lot of extra work with the symptom experiences, their individual and family sense of self was affected. More and more, the ill children became the main focus of every ones' attention in the family. It was as if the ill children's sense of self was all that mattered. The desired outcome of parents' and the siblings' use of the "keeping the spirit alive" strategies was to help reduce the suffering of the ill children even if it meant that the parents or siblings would experience more suffering. The siblings especially sacrificed a lot or gave up many things in order to help make it better for their ill siblings:

> *Sibling (8-year-old male): Things that you want to do, you just can't...It is can't if you want to go somewhere, "can't" do that many things...*

(4) <u>It is not so Bad, it is Pretty Good</u>

The "it is pretty good" period was a time when the symptom experiences were minimal and considered "*not too bad*" by the children and their families. That is, depending on their perceptions and experiences, some described themselves as feeling good even in though instances when children may have experienced some type of symptom on a daily basis such as a morning headache. Most, but not all children experienced the "it is pretty good" period during the treatment stage referred to as maintenance. It was during this stage that children noted how the hardness of the cancer experience had lessened in relation to experiencing fewer symptoms:

> *Child with cancer (15-year-old female): Maintenance treatment is a lot easier! Besides that I am spending much less time at the clinic, I feel **A LOT** better all the time ...I don't notice feeling a little bit better each month, I feel good each month. But now that I think back of how I felt being on maintenance in August (pause) Yeah, I guess I do feel a bit better each month!*

This period also occurred in between treatment courses. However, the length of time feeling "pretty good" varied and occurred at different time frames for some of the families. For instance, for some it occurred after the children completed their first intensive treatment in which the symptom experiences were difficult, but fortunately as each subsequent treatment occurred, the symptom experiences became progressively less severe. For some families the "pretty good" periods occurred when they least expected it. And for some families the "it is pretty good" periods were experienced more frequently in comparison to other families. However, there were some families who experienced relatively few or no "pretty good" periods.

The "it is pretty good" period was different from those periods where the children

would perk up for an hour here or there during days which were for the most spent dealing with symptoms. Although children and their families could experience brief reprieves from the symptoms during periods where symptoms were more predominant like during the "it hits home," the overall quality of their lives were more symptom-bound as compared to being symptom-free or reduced. The "it is pretty good" period involved those times where the children were experiencing overall fewer and less severe symptoms as opposed to those times when symptoms were more severe. It was during this period that some children referred to their symptoms as "everyday experiences." As well, although children did experience periods of feeling sick during the "it is pretty good" period, they were short in duration. The "it is pretty good" period was longer with the children feeling good for the most part:

> *Mother: Yeah, the summer was great. She was strong, she was running again, she was. Oh yeah!*
>
> *Interviewer/Researcher: If you had to sum up the last couple of months what it's been like, what would you say?*
> *Child with cancer (17-year-old female): Um (pause) it's been pretty good but sometimes I haven't been feeling very good, but overall it is pretty good.*

It was during the "pretty good" periods that the children realized what it felt like to feel relatively well, having lost that feeling because of the cancer-symptom trajectory. The children really appreciated feeling well again even if it was not permanent. In fact some of the children pointed out that having been sick made them recognize or acknowledge what "*feeling good*" really felt like:

> *Child with cancer (14-year-old female): Like you get so used to feeling sick, that when you finally feel better (pause) you know it is like wow "I feel so much better and different, I didn't even know how crappy I felt before because I got so used to it!" ...it is like everyday, like if you wake up and feel tired and icky single*

everyday, then every morning you don't expect to wake up and feel energized, you just you know wake up and feel like the day before, so that is what becomes normal. That is for you because that is how you feel everyday, that's how you are going to feel the next day, that is what is normal for you.

When children developed symptoms during this period, often it was in relation to the chemotherapy. However, the symptoms usually only lasted at the most, two to three days following the chemotherapy. Symptoms and feeling sick would also result from the children experiencing normal childhood illnesses which points to a return to a "normal" childhood illness course:

Child with cancer (14-year-old female): Sometimes I get colds and stuff really easily.

However, even experiencing the common childhood illnesses was still tied to the cancer:

Yeah I get more colds than before because I still have, maintenance still keep my blood counts at a certain level, like still kind of a low level...

To some extent the good periods helped the children believe more in themselves and that they had the strength to get through the cancer-symptom trajectory. It was during these times that they did not define their worlds solely in the terms of being sick. In fact, the children saw themselves as healthy to varying degrees even though they still were being treated for their cancer. They were just feeling "*a little sick*" or while not feeling 100 percent better expressed feeling at perhaps "*80 to 85 percent*" better.

Another positive aspect of this period was that the children thought less about being diagnosed with cancer. This was in contrast to the transition periods where they experienced more symptoms:

Child with cancer (15-year-old female): You are always reminded of it because you are always sick, you are always going for an appointment or you are always

you know, people looking at you strangely because you don't have any hair.

Having good periods helped the children go back to the clinic for treatments because they knew that feeling sick was not permanent. However, at the same time, it made it harder to go back knowing that the treatment would make them feel bad again. Having a taste of the "good life" helped them but also had a downside.

Because symptom experiences in the "it is pretty good" period were experienced or perceived not to be not as severe, families could function more like they did before the cancer diagnosis. Families took advantage of these times to take time to do "family things":

> *Father: We actually (pause) managed to go on a family vacation last winter in March and suddenly we got to feel normal again or as close as* ***ever*** *it was. She was still having her problems (pause) but you know it was pretty darn good (laughs), relatively speaking.*
>
> *Sibling (7-year-old female): I think she's pretty good...I can go swimming with her and play games with her.*
>
> *Sibling (8-year-old female): I'm looking forward to having a good year and having fun.*
> *Interviewer/Researcher: And what do you mean by a good year?*
> *Sibling (8-year-old female): Like my sister not being really sick and getting better and so we can do more things together and having fun all year.*

During these periods, children often were able to resume a lot of their daily activities. In turn, it allowed a time for the parents to breath a sigh of relief and in fact provided a period where they could feel good:

> *Mother: Oh it is such a relief when you feel that she can go to school, you know that she feels better and so on.*
>
> *Father: Mary was just running to me "daddy, daddy, daddy...", you know and she was running. You know that means she's okay, she can run and I was happy. We went bike riding and she was tired but she did okay. She didn't complain that she*

was in pain. It was a little bit uphill, she started pushing her bike so that's like it wasn't nothing like fast but so I slowed down and just kind of sat down...We had a good time so that's important you know.

Relief from symptom experiences meant for the parents that their children could do "*kid things*" again. This helped parents to maintain their sense of hope and belief that everything would work out:

Father: You just have to believe it, you know it's going to be okay. If I see her swimming in a pool, it's easier to believe than when your child is in a wheelchair.

Knowing that their child could once again "*be a kid*" was very important to parents and siblings. In addition to their brother or sister surviving cancer, the only other thing that siblings wished for or wanted was that their ill sibling be happy:

Sibling (12-year-old male): Seeing her happy! That is what makes me happy...When she is running and playing.

Although parents still found it important to continue applying the strategies that helped to maintain their children's spirits, the parents also directed a bit more attention toward themselves and their spirits. This included participating in activities that allowed them to take time to do things they liked to do as well as being with or spending more time with their spouses and healthy children:

Father: Get away from everybody, if you can and just take time for yourself (pause) because you and your wife need it.

Families took advantage of this period to live life like it was prior to the cancer diagnosis. However, they could never quite capture their old way of family life as most parents noted: "*life is never the same.*" Regardless of how well the children felt, parents in the back of their minds appreciated and feared that things could always change for the worse, that is, children could once again enter any of the other more difficult periods such

as "it hits home." There was always the fear of the symptoms returning or worse, relapse:

> *Mother: Well he looks, acts, and feels better,* ***BUT****...*
>
> *Father: When she's feeling stronger, when she looks healthy that helps a little bit. But then you know that what is coming up is a very tough ride with the chemotherapy. You know, you're almost guaranteed she's gonna be in the hospital again.*
>
> *Father: I think she is okay but you know it's going to change in a couple of days. You know, you don't want to think about it, it's a possibility you know, anything can happen...You know, like she probably can get the relapse too, that's kind of what I'm worried about you know.*

For the siblings, the "it is pretty good" transition period meant that they could also interact with their brother or sister in a normal way which often meant they could play together. For the siblings, feelings of sadness were not as predominant as they had been during the rougher periods. The siblings also took of advantage of this period to try to spend more time with their good friends and parents. For example, in one family where the adolescent child with cancer had just entered the maintenance stage of cancer and was now experiencing fewer and less intense symptoms, both the child and her family were able to resume more activities in the non-cancer world because the child did not have to be watched as much as before. The mother recalled one weekend in which she spent more time with one of her other adolescent daughters and how this same daughter revealed that she was glad that she "*had her mother to herself.*" Moreover, her daughter wanted to take advantage of this time and expressed wanting do things like that involved: "*just the two of us.*" Time spent with their parents during the cancer-symptom trajectory was valued by siblings. Although siblings never resented the extra care that their ill siblings received, on hindsight they nonetheless wished that parents could have spent more time

with them:

> *Sibling (14-year-old female): Um...I don't know. If they (parents) could maybe try and take them (siblings) out like just every once in a while...just so they (parents and siblings) can actually see what's going on cause when you're at home and they (parents) call and you hear everything that's going on and you still don't know, like know, cause you're not there...But it is kind of hard to really pay a whole bunch of attention to the other kids when one of the kids is going in for treatments.*

> *Sibling (10-year-old male): It (cancer experience) made me feel left out and lonely...They should get involved with the siblings a lot more. If they ask you to play a game I think that one of you should take time out and just play with the child and even though you are worried about your child that is having cancer you should also spend more time with the other children to. Because I got left out quite a bit.*

> *Sibling (8-year-old female): I would say that they should pay a little more attention than what they would usually pay. Like how they are right now cause then maybe their other child who isn't sick would not feel left out.*

Considering the effect symptom experiences had on the family unit and how it functioned, experiencing the "it is pretty good" periods were vital to families' spirit and sense of self. Such times helped to give the families a break in the routine of cancer. Children and their families often expressed that they needed such breaks. Even younger children expressed the need:

> *Child with cancer (5-year-old female): I wish I could have two weeks off! (Referring to two weeks off from the treatment)*

The children's and families' perceptions of the symptom experiences helped to determine whether or not they would experience many or few "it is pretty good" periods. Even if the children had relatively few symptom experiences, this did not necessarily guarantee that children and their families would feel good and was determined by the children's prognosis. For children who had a poor prognosis, it was much harder for

families to feel good, even when the children were experiencing few symptoms. Moreover, in such cases, the children's temporary lack of symptom distress only reinforced that things were not quite right, that something bad was about to occur. It was like experiencing the calm before the storm.

(5) <u>It is Nasty</u>

This transition period best describes a time when the children's whole world is defined solely by their symptoms because the symptom experiences predominated their worlds. The children and families described their lives as *"being on hold."* The children were feeling so rotten that nothing else mattered in the children's or their families' lives except for how the children felt. Symptom experiences associated with "I feel crappy" or "I feel wiped out" especially dominated this phase and usually the children experienced multiple symptoms resulting in them feeling horrible all over:

> *Child with cancer (14-year-old female): I was just feeling so sore all over, I mean I just felt like a **BIG BRUISE**...like if anybody could would just poke you anywhere you felt like a big bruise, just feeling so YUCKY! It was just a combination of things.*

This stage was perceived as nasty by the ill children and their families because in fact, the symptoms were being "*nasty*" to the children. For the children the nastiness was experienced in relation to all the pain and suffering they encountered directly from the symptoms. For the family it was perceived to be nasty because they had to watch the children go through such rough times. It was so painful for parents and the siblings to be on the outside watching the children suffer.

Children who had more experiences with increased symptom distress tended to be viewed to be sicker by other families attending the cancer clinic. The pale, tired looking

child lying on the couch in the cancer clinic receiving treatment was perceived to be sicker in comparison to the child up walking around the clinic even though the latter child may have had a harder time going into remission. Children and their families who had to deal with more symptoms generally were viewed as having a rougher time with the cancer-symptom trajectory. Such families were seen to be "*hit harder.*" For instance one adolescent male child experienced so many complications during his first year of treatment that he and his family besides dealing with the complications, were constantly dealing with symptoms resulting from the complications. The family basically spent most of their time in the hospital and was judged by other families to be going through a rougher time than most other families. In fact, because of the child's rocky symptom course, this family was given or assigned special status by other families attending the clinic. The families and the children especially watched out for this child and family and tried to ensure that they were comfortable while in clinic.

It was during the "nasty" period that children and families would sometimes feel like quitting:

> *Child with cancer (15-year-old female): Yucky...When I really really felt terrible and I felt like you know I can't take anymore, there can't be anything more horrible than this. If there is something more horrible than this, I don't want to experience this. Like I would rather die than experience anything more horrible than this. I would rather stop now and take my chances with it coming back and me dying or take a small chance that it might not...*

When the symptoms became overwhelming especially during the period of "it is nasty," some children questioned whether getting through the cancer treatments was worth it. The symptoms were not as easily recognized as part of the territory of getting better. This would at times result in children of all ages questioning the possibility of

switching to a different type chemotherapy regimen or way to receive therapy:

> *Mother: The doctor said what they would normally do is just use whatever treatment they have used in the past that seems to work, but if you are part of this research project then you are either A,B,C, or D of the clinical trials. So Celine's question is, you know, "if I was just going on the previous best or whatever, how would it be different, and would it be this long, this that and so on." She knows that Arm-D seems to be the toughest one...*

Parents also had a hard time accepting the children's increased suffering, however, they still were more hesitant in switching to another chemotherapy regimen. In the end although parents wanted to see less suffering in their child, and wanted them to be psychologically and physically comfortable, seeing their child survive cancer still dominated:

> *Mother: But then you know we (child and parent) have talked, we talked about what may be the toughest treatment is the one that will do the most good...Well, you know, you need to think whether she is going through more torture than necessary, but on the other hand, if it is going to be the one that works best in the end...*
>
> *Father: The thing is she needed a blood transfusion. If she didn't get it, she was going to die so regardless of where she got the blood, that blood is saving her for now, regardless of what happens now or in fifteen or twenty years (referring to her getting sick because of the transfusion). Heh, she had fifteen, twenty years or five years, whatever the case may be and that's (pause) I don't know, that's the way my attitude has been every since I've grown up you know, when there is something to do, do it...Yeah and the same thing with the treatment, okay you guys know it's cancer, just get on it and not fool around...*

The symptoms were seen to be attacking the children, and parents feared that the children's will to continue would be squashed. Accordingly, families had to fight back in order to maintain their children's sense of spirit to go on. Understandably the parents directed the keeping the spirit alive strategies at trying to boost the ill children's spirit. Taking care was an especially important strategy used by families during this period.

Both the parents and siblings tried whatever they could to help the children feel a little better.

Being present was also another important strategy. However, although the children wanted to be there with their families as well wanting their families to be with them, "being there" only in mind and not body was what the children desired. That is, physical contact was to be avoided and was completely not wanted as even the slightest touch would cause the children further suffering. It was like "look but don't touch" type of phenomenon.

It was also very important for parents and siblings not to get discouraged even with all the uncertainties experienced in this period. They needed to believe that things would work out well and the children's suffering would be over soon; it was important for them to hold on to their belief that they would get through it:

> *Sibling (8-year-old): Well you have to have confidence that like your brother or sister's going to be alright. And that..something might happen to them but they're sooner or later gonna get better...Well, how I found my confidence was that I asked my parents what was gonna happen and then I believed in my parents and so then I just got confident...confidence it means to believe that something's gonna be all right even if like something was really bad right.*

The ill children needed to know that their families believed that their suffering would not last forever. Believing that experiencing the nastiness would not be in vain or futile, was necessary in order to justify the suffering resulting from the nastiness of this transition period.

It was especially necessary for families to be patient during the "nasty" times as often they were not living one day at a time, but as most parents noted, "*it was more like living moment-to-moment.*" The extra work needed for this period was intense. There

was so much to do that children and their parents often went through the motions of getting through it. They would use the strategies without really thinking about them. In fact some of the children described it as a time when their bodies were still fighting, but their minds were too tired at that point to fight.

While rallying against the symptoms brought the children and families closer together just by the very fact that they had a common goal of getting the children to feel better, family members at the same time felt disconnected from each other as no longer were they spending any time do things that families normally do. Their world evolved around the symptoms, and not much more. Families, while sharing a common goal, were also not existing as a family unit. They were rarely together as a whole, between parents taking turns staying at the hospital and siblings have to spend their time with relatives or a good family friend. This caused a lot of upset, anxiety, and distress for families. Accordingly, it was important for parents and siblings to try to take some time for themselves, even if it was for a relatively short time. For some parents it involved taking cigarette breaks while staying at the hospital or just getting a chance to get a shower at home in between spending time at the hospital. For the siblings, taking time involved such things as having to play a quick video game or having a friend or relative take them out for a brief lunch date. Having a good laugh, as morbid as it may have seemed, was also another way to take time for oneself.

Taking time for oneself was also very important to the ill children and involved the ill children focusing solely on themselves and giving attention to their body and getting it better. All their energy was directed at getting over the nasty transition period.

For some children, it involved both their minds and bodies fighting, whereas for some it involved their bodies being responsible for the fight.

Experiencing periods of nastiness in relation to the symptom experiences became even more difficult to bear especially when other stressful events became overwhelming. For some, the nastiness was not always only related to the symptom experiences, but to stressful events other than the cancer-symptom trajectory. For example, one mother experienced the "it is nasty period" in relation to financial, marital, and child discipline problems that all occurred at the same time. This mother defined her life at this period as extremely ugly time. She perceived her son to be going through a rather "*nasty*" or "*ugly*" time in relation to his cancer-symptom trajectory even though he did not feel his symptoms were as "*nasty*" as his mother thought. In effect the nastiness resulting from other stressful life events had an effect on her perceptions of her child's cancer-symptom experiences and further demonstrates how individual members of family units can be in different transition periods during the cancer-symptom trajectory.

(6) It is Dragsville

This period was a time when children and their families were becoming both physically and mentally tired. Their physical and mental fatigue was related to having to deal with the cancer- and treatment-related symptoms and all the rough times associated with the cancer-symptom trajectory. The children and their families were getting tired of many things including having to go to clinic frequently, the constant treatment regimen and adjusting their plans around the treatment, preparing and taking the many medications, not being able to go out with friends, seeing other children suffer through

the cancer-symptom experiences only to finally have succumb to the cancer, and so on. The hardness in relation to the constant restrictions and extra work was especially contributing to how children and their families responded. Children and families simply got tired of dealing with the cancer and all its symptoms day in and day out:

> *Mother: I can tell she (adolescent daughter with cancer) is tired of it.*
>
> *Mother: But from time to time he'll get angry and just kind of like, kind of sucks because everybody else is and I have to be at home blah, blah, blah... "Man, their life sucks" sort of thing, you know?*
>
> *Father: It is getting to the point where it is time to get along and it is not over yet. I mean it is starting to get to the point where it is starting to be long you know. (pause) But with the support of my wife and my kids and our family, we'll get through it.*

The children basically became tired of feeling sick all the time. The tiredness was only compounded by symptom experiences that remained constant. Even just feeling a little sick became a drag for them because even a "*little sickness*" still caused changes in their lives and involved extra work and effort for them in maintaining a sense of spirit. Likewise, the children's parents and siblings became tired of the extra work, and this included all types of work from the physical to the emotional to the social to the mental. They too would refer to certain periods as "*shitty!*" Children, parents, and siblings more often felt cranky during this period. Once again, it was harder to carry out daily functions.

Symptoms that lingered after treatment was completed were especially difficult to tolerate. This was because families had anticipated that once treatment was completed everything would return to "normal" and the hardness related to the cancer-symptom experience would resolve. However, when the hardness remained especially in relation especially to the extra work and restrictions, families became tired and discouraged. For

one family in which the child's headaches remained for some time after completion of his treatment, the tiredness of the whole cancer-symptom experience was evident in this mother and son when they would come to clinic for follow-up appointments. The mother would freely and frequently express that she was tired. Both mother and son at times looked tired. Moreover, a sense of discouragement in both mother and son at times prevailed. The statement "*things are the same!*" as expressed often by mother and son succinctly summed up their feelings that the cancer symptom experience was dragging on way too long for them.

The feeling of "dragsville" was some times experienced even if the children were progressing well with respect to their cancer remaining in remission. While news of a good prognosis helped the children and their families to maintain a sense of spirit and belief that there was a light at the end of the tunnel and that in the end things would work out, the cancer-symptom trajectory did drag on at times. There was always a fear that the "nasty" period could return with all its "ugly" symptoms. To some extent this period was one of the most difficult to deal with because the tiredness only made it harder to continue on. That is, the cancer-symptom trajectory was slowly wearing down the children's and their families' spirits which in turn made it harder for them to implement the keeping alive strategies.

Understandably, holding on to the belief that one could get through was a significant strategy used during this period. While the other strategies were used, this strategy was what really made the difference. It was important to believe that all the suffering resulting from the cancer-symptom experience would lead to a positive

outcome. Understandably it was during this period where support from significant others was especially needed. The extra support helped children and families to continue to focus on maintaining a sense of spirit by reinforcing their belief that they would get through it.

(7) <u>It is Comeback Time</u>

Three types of "comeback" could be experienced in this period as determined by the type of symptom experienced by the children in relation to the presence or absence of cancer. The three types experienced were labeled as: (i) Cancer-free and fairly symptom-free; (ii) Cancer- and symptom-return; and (iii) Cancer-free but not symptom-free.

(i) Cancer-free and fairly symptom-free

This first type of comeback referred to children who not only remained in remission after completing the cancer treatment course, but also remained relatively symptom-free. The only remaining symptom usually was related to the children never totally gaining back all their strength or physical energy. Some of the children also experienced symptoms such as the occasional headache or upset stomach. Some experienced minor symptom distress on an "everyday" basis. However, most felt the symptoms did not pose too much trouble for them. Knowing and believing that things would work out for them, in fact became a reality for them. Children and their parents and siblings experiencing this type of comeback, were now able to take more time for themselves and their family unit. The children and their families, although having changed in many ways, were able to return to reclaim most of their old sense of self and continue living a lifestyle similar to the one that existed before embarking on the cancer-

symptom trajectory. Children once again could feel well on a daily basis.

Undergoing the treatment, symptom experiences, and all the tough times in relation to the symptoms was after all worthwhile. In fact, having to suffer because of the symptoms and subsequently succeeding in getting through the cancer-symptom trajectory made them feel mentally stronger. They became more spirited with feelings that they could accomplish or do almost anything because after they put up with a lot of symptom distress. However, even though children and their families felt stronger, it was still important to work at maintaining a sense of spirit as the cancer and its memories were still with them. While they experienced more stability and less distress during this period, they also feared the cancer coming back:

> *Child in remission (18-year-old male): It is not death that I fear anymore, but it is the cancer coming back that I fear.*
>
> *Sibling (19-year-old male): I guess in a way I'm always worried about you know if the cancer comes back or if it does and I'm not here or if I've been away to say Calgary, Vancouver you know I will always feel "eerie" about hearing that call.*
>
> *Sibling (16-year-old female): The most difficult thing to deal with now is the checkups because there's always the fear that this thing could come back, but I try not to think about that now because things are going so well.*

As well, all children and their families experienced some degree of stress just because they had to return or comeback to the "real" world. It was no longer necessary to concentrate solely on the cancer-symptom experiences:

> *Father: In a way you are free during the time that your child is sick because there's no, you are so, nothing else matters, phone calls and so on. You owe people nothing, how many sick days you have taken off of work, none of that matters...Yeah it gives you permission, very much so in a way but you have to pay for it later.*
> *Mother: But that is what happens to us now, everything has accumulated and now we have to back track and clean up what we left for a year. And that is what*

really happens, you leave everything, you can't deal with anything any more.....that's all, you leave your bills and you don't care.

(ii) Cancer- and symptom-return

The second type of comeback involved the children's cancer relapsing. The return of the cancer could occur anytime during their first bout with cancer or after the children had successfully completed treatment. Often parents and the children knew the cancer had come back even before their physician made the diagnosis. Their knowledge was based on the return or the "comeback" of the symptoms that first led families to seek out help in the first place:

Father: No. No, it was one of the worst times because of the fact that we were seeing the symptoms coming back that actually got us to the doctors in the first place.

A relapse of the cancer was especially hard on the children and their families. The hardness was of course related to the children and families feeling that death was once again close by. As well, the hardness was related to having been betrayed by the symptom trajectory. As part of the unspoken and assumed agreement that children and families had made with themselves or their spirits was agreeing to endure the cancer treatment and the resulting symptoms with the provision that there would be "*short-term pain for long-term gain.*" However, this agreement was not honored in families where the children had relapsed. It was like their symptoms had betrayed them. This resulted in children and their families becoming even more discouraged or dejected. Maintaining a sense of spirit became even more difficult. It was especially difficult if the children had gone through most or all of the prescribed treatment regimen before relapsing:

Father: It's you know, it's really discouraging (pause) because she was almost

two years into treatment when she relapsed and if there is a relapse it usually happens is in the first six months or so (post bone marrow transplant).

For the children it meant enduring more symptoms which already having gone through the cancer and its treatment once before, made it more difficult for them to accept as this time they knew what they were in for, as well as knowing how physically and mentally bad they could possibly feel. It was not so much death that they feared, but all the symptoms that they would have to endure. Their parents and siblings also found it harder because once again they put their life on hold in order to help the ill children get through the symptom experiences, but this time the outcome was even more uncertain. Although the children who relapsed in this study and their families all agreed to once again undergo treatment, they nonetheless wondered at times if treatment a second time around would be worth it. Their questioning stemmed from the fact that the children would have to suffer once again as a result of the symptom experiences.

(iii) Cancer-free but not symptom-free

The third type of comeback time was related to those children who although cured of cancer, still experienced a great deal of symptom distress. There was a "comeback" of a cancer-free body, but the children's symptoms did not subside and in fact for some, only got worse. These were children who continued to experience symptoms such as extreme fatigue or ongoing nausea and vomiting. Children and families described life as "*not good!*" or "*things are the same!*" Children would describes themselves as feeling "*really sick*" or "*wiped out*" or "*not good.*" They were living the same life as they did when the children were receiving the cancer treatment. They were in fact still prisoners of the cancer-symptom trajectory, however, but now the symptoms now became the illness.

This type of comeback also resulted in the children and families once again experiencing other transition periods such as "it is nasty!"

Children experiencing this last type of comeback could not resume a lifestyle that had less cancer-related uncertainty, work, restrictions, emotions, and loss. As well, the children's parents and siblings could not resume a life that allowed them to take more time for themselves. Life was still on hold. Just like it was for the children whose cancer relapsed, the symptoms had once again betrayed them. The children understandably became even more discouraged or dejected. Some families felt that most health professionals, friends, and families were giving up on them and no longer wanted to be part of their cancer-symptom journey. In fact some of families experiencing this last type of comeback noted that some friends and family could not understand why their children still presented with symptoms because "*after all the cancer was cured.*" The families got the impression from others that their children's symptoms were no longer justified. Basically it was like being told that the children's symptoms were no longer real, and that it was time to move on.

Although families experiencing this last type of comeback were told that the symptoms were definitely not a repeat of the cancer experience they, nonetheless, could not help but wonder otherwise. They had already once before been through that scenario where they were told that their children's symptoms were not too serious when in fact they were serious. This time around families were even more cautious in approaching symptoms; families no longer treated any symptom experience with passiveness, disregard, or indifference.

Children and families who experienced ongoing symptoms had to maintain a sense of spirit by believing that things would get better. They also made sense of it by rationalizing that things could always be worse; that is, at least the cancer was under control. Knowing and believing that the cancer was under control in spite of not being symptom-free was what helped them to maintain their hope and faith:

> *Mother: Nothing has changed and we don't know if it will, but at least his cancer is under control...Things will get back on track once this thing (the symptom distress) is under control.*

(iv) Summary of "It is comeback time"

Although a sense of uncertainty was experienced throughout all the transition periods that children and their families passed in and out of, it was perhaps during the period of "it is comeback time" that families experienced the most uncertainty. This included the uncertainty of whether or not the cancer and symptoms would remain suppressed or contained, or whether or not the symptoms and cancer would progress. When symptoms occurred in this period, most found them harder to deal. Families now knew the symptoms could be an indication of more than just the flu. The "comeback" period as one mother noted was "*a very unsettled time.*" Regardless if the children were symptom-free or symptom-bound the children's cancer-symptom trajectory could go either way and knowing what period the child and family would end up in again was so uncertain, so unknown. Any type of comeback was always possible.

Conclusion

This chapter demonstrated the significance that children's and families' personal meanings of the cancer-symptom experiences had in shaping how they responded to

keeping the spirit alive. Personal meanings affected the degree of roughness experienced by them and how they used the "keeping it alive" strategies which in turn, affected their way of being in the world. Their way of being in the world was dynamic as evidenced by their passage through the transition periods. The transition periods were a reflection of how children and families experienced the overall cancer-symptom trajectory as greatly influenced by the children's and families' assigned personal meanings of the cancer-symptoms. This chapter afforded the reader a greater understanding and appreciation of the lived experience of the cancer-symptom trajectory as experienced by children and their families.* The next chapter examines and discusses the findings in relation to existing research that is concerned with the experience of childhood cancer. Recommendations for research, education, and practice are also discussed.

***Note:** The reader is also referred to Appendix R for examples of two families' illness narratives: one of a family with a preschooler experiencing cancer and the other of a family with an adolescent experiencing cancer. These narratives demonstrate how families experienced keeping the spirit alive while getting through all the rough spots related to the cancer-symptom experiences. As well, both narratives illustrate the differences and similarities experienced by the preschooler and adolescent child. It is hoped that through these narratives, the reader will gain a greater understanding and appreciation of the lived experience of the childhood cancer-symptom trajectory.

TABLE 6: CHILDREN'S AND FAMILIES' LIVED EXPERIENCE OF CHILDHOOD CANCER-SYMPTOMS: PASSAGE THROUGH THE TRANSITION PERIODS

TRANSITION PERIOD	CHARACTERISTICS	RELATIONSHIP TO GETTING THROUGH THE ROUGH TIMES	RELATIONSHIP TO KEEPING THE SPIRIT ALIVE STRATEGIES	RELATIONSHIP TO A WAY OF BEING IN THE WORLD
"IT IS JUST THE FLU... ANYTHING BUT CANCER"	•beginning of the cancer-symptom trajectory •triggered by symptoms in the child that point to something that is not quite right •usually lasted a couple of months	•at first symptoms are viewed to be minor and children describe themselves as "feeling sick" •later symptoms are viewed to be more serious in nature and children begin to feel "really sick" or "really nasty" or "really scared" •initially children and families could continue on in their daily lives; life was not too hard •as symptoms progress, life gets harder with more rough spots to get through •as symptoms progress there is more work in managing the symptoms; restrictions begin to affect life; and there is uncertainty to what the symptoms really mean	•at first use of strategies was not changed or focused on •as symptoms progressed and families begin to take them more seriously, use of strategies become more necessary especially coming to know , taking care, holding on to the belief	•at first sense of self not affected much and can carry out most of their life activities •as symptoms progress children begin to change and families can no longer carry out their daily routines; more discomfort •children were becoming more aware of their bodies **Table 6 continued➡**

TABLE 6: CHILDREN'S AND FAMILIES' LIVED EXPERIENCE OF CHILDHOOD CANCER-SYMPTOMS: PASSAGE THROUGH THE TRANSITION PERIODS

TRANSITION PERIOD	CHARACTERISTICS	RELATIONSHIP TO GETTING THROUGH THE ROUGH TIMES	RELATIONSHIP TO KEEPING THE SPIRIT ALIVE STRATEGIES	RELATIONSHIP TO A WAY OF BEING IN THE WORLD
"IT IS A BLUR"	•begins abruptly and in a rough manner •kicked in the face feeling •feeling that symptoms betrayed them	•symptoms now defined as nasty and are to be feared - no longer considered minor or normal •the rough spots become harder •uncertainty in relation to the outcome of cancer	•coming to know, taking care, being there, and taking one day at a time strategies were especially important	•the family's sense of self was now merging with the child's •changes in lifestyle were now apparent - at this point families realized that life would change forever
IT HITS HOME	•family now really begins to understand what "getting through" meant - no way to avoid the suffering •war declared on cancer symptoms •real learning period •occurred each time children received a new course of treatment or when they showed new symptoms	•symptoms continued to be seen as "hard," "yucky," "exhausting and so on - all serious •symptoms "hit home" •symptoms were considered both enemy and friend in getting through all the rough times •families based the severity of child's cancer in relation to the "hardness" of the symptom experiences	•all the strategies were relied on but "coming to know," being present and spending time with the children, and "putting cancer in its place" were especially important •coming to know about the symptoms; and how to best care for the child •trying to put cancer in its place but was harder to do so with increased symptom distress	•more and more the ill child became the focus •parents and especially siblings made more sacrifices •children becoming more aware of their bodies; body becomes sensitive **Table 6 continued→**

TABLE 6: CHILDREN'S AND FAMILIES' LIVED EXPERIENCE OF CHILDHOOD CANCER-SYMPTOMS: PASSAGE THROUGH THE TRANSITION PERIODS

TRANSITION PERIOD	CHARACTERISTICS	RELATIONSHIP TO GETTING THROUGH THE ROUGH TIMES	RELATIONSHIP TO KEEPING THE SPIRIT ALIVE STRATEGIES	RELATIONSHIP TO A WAY OF BEING IN THE WORLD
IT IS NOT SO BAD, IT IS PRETTY GOOD	•reduced symptom experiences •occurred during maintenance stage of treatment course or in-between treatments	•symptoms defined as "not too bad" or as "everyday " •parents and children still worried about returning symptoms which made this period still hard to deal with •rough spots were not as rough	•still important to apply the strategies •taking time for oneself and cherishing the good moments were predominant	•time to resume some old activities •siblings could spend more time with their parents •family members felt more like their old selves •a time to feel good again; more awareness of what a "healthy body" feels like
IT IS NASTY	•could occur anytime when the symptoms were the dominant force in the children's lives	•rough spots predominated - symptoms especially "hard" •even rougher than "it hits home" period •"yucky," "sore", "wiped out" feelings	•had to really struggle to maintain a sense of spirit •being present, taking care, holding on to the belief, living moment by moment, and taking a little time for oneself, were all important	•life truly on hold •nothing else matters except how the child was feeling •parents' and children's sense of self merged •siblings on the outside •body sore all over; very sensitive

Table 6 continued➡

TABLE 6: CHILDREN'S AND FAMILIES' LIVED EXPERIENCE OF CHILDHOOD CANCER-SYMPTOMS: PASSAGE THROUGH THE TRANSITION PERIODS

TRANSITION PERIOD	CHARACTERISTICS	RELATIONSHIP TO GETTING THROUGH THE ROUGH TIMES	RELATIONSHIP TO KEEPING THE SPIRIT ALIVE STRATEGIES	RELATIONSHIP TO A WAY OF BEING IN THE WORLD
IT IS DRAGSVILLE	•period when children and families were becoming both physically and mentally tired of the cancer-symptom trajectory •time and reason varied between families	•rough spots were constant and compounded by the symptom experiences •children and families more often felt "cranky" during this period	•holding on to the belief of getting through was especially important •More difficulty in implementing strategies	•way of life dragging on •"crankiness" among family members •children become tired of their regulated and engineered bodies
IT IS COMEBACK TIME	•unsettling period •three types of "comebacks" determined by the cancer-symptom experience: •Cancer and symptom-free or fairly symptom-free •Cancer and old symptoms return •Cancer-free but not symptom-free	•could range from very few rough spots to many rough spots as determined by the type of cancer-symptom experiences	•use of strategies depended on the type of comeback - however, regardless of type of comeback, strategies were always needed	•varied from living life once again to barely surviving; from feeling more like one's old self to feeling totally different; from feeling a sense of well-being to feeling minimal comfort •body could be experienced in many ways depending on the type of comeback

CHAPTER VII

DISCUSSION AND CONCLUSIONS

Introduction

In this chapter the findings of the study are discussed in relationship to the two substantive theories that emerged from the data: "Keeping the Spirit Alive" and "Children's and Families' Lived Experience of Childhood Cancer-Symptoms." Attention is given to the study's research questions in the discussion of the findings. Existing research and the study's theoretical underpinnings are integrated into the discussion. Recognizing this study produced considerable findings, discussion here focuses mainly on the core categories of the two substantive theories: (1) Getting through all the rough spots; (2) Keeping the spirit alive; (3) Personal meanings of the cancer-symptom experiences; and (4) Passage through the transition periods. Children's experiences with symptom relief is also part of the discussion. "A Lifelong Journey," a metaphor for the childhood cancer-symptom experience, further lends to an understanding of how cancer was experienced and conceptualized by children and families. This chapter concludes with recommendations for research, education, and practice.

Discussion of the Two Substantive Theories: Keeping the Spirit Alive and Children's and Families' Lived Experience of Childhood Cancer-Symptoms

Through the course of this study two substantive theories evolved delineating how children and their families experience and respond to cancer-symptom experiences. A strength of conceptualizing the childhood symptom-cancer experience in a process-oriented framework is that it allows one to appreciate the interplay of the core categories

and subcategories that emerged from the data. Hence, a more comprehensive understanding of the children's and families' experience was made possible. Developing illness narratives further added to an understanding of their experiences with the study's two central phenomenons. Given the longitudinal nature of data collection, one can be more confident that the categories and their relationships are credible.

The substantive theories that emerged support existing literature that speak to the hardness of cancer on children and families (Clarke-Steffen,1997; Hinds,1990; Van Dongen-Melman & Sanders-Woudstra,1986; Varni & Katz,1987). While research has acknowledged that certain cancer-symptoms such as pain can be very hard on children and families and points to their suffering (Ferrell et al., 1994; Rhiner et al.,1994), findings from this study provide greater detail as to the effects that cancer-symptoms can have. Specifically, it was revealed that an interdependent relationship existed between the cancer experience in general and the symptoms experienced by children with cancer. Symptom experiences in and of themselves could not be understood without taking into consideration the whole cancer experience. Moreover, the cancer experience could not be understood without understanding the overall effect cancer-symptoms had on children and families. Children's and families' ways of being in the world in response to the cancer-symptoms was described and presented in process-oriented manner. To date, no theories have been developed that link children's cancer-symptom experiences to children's and families' responses to cancer, despite the fact that cancer-symptoms are repeatedly identified as major source of stress for children and families (Enskär, Carlson, Golsäter, & Hamrin, 1997; Ferrell et al., 1994; Hinds, 1990; Hogan, 1997; Ritchie, 1992;

Rhiner et al., 1994). Although further work is necessary to confirm or refute the major categories of the two substantive theories, the linkage of cancer-symptoms to families' responses to cancer on a daily basis, will afford both researchers and clinicians a foundation from which to develop interventions that will help to improve the overall quality of life for children with cancer and their families. Critical here, is conceptualizing the relationship of factors and outcomes to the cancer-symptom trajectory as a complex process that contains multiple facets and implications for children's and family's well-being. Structural equation modeling which allows for the simultaneous consideration of multiple pathways between constructs will help to confirm or disconfirm associations between children's symptom experiences and other variables in a hypothesis-testing manner. Recognition of the interrelatedness and individual variability of factors salient to the cancer-symptom trajectory would eventually allow for the design and evaluation of intervention and prevention programs. However, before applying the method of structural equation modeling to the study of children's cancer-symptom experiences, quantitatively represented variables specific to the children's cancer-symptom experiences need to be developed.

(1) Getting Through all the Rough Spots

The literature related to the impact of childhood cancer on children and families describes the presence of numerous stressors such as uncertainty, confusion, despair, worry, and caregiver burden (Clarke-Steffen, 1997; Hinds, 1990; Neville, 1998). Such stressors were also identified in this study. However, this study further showed that children and families could not definitely pinpoint what the most difficult aspect of

experiencing childhood cancer was. That is, all the rough spots were difficult for families. Although during certain periods there were fewer rough times, children and their families nonetheless expressed that it was still difficult to experience cancer because there was always something to deal with. This was even the case once treatment was completed and the children remained in remission. Acknowledging that there is always something for children and their families to bear in relation to cancer is significant and has implications for professionals caring for these individuals. Professionals need to acknowledge that the connection between cancer and symptoms experienced by children remain strong years after treatment had ended. The effects of the children's symptoms should always be acknowledged in the care of children with cancer.

Most important in relation to the psychosocial problem "getting through the rough spots," was that it was not only the rough spots in and of themselves that made cancer difficult. Rather it was more the "getting through" that contributed to the hardness of the cancer experience. Children and families had to get through as opposed to get over or around the cancer. "Getting through" appears critical to surviving as well as living through cancer in that it implies the need to face up to and confront all its rough spots. This makes sense considering there were so many rough spots or barriers or obstacles to confront. Each barrier had to be broken down in order for children and their families to be able to continue on with life. Whereas with "getting over" the family may have survived the cancer, it was only by "getting through" could families continue to live life and live through cancer, regardless if the children survived the cancer or not. "Getting over" the cancer was not good enough as some barriers could still remain preventing one from

really living through cancer. "Getting over" also implies that once the cancer treatment is completed then the cancer is no longer a part of one's life, that one is over cancer. But as was made evident by the children and families, one truly never gets over cancer; that is, it always remains a part of the individual and family. This was the case even for children in the study who were had remained cancer-free for a period of five years or greater; certain passages of the cancer experience remained with them forever. These children and their families while able to resume a life that could be characterized as "normal," nonetheless approached and lived life differently than they did prior to experiencing cancer. Clarke-Steffen (1993) also found that families experienced a different type of normal after experiencing childhood cancer and referred to it as a "new normal."

While the cancer experience no longer dominated the life of those families in which children remained cancer-free and while certain details of the cancer experiences faded over time for them, they nonetheless still spoke of cancer as being a part of their life. As well, there was always the fear of recurrence of cancer in the children or being taken ill with a new form of cancer. The fear was especially evident during the times that the children in remission had any new experiences with symptoms. Children and families in effect had to work at getting through cancer for their rest of their lives. Even though the cancer remains with the individual and family, they still are able to continue living if they experienced "getting through" as opposed to "getting over" the cancer-symptom experience. To date, "getting through" has yet to be identified or labelled in the literature as part of the basic psychosocial phenomenon related to childhood cancer. However, it seems more complete to include "getting through" as part of the phenomenon because it

more aptly depicts the suffering and hardness that results because of illness.

Further research that examines how "getting through" is conceptualized by those who experience childhood cancer may to add to a greater understanding of the experience of suffering in children and their families. Comparing those families who conceptualize cancer more as a "getting over" experience as opposed to those who view it more as a "getting through" experience is worthy of research attention. Areas that could be explored include identifying those barriers that children and families find are more difficult to "get through." Perhaps those who are more likely to conceptualize cancer as a "getting through" experience are more accepting of the suffering and are able to deal with it because of some unique quality within them that is tied to their sense of spirit. At the same time, acceptance of the suffering associated with cancer may also contribute to the children's and families' reluctance to seek out help for symptom distress. The study of the relationship between symptom distress, suffering, and "getting through" or "getting over" may add to an understanding to how individuals seek out help. How children's and families' conceptualizations of "getting through" and "getting over" change over the years need to be studied longitudinally.

(2) <u>Keeping the Spirit Alive</u>

As unbearable as it was at times for children and their families to get through the cancer-symptom experiences, they nonetheless persevered. Families attributed their perseverance to the spirit within the child or family. Comments in the pediatric oncology literature such as "the children's responses suggest a resolute spirit that accepts cancer and goes on with life" (Hockenberry-Eaton & Minick, p.1030, 1994) support the

importance of the spirit in children with cancer. Yet despite this, the spirit in children with cancer has received minimal attention from researchers. The focus has been solely directed at studying the sense of self in children. In fact some would even argue that the spirit can be equated with one's self or that because it is difficult to truly measure the spirit in children that the spirit does not exist. Yet in this study, parents did see the spirit and self as two separate entities. The need for research in this area is needed to help confirm or refute the existence and importance of the spirit in children experiencing illness. Although understanding spirituality and spiritual distress is beginning to be studied in children experiencing illness (Pehler, 1997), children's perspectives are usually not accessed. Moreover, how ill as well as healthy children conceptualize "spirit" is not given any consideration.

Because of the importance assigned to the spirit by children and families in getting through, it became apparent that the process of keeping the spirit alive was necessary. Children and families responded to the rough spots of the cancer experience by applying the process of "keeping their spirit alive" process and its strategies. Research directed at identifying core processes with respect to children's and families' responses to childhood cancer is relatively new. Processes that have been discovered include reconstructing reality in families adapting to the diagnosis to childhood cancer (Clarke-Steffen, 1997) and the self-sustaining process used by adolescents to maintain hopefulness (Hinds & Martin, 1988). However, none of these processes nor others specific to childhood cancer have been applied to the management of cancer-symptoms by children and their families. "Keeping the spirit alive" process is the first process that

takes into account how children and families respond to cancer-symptoms. Moreover, a strength of the "keeping the spirit alive" process is that it can be applied not only to the hardness of the cancer-symptom experiences, but to all rough spots of the cancer experience. However, regardless of the rough spot to which the process is being applied, the symptom experiences or more specifically the personal meanings of the symptom experiences still figure in how children and families respond. That is, much of the children's and families' general perseverance can be attributed to the symptom experiences. This reinforces the close relationship of the overall cancer experience to the cancer-symptom experiences. It was because of the symptom experiences that children and their families recognized the need to make use of the "keeping the spirit alive" strategies. The meanings children and families assigned to the symptom experiences also influenced the way they applied the "keeping the spirit alive" strategies which in turn affected their way of being in the world. By conceptualizing the cancer experience as a cancer-symptom meaning experience, it became evident that the process of keeping the spirit alive and the way of being in the world were dynamic experiences for the children and families. There was movement from one transition period to another.

In "keeping the spirit alive," the array of strategies used by children and families varied from "coming to know," to "taking one day at a time," to "cherishing the good moments." Significant to these strategies is that each appeared to reduce the intensity of certain experiences, and made them easier to bear. For example "coming to know" helped to reduce the uncertainty that children and families. "Taking one day at a time" helped to deal with the extra work and multitude of feelings experienced by children and

families. Strategies ultimately helped to reduce the level of discomfort felt by children and families and increase their sense of well-being. However, an even more important finding related to use of the "keeping the spirit" strategies, is that the strategies were used by the children, siblings, and parents alike. That is, both child and adult participants relied on the same strategies. In spite of developmental differences, children and families shared a common ground in how they approached and dealt with cancer. This makes sense considering the use of the strategies affected the individual's way of being in the world and regardless of age, the desired way of being was to be able to "really" live life, maintain one's sense of self, and feel connected to family and friends. In effect, a way of being in the world could be equated what the need to feel human, a need shared by young and old alike. However, although children, parents, and siblings relied on the same strategies, there was an uniqueness as to how children and their families approached the strategies in getting through all the rough times. While in reality they had no choice in having to get through if they hoped to survive, they did have a choice with respect to how they could respond in their own unique manner. Nonetheless, acknowledging that a repertoire of strategies in "keeping the spirit alive" is shared by both children and adults will be of benefit for nurses and other professionals who are responsible for the care of children with cancer and their families. Further research is warranted in describing the differences between how children and families approach the strategies. As well, research is needed to be more clearly delineate how use of strategies vary in relation to the "transition periods."

(3) Personal Meanings of the Cancer-Symptom Experiences

This study supported the position proposed by Tishleman and colleagues (1991) that the children's symptoms represented the meanings cancer had for them and their families. The symptoms were a source of knowledge for children and families with respect to the health status of the children which explains why they needed to be kept informed about the type of symptoms that could result because of the treatment. This need to know about potential cancer-symptoms helped to give meaning to the children's changing condition and is consistent with past research. For example, Mercer and Ritchie (1997) in surveying the needs of parents with cancer noted that at least 80% of parents had the need to be told about symptoms to be expected as their child's condition changed.

In addition to serving as a source of knowledge, the personal meanings of the cancer-symptoms influenced children's and families' way of living. The meanings children and families assigned to the cancer-symptoms were critical to the way they experienced cancer. It was the symptoms that brought with them threats to their spirits which in turn threatened their daily activities, relationships, and sense of self. The meanings that children and families assigned to the symptoms were multiple and evolved as a continuous interpretive process. Moreover, the symptoms were viewed not just as singular physical states (e.g., nausea) but as whole experiences that occurred within a particular context. The strength of viewing symptoms as "whole" experiences is that it allows for an understanding of what the symptoms mean to the children and their families; that is, the symptom experience represented multiple layers of meanings.

The finding that symptoms have multiple layers of meanings has implications for

how symptom experiences are managed. Health professionals need to consider symptoms as they are experienced by children within a particular context in order to arrive at an understanding of what children are experiencing. Most important is the need to re-evaluate the way in which health professionals assess children's cancer-symptoms. Although symptoms are multidimensional in nature, to date standard practice to symptom evaluation continues to be unidimensional in nature, in the form of self-report scales (Ross & Ross, 1988). On these scales the children are asked to rate some facet of a particular symptom, usually its intensity. However, as was demonstrated in this study, the children often did not see the value of this method as the ratings seemed irrelevant to them as the ratings really could not capture how they were feeling. Developing a scale that is framed within a meaning-centred approach may provide for a greater understanding of what symptoms are perceived to be a problem to the children. In addition to accessing the children's assigned meanings, the scale could also incorporate children's self-reports of the prevalence, frequency, severity, and distress related to their symptom experiences. Evaluating children's symptom experiences within a multi-dimensional framework will result in a more accurate understanding of what children are experiencing.

Lastly, the fact that children of all ages assigned meanings to their symptom experiences supports the theoretical assumption that children can be active research participants especially when appropriate research methods are used.

(4) Passage through the Transition Periods

The varied transition periods that emerged from the data further reinforced the

significance that symptoms played in the lives of children with cancer and their families. Because of the symptom experiences, life could be experienced in various transition periods from the "it is just the flu" to "it is comeback time" transition period. It was the meanings that children and their families attributed to the cancer symptoms that greatly determined the way "keeping the spirit alive" was approached and what transition period the children and families were moving through. For example, experiencing life in the "it is pretty good" transition period was in part due to viewing symptom experiences as "everyday" symptom experiences. For some time, transition has been a concept of interest to nurse researchers, clinicians, and theorists (Schumacher & Meleis, 1994). Nonetheless understanding how children and families transition or pass through the childhood cancer-symptom experience has not been given attention. Definitions of transition found in the nursing literature lend support to the attributes associated with how children and families in this study passed or moved through the transition periods. This includes acknowledging that transition: (1) involves both a process and an outcome of complex person-environment interactions (Chick & Meleis, 1986); (2) may involve more than one person and is embedded in the context and situation (Chick & Meleis, 1986); (3) denotes change in health status, in role reactions, in expectations, or in abilities, and in the needs of all human systems (Meleis, 1986, 1991); (4) results in temporary loss of familiar reference points of significant objects or subjects (Meleis, 1986); (5) requires the individual to integrate new knowledge, to alter behavior, and therefore, change the definition of self in social context, of a healthy or ill self, or of internal and external needs, which affects the health status (Meleis, 1991). Schumacher and Meleis (1994) note

that meanings are critical to how transitions are experienced and draws attention to the importance of understanding a transition from the perspective of those experiencing as became apparent with children and families transitioning through the cancer-symptom trajectory.

The various transition periods that children and their families could go through not only provided evidence that the cancer-symptom experiences were much more than some singular physical or psychological event, but that how symptom experiences were perceived by children and families affected such things as coping responses, symptom expression, and activities of daily living. This suggests that the phase of the treatment regimen or cancer course that children are experiencing may not be the only factor that determines the overall degree of difficulty and hardness for children and families experiencing cancer-symptoms. Accordingly, one cannot assume that the degree of hardness experienced by children and families is directly and solely related to the degree of intensity of the treatment that children are receiving. Interestingly, in a study that examined symptom severity, frequency, and distress in children with cancer, it was revealed that although symptom distress was relatively higher among inpatients, children with solid tumors, and children undergoing anti-neoplastic treatment, there was also great individual variation in the symptom characteristics (Collins, Byrnes, Dunkel et al., 2000). Accordingly transition periods related to the meanings children and families assign to their cancer experiences may be of value in determining how children and families are managing or adapting to cancer when considered in relation to a particular phase of the treatment regimen or cancer course. Future research determining how transition periods

relate to the phases of the treatment regimen or cancer course is warranted.

A Way of Being in Relation to the Personal Meanings and Transition Periods

Related to the personal meanings and transition periods was how children and families existed in their worlds. Most notable was the effect symptom experiences had on the children's changing sense of self. The children's sense of self was greatly affected by, and tied to the type of symptom experiences that the children were getting through. This supports the theoretical assumption that cancer is identity-altering (Mathieson & Stam, 1995). Depending on the degree and severity of symptom distress, children could feel completely like themselves and connected to their world, to feeling not quite like themselves, unconnected to many things important to them. Although previous research has indicated that cancer has an affect on children's sense of self (Enskär et al., 1997; Hockenberry-Eaton, Hinds, Alcoser et al., 1998; Hockenberry-Eaton & Minick, 1994; Rechner, 1990), most of the work is not specific with respect to how children's sense of self is related to the cancer-symptoms. Additionally, except for Bluebond-Langner's (1978) study that explored how children with cancer come to know that they are dying, no other research has conceptualized the self in children with cancer as something dynamic and process-related affected by the changing context. Bluebond-Langner's work depicted how children's self-concepts changed as they acquired information about themselves and their health status. Part of the information that children relied on was how they felt in relation to their symptom experiences. However, Bluebond-Langner's work was specific to children who were dying, and focused more on the children's cognitive understanding of the cancer experience as opposed to their emotional understanding.

Nonetheless, Bluebond-Langner's work reinforced the need to adopt a process-oriented approach to understanding how children experience cancer.

Although children experienced a dynamic sense of self throughout the cancer-symptom trajectory, they as well as their parents believed that overall what made the children unique had remained the same. Even with the changing attitudes and a changing way of life, children felt at the end of cancer treatment that they remained the same person as they were prior to the cancer diagnosis. Research also supports the finding that children with cancer while at times did not always feel like their "normal" selves or like "healthy" children and did things differently from their peers (Enskär et al., 1997; Hinds & Martin, 1988; Hockenberry-Eaton et al., 1998; Rechner, 1990; Weekes & Kagan, 1994), nonetheless they viewed themselves as normal and the same (Aamodt et al., 1984; Rechner, 1990). These findings and the children's statements that they had not changed, seem contradictory to what children actually experienced in this study as is evidenced by their changing sense of self throughout the changing symptom trajectory. Additionally, from a developmental perspective and irregardless of the cancer diagnosis, one would expect the children's self to undergo hierarchal developmental changes. Perhaps what actually remained constant in the children was their sense of spirit as opposed to their sense of self. Further study is warranted to clarify how children and parents conceptualize a sense of spirit in relation to the sense of self.

Findings from this study also revealed that in addition to a changing sense of self, children also experienced a changing body and became more aware of their changing body. Their changing body and the sensitivity to their changing body came about because

of the changing symptom experiences. It was not until they experienced negative changes in their bodies that they truly could appreciate what it felt like and what it meant to be healthy. To date, conceptualizing the changing body in children with cancer or other childhood illnesses has received minimal recognition in the literature. A notable exception is Mulderij's (1996) work on accessing perceptions of children whose bodies experienced some type of disability. In a phenomenological study Mulderij (1996) accessed the perceptions of physically disabled school-age children and revealed that perception of the body was a central category in the lives of children who were restricted in their movements due to conditions such as cerebral palsy, spina bifida or muscular dystrophy. The disability resulted in the children no longer experiencing the lived body in silence. That is, children now became sensitive to their bodies. Mulderij (1996) revealed that "having a body" dominated in children with physical disabilities and that the children experienced a rebellious, unreliable, sensitive, dependent, conspicuous, vital, and "in therapy" body. Mulderij's astute and unique conceptualization of the disabled child's body laid the foundation for the researcher to understand how children with cancer perceived their changing bodies in relation to their cancer-symptom distress. Although differences did exist in Mulderij's work and the findings of this study on childhood cancer, there was the commonality that disabled children and children with cancer experienced not only a "lived body," but also were aware of their lived bodies.

The need for children to assign meanings to the cancer-symptom experiences as affected by an increasingly awareness and experience of the "lived body" lends support that the self, spirit, and body do not exist as distinct entities but are interrelated and

reciprocal, affecting each other and being affect by each other. Even when one's own body becomes an object for one's own scrutiny, van Manen (1998) notes that body is never totally objectified. Nor can one separate their body from their sense of self as it is the body that makes it possible to see, hear, feel, and sense other things in the world (van Manen, 1998). Future work is warranted to further detail the perceptions of the body in children with cancer. This includes examining the differences in perceptions in children experiencing different cancer trajectories.

Another significant, previously unreported finding revealed in this study relates to the fact that both the children's and individual family members' sense of self were affected by the symptom experiences. Indirectly and directly, the families' sense of self was tied to the children's symptom experiences to the point that the symptoms affected how family members felt and experienced being a family. This finding lends support for the theoretical assumption that children's symptom experiences need to be considered within the context of the whole family. Not only was the family integral to the expressions of symptoms by children, but the children's symptoms determined the family's way of being in the world. The family unit itself could be "more or less" a family depending on the degree and severity of the children's the cancer-symptom experience.

A troubling finding in this study was how siblings were affected by the changing cancer-symptom trajectory. Parents became closer to the ill children and to some extent maintained their self by merging with the ill children's self when cancer-symptoms predominated. In contrast, siblings and to some degree fathers, felt more like outsiders to the children's cancer-symptom experiences. Siblings especially experienced feeling

isolated from their parents and ill siblings. Not being able to participate in their ill sibling's care in general and especially with respect to symptom relief, only increased the siblings' feelings of isolation and sadness. The isolation felt by them was related to the many losses that they experienced. Previous work lends support to the finding that siblings experience childhood cancer as a loss (Sloper, 2000). However, the profound sadness experienced by siblings because of the many losses has not received attention. Because of the losses and prevailing sadness, the sense of self in siblings was weakened. They defined their world through the experiences of their ill siblings. Experiencing a weakened sense of self and profound sadness throughout the cancer-symptom trajectory points to the need for more research directed at understanding the experience of childhood cancer from the perspectives of siblings. While research attention has been given to the impact of childhood cancer on siblings in general (Barbarin, Sargent, Sahler, et al., 1995; Ross-Alaomolki et al., 1995; Sloper & While, 1996), minimal attention has been given specifically to siblings' perspectives about cancer-symptoms and their involvement in the care of their ill brothers or sisters. Interestingly, research describing siblings' experiences with their terminally ill brothers or sisters revealed that siblings who participated in their ill sibling's care and in activities centred on that child's death (e.g., attending the funeral service) had higher self-esteem in comparison to those siblings not involved in such activities ($p=0.001$) (Michael & Lansdown, 1986). Lauer and colleagues (1985) also reported similar findings and in fact, found that siblings who participated in the care of their ill sibling found the experience more comforting, felt less isolated, and perceived that relationships with their parents improved. These findings lend support to

provide siblings the opportunity to become more involved in their ill siblings' symptom management.

Acknowledging that the cancer-symptom experiences affect the families' sense of self as well as the children's, lends greater support for the need to adequately manage children's symptom experiences throughout the course of the cancer-symptom trajectory. Knowledge of the effect that the cancer-symptom experiences have on the children's and families' sense of self is of value because it may help health professionals to provide more sensitive and appropriate care. The findings suggest that nurses and other professionals need to be cognizant of siblings' feelings and develop interventions that will assist them in getting through the cancer-symptom trajectory. Research examining the social support interventions received by school-age siblings of children with cancer revealed that siblings' perceptions of their own need for social support were not always congruent with those of their parents (Murray, 2001). Seeking siblings' perspectives on their own needs and preferred types of social support is thus essential.

Experiencing Symptoms and Symptom Relief

How children experienced symptoms and symptom relief proved to be a complex phenomenon that was affected by their own perceptions as well as their families' views about symptom experiences. Children and families identified many facets to what constitutes a symptom, and what made a symptom difficult to get through. They found it difficult to pick and chose what symptoms qualified as the most distressing. All symptoms were labelled as distressing, although the context in which they occurred and the meanings assigned to them varied. As expressed by the children, "*they all sucked.*"

Children also reported that although they learned to adapt to symptoms especially "everyday" symptom experiences, they really "*never got used to them*" or to the cancer experience in general. This finding stands in contrast to research revealing that children experience getting used to the cancer, treatment, and resulting side effects and symptoms (Hockenberry-Eaton & Minick, 1994). These conflicting findings may in part be explained by how the children defined "*getting used to.*" In Hockenberry-Eaton and Minick's study (1994) "getting used to" was equated with becoming accustomed to cancer and its treatment. In this study, children viewed "getting used to it" as an experience that involved not only becoming accustomed to the symptoms, but also as learning to like it or becoming comfortable with it. Children in this study stressed it was important not to become comfortable as if one did there would be little incentive to deal with all the roughness, especially the roughness of the cancer-symptoms.

Yet despite never really getting used to the symptoms, only certain symptoms warranted attention with respect to symptom relief. While traditional symptoms that have in the past been a focus of symptom management such as pain and nausea were attended to, symptoms such as fatigue were often not considered as part of the management plans. Symptom experiences labelled as "everyday" experiences also did not warrant attention. While children and families would usually seek out help for symptoms deemed severe in intensity, this was not always the case with symptoms rated mild to moderate in degree. Even those symptoms that were managed did not always result in complete relief. Instead, children found that attempts to relieve symptoms usually only "*sort of helped.*" At times the only way for children to deal with the symptoms was to sleep. While this strategy did

not relieve symptoms, it nonetheless afforded the children a break from the symptoms. This "*sort of helped*" attitude was accepted by the parents. As well, parents felt that any strategies that they implemented only somewhat helped to relieve their children's symptom distress. Fathers especially felt that their contribution to their children's symptom relief was minimal.

The lack of achieving better symptom relief could in part be related to children's and families' belief that experiencing symptom distress was part of getting through the cancer experience and that achieving complete symptom relief was not possible. That is, it was expected that children would have to experience some short-term pain in order to survive the cancer. Therefore, seeking out help was not warranted. The finding that children also were able to at times function adequately while experiencing certain symptom experiences may have contributed to children not seeking out help. This raises the question about how much better children could function if such symptom experiences were managed.

Although lack of adequate symptom management has been previously reported (Pederson et al., 2000), it still continues to be a problem among children with cancer as was evident in this study. This could be related to health professionals' perceptions of which symptoms warranted more immediate attention. While there is an urgent call to improve on symptom management in terminally ill children (Wolfe et al., 2000) or in symptoms associated with more overt distress such as pain related to painful procedures (Adams, 1990; Bradlyn et al., 1993; Jay et al., 1987; Jay et al., 1983; Katz et al., 1980; Reeb & Bush, 1996), the call to improve day-to-day symptom experiences or those that

are more subtle but nonetheless still a source of discomfort, is not as apparent in the literature. Research is warranted to gain a better understanding of how certain symptom experiences are perceived by health professionals as well as children and families.

From a practice perspective, the study's findings lend support for nurses and other health professionals to be more vigilant in assessing and managing children's symptom experiences. The challenge for health professionals as well as parents is to support a communication interaction style that maximizes interactional comfort and trusting relationships between children and adults who care for them (Garbarino & Stott, 1990). Viewing symptoms as experiences as opposed to singular states and understanding what the symptoms mean to children and families would assist professionals in their care of providing symptom relief.

A Life-Long Journey: A Metaphor for the Childhood Cancer-Symptom Experience

Both substantive theories help to facilitate an understanding of how children and families experience the complex phenomenon of getting through all the rough spots of childhood cancer. The illness narratives, however, provided a basis for understanding how the complex phenomenon affected the children's and families' biographies by contextualizing illness events and illness symptoms. The illness narratives brought to life what children and families were experiencing. As supported by families' stories, getting through the cancer-symptom experiences was like going on a life-long journey. Words such as "*journey*," "*bumps*," or "*roadblocks*" punctuated their stories. However, instead of embarking on a pleasure cruise or a family vacation, children and their families were about to go on one of the most powerful, turbulent, and tough journeys of their life: the

life-long journey of cancer. From the very start of being informed of the cancer diagnosis, all previously planned routes or travel plans were put on hold. New "roadmaps" now guided their lives.

"Roadmaps" for the children and families had two meanings for them. First, there was the roadmap that described the children's treatment course specific to the type of chemotherapy and/or radiotherapy that children would receive over a specific time frame. The treatment course was mapped out on numerous pages and was given to children and their parents to assist in their understanding of the treatment course and what was ahead of them.

While children were going on a journey in relation to the chemotherapy or treatment course, they also were going on a journey in relation to the cancer-symptom experience. However, the roadmap that guided the children and families on this journey, although related to the first roadmap, was nonetheless different and stood on its own. Although not explicitly given the label "roadmap" by children and families, a second roadmap did exist for them. This second roadmap that guided the children and families was the roadmap of "passage through the transition periods." And it was the assigned personal meanings to the children's cancer-symptom experiences that determined what transitions periods or pathways that children and families embarked upon and traveled down. That is, it was the assigned meanings that determined the children's and families' journey in life while getting through the cancer-symptom experiences.

The transitions periods or pathways that children and families could travel down varied from their original travel plans. Some pathways were stormy and dangerous with

many wrong turns or dead ends, others were long and arduous or exhausting, while others seemed less taxing, and almost pleasant. Regardless of the path that children and families undertook, they had to get through the path in its entirety in order to get to the endpoint or their desired destination. A detour was not an appropriate option as it could result in a more dangerous outcome: that of coming to a dead-end. Going around or getting over a particular pathway was not advisable despite all the potholes that children and families experienced because of getting through the pathways.

Every journey traveled was unique for each child and family with different turns and stops. And as always, it was the personal meanings assigned to the children's symptoms experiences that in the end determined the roads or paths that each family would in their own unique way, travel down in order to get through the cancer-symptom trajectory.

Summary of the Major Findings

In summary, the major research findings of this study are as follows:

•That the cancer experience is a complex experience that cannot be reduced to specific experiences.

•That symptom experiences are an integral part in how children and families experience cancer and in fact, cannot be separated from the whole cancer experience.

•That symptom experiences were a family affair; while only the children experienced the cancer-symptoms, every family member experienced the distress associated with the symptoms.

•That the meanings children assign to their symptoms are critical to understanding and

evaluating their symptom experiences.

•That how children and families perceive their sense of self is greatly affected by the symptoms experienced by children.

•That something other than one's sense of self, that is, a sense of spirit, may play a role or contributed to children and their families getting through the cancer-symptom experience and helped maintain one's sense of self and sense of well-being.

•That children and families relied on the same "keeping the spirit alive" strategies in getting through the cancer experiences, although each individual approached the strategies in their own unique way.

•That the family unit is still the most important source of strength for children with cancer and their families.

•That children and families experience transition periods throughout the cancer-symptom trajectory that may not be solely defined in terms of the children's treatment regimen or cancer course.

•That use of "keeping the spirit alive" strategies varied as children and their families moved from one transition period to another.

•That the meanings children and families assigned to the symptom experiences determined how they moved and changed through the transition periods.

•That each child and family experience transition periods in their own unique way; there was no one common journey experienced by all.

•That the symptoms were not so much single states that resulted from a particular cause and led to specific effects or outcomes, but instead represented multiple levels of

meanings that were connected to the children's changing contexts.

•That all symptoms experienced by children basically "sucked!"

•That sadness as opposed to any other emotion (e.g., anger, loneliness) was experienced the most by children and their families.

•That children and their families experienced some unrelieved discomfort in relation to the symptom experiences. Expecting complete symptom relief was not realistic to them.

•That children with cancer developed not only a greater understanding of their sense of self, but also became more sensitive to their changing bodies.

•That the experience of cancer cannot be seen as one sole narrative to be lived and relived by children and their families in its telling, but instead involves children and their families living and reliving many different stories throughout the cancer-symptom trajectory. As emphasized by many of the children and their families, cancer once only one part or one story in their lives, and that it is a never-ending story or journey.

•That the cancer-symptom experience is best described as a "bittersweet" experience with many layers of sadness, bad times, and suffering, as well as many layers of joy and good times.

Recommendations

This study has demonstrated many implications for the direction of how future research, education, and practice in relation to children's cancer-symptoms experiences should be pursued. Some of the more significant implications in the form of recommendations are discussed in this section.

(1) **Recommendations for Research**

•This study supports the need for further investigation in many areas related to the cancer-symptom trajectory. In order to enhance theory development and confirm or refute the main concepts of both substantive theories, research that examines the childhood cancer-symptom trajectory needs to be undertaken in a larger sample of children with cancer. As well, research that focuses on a particular type of cancer or age range of children needs to be conducted in order to see if the two theories' main categories are supported regardless of the children's varied characteristics. Further study will lead to refinement of the two substantive theories. In fact concepts related to the process of passage through the transition periods may emerge that lead to the development of a third substantive theory.

•Applying the study's two substantive theories to the study of children experiencing illness conditions other than cancer should be undertaken. Such research would facilitate an understanding of how children with different diagnoses and symptoms experiences get through their illness.

•Researchers need to undertake longitudinal, prospective research studies that will further aid in the investigation of the direction of causality of children's cancer-symptom experiences as well as help to elucidate developmental changes. Longitudinal research that involves healthy children would be of value to understand how healthy children and their families respond overtime to common childhood illnesses and related symptom experiences.

•Research attention needs to be directed at studying in a more detailed manner how the "keeping the spirit alive" strategies change and vary throughout the transition periods and

how they are affected by the meanings that children and families assign to the differing cancer-symptom experiences.

•Studying how nurses and other health professionals can help children with cancer and their families transition through the cancer-symptom experiences is needed. This includes exploring health professionals' perceptions related to keeping the spirit alive in children with cancer and their families.

•Examining whether "keeping the spirit alive" is a process that children undertake to get through other life experiences that are described as hard, traumatic, and challenging is warranted. While "mobilizing the spirit" is recognized as a common, if not universal, phenomenon in adults experiencing traumatic experiences, further examination is needed before one can make this claim with children. Such research may result in the development of a formal theory specific to the process of keeping the spirit alive in children.

•There is the need to develop an instrument that measures children's symptom experiences according to the meanings that they assign to their symptoms. A "meaning-centred" measure which includes self-assessment of symptom prevalence, frequency, severity, and distress would help to provide for a more comprehensive and accurate understanding of what children with cancer are thinking and feeling in relation to their symptom experiences. Development of the instrument would first involve confirmation of the eight personal meanings in relation to the symptom states that emerged from this study.

•The potential for tool development with respect to the various transition periods is

evident and includes development of tools that assess how children's symptom experiences, parent care giving behaviors, and children's and their families' sense of self change throughout the transition periods.

•Following development and confirmation of reliability and validity in the meaning-centred symptom and transition periods scales, research examining quality of life in children with cancer and their families could be undertaken.

•Studying transition periods in combination with the phases of treatment regimen and cancer course is warranted in order to determine the degree to which the periods and phases covary or relate to each other. Findings from this examination will most likely add to a more comprehensive understanding and detailed account of how children and their families proceed through the cancer-symptom course.

•Recognizing the majority of children and their families were Caucasian, research attention needs to be directed at how children from other ethnic and culture groups experience childhood cancer symptoms. To date, there is minimal understanding with respect to the role culture plays in children's cancer-symptoms experiences and childhood cancer in general. Symptoms have been conceptualized as an expression of the person's reality that not only represent the meanings the illness has for the involved person, but reflect both personal and cultural experiences (Tishelman et al., 1991). This further supports the need to involve children from varied cultural backgrounds in the study of cancer symptoms (Woodgate & McClement, 1998).

•Further study of what the concept "spirit" means to children with and without cancer needs undertaking. From a symbolic interactional point of view, the concept "spirit"

could be further elaborated in terms of its definition and workings. A concept analysis of the "spirit" and the "self" would help to elucidate the different attributes of both concepts and provide direction for research.

•Considering children and their families got most of their strength from each other, that is from within the nuclear family unit, the issue of social support needs further examination. Questions such as "how should available resources and funds that are meant to promote support in children and their families be distributed or allocated?" or "Should resources go directly to families instead of agencies or personnel that serve to help children and their families get through the cancer-symptom trajectory?" need to be re-examined.

•Keeping the family unit together was a major concern of children and their families. Accordingly, intervention studies that facilitate maintaining the family unit need to be undertaken.

•Further study of the experience of sadness in the lives of children with cancer and their families is warranted considering sadness was a prominent emotion in their lives.

•Research directed at examining how cancer affects the sense of self in siblings throughout the cancer-symptom trajectory needs more detailed examination considering that in addition to experiencing feelings of sadness, siblings experience cancer more as outsiders compared to other family members.

•Intervention studies that facilitate children and their families in "keeping the spirit alive" need to be planned. This would involve interventions that facilitate the use of "keeping the spirit alive" strategies and the identification of ways in which nurses and other professionals can protect the presence of the human spirit in the health care system.

•Intervention studies that facilitate the involvement of siblings in the care of the children with cancer are warranted considering most siblings wanted to be involved in the care of their ill siblings, but were not always afforded the opportunity.

•Intervention studies that aim to strengthen parents' confidence and ability to care for their healthy children and ill children with cancer are needed.

•Intervention studies that facilitate the involvement of fathers in the care of their children or help fathers feel that they are contributing to helping their children get through the cancer-symptom experience are warranted.

•Intervention studies that focus on reducing minimal symptom distress are indicated. Research is now being undertaken in this area, however, more attention needs to be given to the children's "everyday" symptom experiences. Although children in this study demonstrated their ability to carry on despite "everyday" symptoms, perhaps their quality of life may further be enhanced by controlling the "everyday" symptoms. Accessing health professionals' experiences with "everyday" symptom experiences and symptom management strategies that only partially relieve the children's cancer-symptoms would contribute to developing a treatment plan that focuses on all types of symptoms.

•More research attention needs to be directed at how non-pharmacological interventions can relieve symptom distress in children, especially unique and strategies initiated by the children. Children in this study talked about their self-initiated strategies yet these strategies were not always recognized by their care givers, nor were children fostered in making the most of these strategies (e.g., used in combination with pharmacological strategies).

•There is a need to develop research-based child developmental and family life cycle theories specific to children who have experienced life-threatening illness considering this study revealed that the children's and families' sense of self was greatly affected by cancer and cancer-symptoms.

•Further development of illness narratives that depict children's and their families' experiences with cancer and other life-threatening illnesses should be encouraged because such narratives provide a personalized, sensitive approach to contextualizing the illness experience.

(2) Recommendations for Education

•Findings from this study in and of themselves need to be disseminated to the community of oncology nursing and other professional groups who care for children with cancer and their families. Journal articles, conferences, and scientific meetings will aid in presenting the findings to those directly involved in the care of children with cancer.

•In addition to the general knowledge of symptom experiences that can occur in children due to cancer and its treatment, health care providers need to be educated about how symptoms can vary in each child, as determined by the children's personal meanings and the specific transition period that the children are experiencing. A firm and sound knowledge base of children's symptom experiences is necessary if professionals hope to provide quality care.

•Health professionals as well as families need to be made aware of the effect that the cancer-symptom experiences have on the children's and families' sense of self. This awareness in turn may help professionals and families respond to children and all family

members in a more sensitive and appropriate manner.

•Children and their families need to be taught and encouraged by health care providers that "it sort of helps" responses to symptom distress is not acceptable. Striving for "it really helps" should be the focus. Health care providers must be aware that more should be done when symptom relief is not achieved.

(3) Recommendations for Practice

•Considering the variability of symptom experiences in children, health care providers need to be consistent and thorough in assessing children's symptoms throughout the cancer-symptom trajectory.

•Health care professionals need to value children's self-reports related to their symptom experiences and be consistent in obtaining children's self-reports throughout all the transition periods of the cancer-symptom trajectory.

•Nurses and other health care providers need to encourage and teach children and their families that taking medication for the purpose of symptom relief from "everyday" symptoms is appropriate and may help to improve their quality of their day-to-day living.

•Nurses and health professionals need to support parental participation in relieving children's symptom distress. This includes reinforcing to parents that "being there" even if it just involves sitting beside their child is an intervention that is highly valued by children when they are experiencing a lot of distress.

•As was evident in this study, children did develop their own unique self-initiated strategies to reduce symptom experiences. Accordingly, nurses and other health professionals need to be aware of and support the use such strategies. Acknowledging and

respecting children's choice of self-initiated intervention strategies will help to empower children with a sense of having some control over their symptom experiences.

•More attention needs to be given to healthy siblings considering they experience a profound sense of sadness that often is not recognized by their parents or professionals. In order to help siblings deal with getting through the cancer-symptom experiences, support programs that promote siblings feeling more like insiders and less like outsiders, need to be formalized and established. Such programs would include teaching siblings how they can help to comfort their ill siblings who are experiencing symptom distress.

Conclusion

Findings from this study lend support to existing knowledge about children's cancer-symptom experiences, and how children and their families experience the cancer-symptom trajectory. At the same time, new discoveries unfolded during the course of this study. A strength of this study was that it added to the body of knowledge available about how children with cancer and their families perceive the children's cancer-symptom experiences; an understanding of the pediatric cancer-symptom experience within the context of the family unit evolved. Accordingly, results from this study provide nurses and other professionals with a new perspective about children's cancer-symptom experiences and further direction as to how they can best care for children and the families. Future research is necessary to verify and expand on the study's findings.

To conclude, findings from this study provide the foundation for development of research and education programs specific to children's cancer-symptom experiences that will aid nurses and other professionals in the care of children with cancer. Keeping this in

mind, all future investigations and interventions should be focused on the long-term goal of enhancing the quality of life in children with cancer and their families.

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APPENDICES

APPENDIX A

VERBAL REQUEST FOR PERMISSION TO RELEASE NAMES*

Roberta Woodgate is a nurse and doctoral student at the University of Manitoba. She is doing a study to learn about children's cancer-symptom illness experiences.

Roberta would like to invite you and your child to participate in her study. Information shared with Roberta is strictly confidential. Whether or not you decide to participate will in no way affect the care your child receives.

Would it be alright with you if I gave her your name so she can talk to you and explain the study? By agreeing to release your name, you would not be agreeing to be in the study but to just hear more about the study.

(If agreeable, the parent's name is given to the researcher and the nurse thanks the individual. If the parent declines, the nurse thanks the individual for his or her time.)

***To be used by the Pediatric Oncology Nurse Clinician of Children's Hospital.**

APPENDIX B: INTERVIEW SCHEDULES

OPEN-ENDED INTERVIEW GUIDE FOR PARENTS

General Grand Tour Question: Please tell me a little bit about the course of your child's illness thus far? How would you describe a "normal" week?

Additional questions:

1. What was your life like prior to the diagnosis?
   What was your reaction to the diagnosis?
   Can you tell me what it has been like since your child was diagnosed with cancer?

2. Describe to me what you recall thinking at the time of the initial diagnosis (or first treatment or near the end of your child's treatment or relapse)?

3. What types of symptoms has your child had or does have? Please describe them (e.g., cause, severity, factors influencing symptoms)?

   What do you think caused your child's_____(name symptoms)?

4. How can you tell your child is in_____or feels _____(name symptoms)? (e.g., types of verbal and non-verbal behaviour)

5. What words does your child use for _____(name symptoms)?
   What words do you use to describe your child's _____(name symptoms)?

6. How does your child act when he/she is in _____or feels _____(name symptoms)?

   How does it make you feel when your child is in _____ (name symptoms)?
   What does it mean to you when your child is in _____ (name symptoms)?

7. When your child is _____(name symptoms), what does your child do for him/herself that seems to help?

8. When your child feels or is in _____(name symptoms), what do you do to help relieve the _____(name symptoms)?

9. How can you tell when those strategies are working?

10. What do health professionals to do for your child when he/she is experiencing is _____(name symptoms)?

What would you like the health professionals to do for your child?

Do they do anything for you?
Would you like them to do anything for you?

11. What is it like having a child with cancer?
How does it make you feel?
What does it mean to you?
What is the worse thing about your child having cancer?
Has anything happened that is good because of the cancer?
What things are different about your life now than before your child had cancer? (Talk about the good and bad things that have happened.)
What is different about yourself? Do you see yourself differently?
Have your relationships changed with your partner; children; or friends?
What is the most significant change in your life that has taken place because of your child's cancer?
What do you expect for the future?

12. What experience(s) has occurred over the last two weeks that you consider significant? (Tell me about the experience in detail including where it took place, who was involved, and what was said or done.)

13. Is there anything you do to help deal with your child's cancer?

Is there anything others do that help you deal with your child's cancer? Was there anything that was not helpful?

14. What is it like having a child with _____ (name symptoms)?
How does it make you feel?
What does it mean to you?
What things are different about your life now since child felt or experienced _____ (name symptoms)?
What is different about yourself? Do you see yourself differently?
Have your relationships changed with your partner; children; or friends?
What is the worse thing about your child having _____ (name symptoms)?
Has anything happened that is good because of the _____ (name symptoms)?
What is the most significant change in your life that has taken place because of your child's _____ (name symptoms)?

15. Is there anything others do that help you deal with your child's symptoms?

    Is there anything others do that help you deal with your child's symptoms? Was there anything that was not helpful?

16. What advice would you give to other parents whose children have been recently diagnosed with cancer ?

17. What advice would you give to other parents whose children with cancer are experiencing _____ (name symptoms)?

18. Is there anything else you can tell me about your child's experiences with cancer and his/her cancer symptoms that is important for me to know?

APPENDIX C: OPEN-ENDED INTERVIEW GUIDE FOR SIBLINGS

General Grand Tour Question: Can you tell me what it has been like since your brother or sister got cancer?

Additional questions:

1. Tell me what you thought about or felt when you were first told that your brother/sister had cancer? (or When your brother had his/her first treatment or ....near the end of his/her treatment or ....cancer came back?)

2. What is it like having a sister/brother with cancer?

3. When your brother or sister gets sick, how does that make you feel?

   What do you think about?

4. When your brother or sister is _____or in _____(name symptoms) how does it make you feel?

   (Terms that the child is familiar with and that are appropriate to the child's level of understanding will be used to denote the symptom(s) in question.)

5. What is the worst thing about your brother or sister feeling _____ or in _____ (name symptoms - use the word that is familiar to the child)?

6. How can you tell your brother/sister is _____or in _____ (name symptoms)?

   What do you think caused your brother's/sister's_____(name symptoms)?

7. What words does your brother/sister use for _____(name symptoms)?

   What words do you use that describe your brother's/sister's _____(name symptoms)?

8. How does your brother/sister act when he/she is in or feels _____(name symptoms)?

9. When your brother/sister feels _____(name symptoms), what do you do?
   How does it make you feel?
   What do you think about?
   Do you do anything to help him/her?

10. What does your mother/father do when your brother/sister feels _____(name symptoms)? How does it make you feel?

11. What do the hospital staff (e.g., nurses or doctors) to do for your brother/sister when he/she is in _____ or feels _____ (name symptoms)?

What would you like the hospital staff (e.g., nurses or doctors) to do for your brother/sister when he/she is in _____ or feels _____ (name symptoms)?

Do they do anything for you?
Would you like them to do anything for you?

12. How are things different since your brother/sister got cancer? (Talk about the good and bad things that have happened.)
How does it make you feel?
What does it mean to you?
What is the worse thing about your brother/sister having cancer?
Has anything happened that is good because of the cancer?
What things are different about your life since your brother/sister got cancer?
What is different about yourself? How have you changed?
Have things changed between you and your mother/father; your sister/brother; or friends/at school?
What is the biggest change in your life that has happened because of your brother's/sister's cancer?

13. What has happened over the last two weeks that you consider most important? (Tell me about it including where it took place, who was involved, and what was said or done.)

14. Is there anything you do that makes you feel better?

Is there anything others do that help you feel better about your brother's/sister's cancer? Is there anything that was not helpful?

15. How are things different when your brother or sister is in _____ (name symptoms)?
What is it like having a brother/sister with _____ (name symptoms)?
How does it make you feel?
What does it mean to you?
What things are different about your life since brother's/sister's became sick with _____ (name symptoms)?
What is the worse thing about your brother/sister having _____ (name symptoms)?

Has anything happened that is good because of your brother's/ sister's _____ (name symptoms)?
What is different about yourself? Have you changed?
Have things changed between you and your mother/father; your sister/brother; or friends/at school?
What is the biggest change in your life that has happened because of your brother's/sister's_____ (name symptoms)?

16. Is there anything others do that help you feel better when your brother or sister is in or feels_____(name symptoms)?

    Is there anything others do that help you feel better? Is/was there anything that was not helpful?

17. What would you tell other children whose brother/sister have been recently diagnosed with cancer?

18. What would you tell other children whose brother/sister is in _____ or feels ____ _____(name symptoms)?

19. If you could have three wishes what would you wish for?

20. Is there anything else you would like to tell me that is important for me to know?

APPENDIX D: OPEN-ENDED INTERVIEW GUIDE FOR CHILDREN WITH CANCER

General Grand Tour Question: What is it like to go the hospital and/or clinic?
(Note: From past experience, this question has demonstrated to be a proper starting point when interviewing ill children. It is a good way to get children to open up.)

1. What is the best thing about the hospital/clinic?

2. What is the worst thing about the hospital?

3. Can you tell me what it is like to have cancer?
   What has it been like since you got cancer?

4. Tell me what you thought about or felt when you were first told that you had cancer? (or When you had your first treatment or ....your treatment was almost over or ....your cancer came back?)

5. Some kids who have cancer tell me they sometimes have pain, or feel sick in their stomachs or feel tired. Have you had any of these feelings? Have you had any others?

   (Terms that the child is familiar with and that are appropriate to the child's level of understanding will be used to denote the symptom(s) in question.)

6. What is it like to have/ or be in _____(name symptoms)?
   What does it feel like / and what do you think about?
   What do you think caused your _____(name symptoms)?

7. What words can you tell me how your _____(name symptoms) feels to you?

8. What makes your _____(name symptoms) bad or better?

9. What do others do when you have _____(name symptoms)?
   (others include your brothers/sisters; friends; teachers; parents; nurses/doctors)

   How do you think they feel?
   What would you like them to do?

10. Is there anything others do to help your _____(name symptoms) go away? What things are not helpful?

11. Are there days when your _____(name symptoms) is worse than other days? Can you tell me about those days or times?

12. How different is your day when you have or feel _____(name symptoms)?

13. How do you feel today?
(Also rate symptoms on VAS)

14. How are things different since you got cancer? (Talk about the good and bad things that have happened.)
How does it make you feel?
What does it mean to you?
What things are different about your life now since you got cancer?
What is different about yourself? Do you think you have changed?
Have things changed between you and your mother/father; your sister/brother; or friends/at school?
What is the biggest change in your life that has happened since you got cancer?

15. What has happened over the last two weeks that you consider most important? (Tell me about it including where it took place, who was involved, and what was said or done.)

16. How are things different when you feel or are in _____ (name symptoms)?
How does it make you feel?
What does it mean to you?
What is different about yourself? Do you think you have changed?
Have things changed between you and your mother/father; your sister/brother; or friends/at school?
What is the biggest change in your life that has happened because of your _____ (name symptoms)?

17. What would you tell other children who have cancer?

18. What would you tell other children who are in _____ or feel _____ (name symptoms)?

19. If you could have three wishes what you they be?

20. Is there anything else that you like to tell me about your cancer and your _____ (name symptoms) that is important for me to know?

APPENDIX E: TABLE 1. STRATEGIES FOR CHILD INTERVIEWS

Developmental Stage & Considerations	Developing Rapport	Interview Strategies
Preschool children: •egocentric •magical thinking •negativism •separation anxiety •limited attention span •lives in the world of the "here and now" •social causal reasoning is evident by preschool years	•approach child gradually & let the child initiate interactions •flexible approach •introduction of the researcher by a significant other	•multiple, short interviews combined with the option to combine with play or art •make use of informal interviews •provide explicit instructions •offer reassurance •short sentences - action-oriented questions, e.g., "Do you cry?" •avoid "why, when, & how" questions & use "what," "where," & "who" questions •focus on events salient to them •focus on the "here & now" •use of concrete symbols, specific physical cues •focus on one variable at a time - complex events should be broken down into simple, more manageable units •avoid double negatives, exceptions in sentences, pronouns •yes or no questions need follow-up questions (e.g., tell me more) •quiet external environment •avoid long silences **Table 1. Continued➡**

TABLE 1. STRATEGIES FOR CHILD INTERVIEWS continued

Developmental Stage & Considerations	Developing Rapport	Interview Strategies
School-age children: •concrete thought •conforms to rules •peers become more significant •have more power to control the research setting in ways younger children do not •increase sophistication in their ability to reason about another's perspective •developing a fine attuned sense of self-presentation	•Avoid putting child in losing position •Allow child to participate in decisions relating to research methods/process •privacy issues become more important	•30 - 45 minutes length of interviews •questions still need to be concrete •multiple interviews •may use longer sentences, past & future tenses, more complex constructions, & implicit conversational rules •recognize even this age group may be unfamiliar with specific terms (e.g., illness) •can use "why, when, & how" questions •interviews combined with games, drawings, sentence completion
Adolescents: •increased abstract thought & deductive thinking •struggles to gain independence	•researcher needs to be aware of the adolescent's increased sensitivity about one's rights & powers - the adolescent may test the researcher •privacy issues •race & sex of the researcher may matter •may be subdued with sensitive issues	•may be interviewed for an hour or more •multiple in-depth interviews •be aware that age alone does not determine the individual's level of cognitive development - strategies employed for younger children may need to be employed

Deatrick & Faux, 1989; Fine & Glassner, 1979; Fine & Sandstrom, 1988; Hatch, 1988; Kotzer, 1990; Romeo, 1986; Ross & Ross, 1984; Stewart, Bussey, Goodman, & Saywitz, 1993; Stone & Lemanek, 1990; Tammivaara & Enright, 1986; Wood, McMahon, & Cranstoun 1980

APPENDIX F: VAS FOR CHILDREN WITH CANCER

No_____bad as it can be

(e.g., pain)

APPENDIX G: STRATEGIES FOR FOCUS GROUP INTERVIEWS

Strategies used that facilitated group interactions with adolescent children and siblings included:

(1) setting ground rules that included respecting each person's opinion, maintaining confidentiality, avoiding put-downs, and letting everyone have a chance to talk;

(2) reinforcing the confidentiality and the voluntary nature of the study;

(3) conducting the interview in a neutral, private area;

(4) using non-directive probes;

(5) beginning the interviews with "warm-up" questions preceding questions that were more sensitive in nature;

(6) watching for any signs of discomfort in participants;

(7) facilitating a balanced discussion; and

(8) ending the sessions with informants having the opportunity to ask questions or discuss any uneasy thoughts as is necessary (debriefing).

APPENDIX H
CHILD/FAMILY DEMOGRAPHIC FORM

I.D. No._____
Date_____

1. Child's age: _____
   Birth date: _____

2. Child's gender: male____ female____

3. School grade: ____

4. Child' cancer diagnosis: _____

5. Date of diagnosis: _____
   Child's age at diagnosis: _____

6. How often has your child been admitted to the hospital? (please give dates and reasons for admission) _____

_____

_____

7. Illness Phase: newly dx.____ midpoint of treatment (first dx.)____

   near treatment completion (first dx)____

   remission____ relapse____ palliative____

8. Type of treatment and dates: chemotherapy (name type/date) _____

_____

_____

radiotherapy (name type/date) _____

_____

_____

_____

surgery (name type/date) _____

_____

9.Other type of therapy (name type/dates) _____

_____

_____

10. Medications to control symptoms: _____

_____

_____

11. Measures (non-drug) to control symptoms: _____

_____

_____

12. Legal guardian(s): mother & father ____
mother____ father____
other_____

13. Marital Status: married_____ common law_____ widowed_____
never married_____ separated_____ divorced_____

14. Occupation of legal guardians: _____ _____
clerical _____ _____
retired _____ _____
labourer _____ _____
professional_____ _____
management_____ _____
homemaker_____ _____
other _____ _____

15. Ethnic background: European____ Aboriginal peoples____
British Isles___ Asian____
Canadian-French____ Canadian-English____
Other____

16. Family income: below $10,000/year ____
$11,000-$20,000/year___
$21,000-$30,000/year___
$31,000-$40,000/year___
$41,000-$50,000/year___
$51,000-$60,000/year___
$61,000-$70,000/year___
over $70,000/year ___

17. Siblings (age/gender): _____ _____
_____ _____
_____ _____
_____ _____
_____ _____

18. Residence: urban_____
rural_____

APPENDIX I: LETTERS OF WRITTEN PERMISSION

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N98/23

Proposal Title: Symptom Experiences in the Illness of Children With Cancer and Their Families

Name and Title of Researcher(s): Roberta Woodgate

Date of Review: May 4, 1998

APPROVED BY THE COMMITTEE: May 25, 1998

Comments: With changes as outlined in your letter of May 14, 1998

Date: June 1, 1998

Karen Chalmers

Karen I. Chalmers, PhD, RN Chairperson
Associate Professor
University of Manitoba Faculty of Nursing

Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

THE UNIVERSITY OF MANITOBA

FACULTY OF NURSING

Room 246 Bison Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-7452
Fax: (204) 275-5464

25 May 1998

Ms. Roberta Woodgate
St. Boniface General Hospital Research Center
Cancer Nursing Research Group
351 Tache Ave.
Winnipeg, Manitoba
R2H 2A6

Dear Ms. Woodgate:

Re Proposal #98/23: Symptom Experiences in the Illness Trajectory of Children with Cancer and Their Families

Thank you for your letter of May 14th. With the changes and clarifications outlined in the letter the proposal is approved. I would like to take this opportunity to wish you every success the completion of your research.

Sincerely,

Karen Chalmers

Karen Chalmers, RN, PhD
Chair, Ethical Review Committee

Health
Sciences
Centre
THE UNIVERSITY OF MANITOBA
Faculty of Medicine
Rheumatic Disease Unit

St-Boniface
General Hospital

HEALTH SCIENCES CENTRE

Department of Medicine
RR 149-800 Sherbrook Street
Winnipeg, MB, Canada
R3A 1M4

(204) 787-2208 (HSC Office)
(204) 787-1920 (Fax)
(204) 787-2392 (Appointments)

Dr H El-Gabalawy, Director
Dr FD Baragar
Dr IM Chalmers
Dr JMG Canvin

Department of Pediatrics
and Child Health
(204) 787-2020

Dr K Oen

ST. BONIFACE
GENERAL HOSPITAL

409 Tache Avenue
Winnipeg, MB, Canada
R2H 2A6
(204) 787-1968 (Office)
(204) 237-2290 (Appointments)

June 9, 1998

Roberta Lynn Woodgate, RN, MN, PhD
St. Boniface General Hospital Research Foundation
Cancer Nursing Research Group
351 Tache Avenue
WINNIPEG, MB
R2H 2A6

Dear Ms. Woodgate:

Re: RI98:066, "Symptom experiences in the illness trajectory of children with cancer, and their families."

Thank you for sending us a copy of the Faculty of Nursing Ethics Review Committee approval of the above noted study. Therefore the Pediatric Research Coordinating Committee has now finalize our approval of your proposal.

Yours truly,

Kiem G. Oen, MD, FRCPC
Chairperson
Pediatric Research Coordinating Committee

KGO:jc

c.c. File
Dr. L. Oppenheimer

THE MANITOBA CANCER TREATMENT AND RESEARCH FOUNDATION
LA FONDATION MANITOBAINE DE TRAITEMENT DU CANCER ET DE RECHERCHE EN CANCÉROLOGIE

☒ M.R. MacCHARLES UNIT
100 Olivia Street • Winnipeg, MB R3E 0V9

☐ ST. BONIFACE UNIT
409 Taché Ave. • Winnipeg, MB R2H 2A6

Records and Registry Access Committee

May 4, 1998

Ms. Roberta Lynn Woodgate, MN, PhD (Cand.)
St. Boniface General Hospital Research Centre
351 Tache Avenue
WINNIPEG, MB
R2H 2A6

Dear Ms. Woodgate:

Re: MCTRF Health Records Access for your study entitled, "Symptom Experiences in the Illness Trajectory of Children With Cancer in Their Families"

I have reviewed your request to access the Manitoba Cancer Treatment and Research Foundation health records in conjunction with the above study. I have consulted with the Director of Records, Ms. Heather Whittaker. I am pleased to advise you that, on behalf of the MCTRF Records and Registry Access Committee, we are prepared to grant you access to the health records in order to obtain demographic and illness information which you are unable to obtain through your interview with the patient or their parents, with the following condition:

> Appendix E (Parents Invitation to Participate and Description of this Study) and Appendix F (Parents' Informed Consent to Participate) be revised to explicitly state that you will also have access to the Manitoba Cancer Treatment and Research Foundation oncology health record. This would most logically go at the end of paragraph four of Appendix E and at the end of paragraph three of Appendix F.

MCTRF is a separate and independent legal entity from Children's Hospital and maintains a separate health record. It would be essential that the parent(s) be aware that they are not only consenting for you to access the child's hospital record, but also the MCTRF oncology health record.

When you require access to the MCTRF health record, would you please present the request to Ms. Heather Whittaker along with a copy of the signed parental consent. Ms. Whittaker can be reached at 787-4187.

The MCTRF Records and Registry Access Committee only approves chart or record access and does not review for the impact on clinic operations. Your proposal notes that you have received

verbal approval from Ms. Vivian Painter, Director of Nursing at MCTRF. Since this study may impact on clinic operations, it may be advisable to reconfirm with Ms. Painter, as you approach initiation of your study.

On behalf of the MCTRF Records and Registry Access Committee, I wish you the very best on this study.

Sincerely,

John M. Farber, MA, Chair
Records and Registry Access Committee
Voice: (204) 787-1325
Fax: (204) 783-6875
Email: john.farber@mctrf.mb.ca

JMF:vg
c: Ms. Heather Whittaker, Director, Records
Dr. Brent Schacter, President and CEO
Ms. Vivian Painter, Director, Nursing

APPENDIX J: PARENTS' OR LEGAL GUARDIANS' INVITATION TO PARTICIPATE AND DESCRIPTION OF THE STUDY

Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

I am planning to conduct a study entitled, "Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families." My study will explore the types of symptoms children with cancer experience and the impact cancer and cancer-symptoms have on children and their families. I would like to invite you and all your children to participate in my study.

Children (ages 5 years to 18 years) who have or had cancer and their parents or legal guardians and siblings are being invited to take part in my study. I am a doctoral student completing my PhD program at the University of Manitoba. My study is under the direction of Dr. Lesley Degner, Professor, Faculty of Nursing, University of Manitoba. As well, Drs. Rochelle Yanofsky, D. Albas, and W. Eaton from the University of Manitoba are also supervisors for my study.

This study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba and the Health Sciences Centre Pediatric Research Coordinating Committee. Drs. S. Israels, M. Schroeder, K. Stobart, and R. Yanofsky give their consent for me to conduct the study. Although these physicians are aware of the study, they have no input into who should participate in the study or how the study should be carried out. During the study, they will not have access to any information you share with me. Dr. Yanofsky will have access to information related to the study's findings because she is one of my supervisors. However, the information given to Dr. Yanofsky will have no details that could identify you or your family.

Your participation in the study means that you and your children would be interviewed each at least two times by me. Children and parents will be interviewed separately. Each interview is expected to take approximately 30 - 40 minutes, and will be tape recorded. All interviews will focus on questions relating to your child's cancer and symptom experiences. I will be asking your child to rate his or her symptoms on a rating scale. As well, I will be asking you to complete a demographic form which asks questions about you and your family such as your children's birth dates. It should take about five minutes to fill out the form. If there are specific questions you or your children do not want to answer, your request and your children's request will be respected. In addition to the interviews, I will with your permission, be spending time with you and your child during certain situations such as when your child attends the cancer clinic. During these times I will be noting how health professionals (e.g., nurses, doctors) interact with your child. I may ask them and you and your child questions during these periods. I also may make a few brief notes. At no time would my presence interfere with your child's nursing

and medical treatment. As well, medications for your child's symptoms would never be withheld during the study. Also, if any situation arises where you would prefer not to have me present, your request will be respected and I would withdraw from the situation. I will also have access to your child's hospital record and the Manitoba Cancer Treatment Research Foundation oncology health record for demographic information.

The decision to participate in this study is entirely your own. If you do not wish to participate, it will in no way influence the care your child receives. The physicians that care for your child will not know if you decide not to participate. Although it is not expected that there will be any immediate benefits to you and your children, I hope the information resulting from this study will help health professionals in the future, to provide better care for children with cancer.

All information obtained will be used for the purpose of my doctoral study. The results may be published in journal articles or a book. In all instances, you and your children's identity would not be discussed or revealed to anyone. Confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). Only I will have access to your name and your children's names. As well, I plan to replace your name and your children's names with a number so that no one will be able to identify that you and your children participated in the study. My supervisors will have access to the data obtained during the study, but your name and your children's names will not be identified on the data. While undertaking the study, all data will be stored in a locked cupboard and computer protected by a password known only to me. Once the study is completed, all data will be stored under lock and key in a filing cabinet at the Cancer Nursing Research Group Office at the St. Boniface Hospital Research Centre for a period of 7-10 years as recommended by the Medical Research Council. After the seven years, all data contained on computer discs and tape recorded material will be erased. Notes contained on paper material will be shredded.

I hope you will consider joining this project. If you decide to participate in the study, a summary of the results will be provided to you, if requested.

If you have any questions about the study, you may contact me at (----------), or Dr. L. Degner at (----------).

Thank you very much for your consideration.

Roberta Woodgate RN, PhD candidate

APPENDIX K: PARENTS' OR LEGAL GUARDIANS' INFORMED CONSENT TO PARTICIPATE

Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

I, , agree to participate and to allow my child to participate in a study entitled "Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families." The study will explore the types of symptoms children with cancer experience and the impact cancer and cancer-symptoms have on the children and their families. Children (ages 5 years to 18 years) who have or had cancer and their parents or legal guardians and siblings are being invited to take part in my study. The study is conducted by Roberta Woodgate, RN, a doctoral student enrolled in a PhD program at the University of Manitoba. The study is under the direction of Dr. Lesley Degner, Professor, Faculty of Nursing. As well, Drs. Rochelle Yanofsky, D. Albas, and W. Eaton from the University of Manitoba are also supervisors for the study.

I understand that this study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba and the Health Sciences Centre Pediatric Research Coordinating Committee. I understand that Drs. S. Israels, M. Schroeder, K. Stobart, and R. Yanofsky have given their consent for Roberta to conduct the study. Although the physicians are aware of the study, I understand that they have no input into who should participate in the study or how the study should be carried out. During the study, they will not have access to any information that I share with Roberta. I understand that Dr. Yanofsky will have access to information related to the study's findings because she is one of Roberta's supervisor. However, I understand that the information given to Dr. Yanofsky will have no details that could identify me or my family.

I understand that by agreeing to participate, this will allow the researcher, Roberta Woodgate, to interview me and my children at least two times. I understand that children and their parents will be interviewed separately. Each interview is expected to take approximately 30 - 40 minutes, and will be tape recorded. All interviews will focus on questions relating to my child's cancer and symptom experiences. I understand that Roberta will be asking my child to rate his or her symptoms on a rating scale. As well, I understand that I will be asked to complete a demographic form which should take about five minutes to complete. I understand that I and my children do not have to answer any questions that we do not want to answer. In addition to the interviews, I understand that

I understand that Roberta will be spending time with me and my child during certain situations such as when my child attends the cancer clinic. During these times, I understand that Roberta will be noting how health professionals (e.g., nurses, doctors) interact. I understand she also may be asking them, myself, and my child questions, and may make a few notes. I understand that if any situation arises where I would prefer not to have her present, I could ask her to leave. I understand that at no time would her presence interfere with my child's nursing and medical treatment. As well, I understand that medications for my child's symptoms would never be withheld during the study. Also, I understand that Roberta will also have access to my child's hospital record and the Manitoba Cancer Treatment Research Foundation oncology health record for demographic information.

I understand that participation in the study is completely voluntary, and that I or my children can withdraw from the study at any time. I understand that if I decide not to participate in the study, the health care of my child will not be affected.

I understand that all information obtained will be used for the purpose of Roberta's doctoral study and in the future, may be published in journal articles or in a book. I understand that in all instances, my identity and my children's identity will not be discussed or revealed to anyone. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). I understand that only Roberta will have access to my name and my children's names, and that she will replace my name and my children's names with a number so that no one will be able to identify that I and my children participated in the study. I also understand that Roberta's supervisors will have access to the data obtained during the study, but that my name and children's names will not be identified on the data. I understand that during the study all data will be stored in a locked cupboard and computer protected by a password known only to Roberta. Once the study is completed, all data will be stored under lock and key in a filing cabinet at the Cancer Nursing Research Group Office at the St. Boniface Hospital Research Centre for a period of 7-10 years as recommended by the Medical Research Council. After the seven years, I understand that all data contained on computer discs and tape recorded material will be erased. Notes contained on paper material will be shredded.

I understand that this study is not expected to have any direct benefits to my children or myself, but may help health professionals in the future, to provide better care for children with cancer. I understand that if I ask, a summary of the results will be provided to me.

If I have any questions or concerns about the study, I am free to contact Roberta or the Roberta's PhD supervisor, Dr. L. Degner, at the following numbers: Roberta Woodgate (-------); Dr. L. Degner (--------)

_____ _____

Signature of Researcher Parent's or Legal Guardian's Signature

Date_____

.....

I would like a summary report of the findings:

____ ____

YES NO

Please mail a summary of the report findings to:

Name:_____

Address:_____

Postal Code:_____

APPENDIX L: EXPLANATION OF THE STUDY FOR THE CHILDREN

Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

Explanation for younger children:

Hi, my name is Roberta and I am a student doing a project about cancer. I would like to learn from you what it is like to be a kid with cancer. This project may help other kids with cancer.

If you agree to help me with my project, I will be spending time with you to learn about your cancer. I will be asking you questions about having cancer such as "what it is like to come to the cancer clinic to get your treatment?" I will tape record your answers and you may listen to the tape recorder. I also would like to spend time with you when you go to the cancer clinic or if you go to the hospital. I may ask you some questions about the hospital and how you feel. You may also ask me any question. You do not have to answer any question that you do not want to. You may also ask me to leave any time that you do not want me around.

I will replace your name with a pretend name so that know one, except me, will know what you said or did. I will not let your doctors or nurses know what you tell me. If you become very sad or upset, I will talk to your parents and get you some help from someone in the clinic like a nurse.

You only have to be in my project if you really want to. If you say no, no one will get mad at you.

If you have any questions about the project, you may at any time, ask me or your parents.

Thank you

Explanation for older children and adolescents:

Hello, my name is Roberta Woodgate and I am a student from the University of Manitoba. I would like to invite you to take part in my research project. The goal of my project is to learn more about what it is like to be a child or teen with cancer and how cancer and cancer-symptoms affects children and teenagers and their families. My project has been judged to be safe and acceptable for you to take part in it, if you decide to do so.

If you agree to participate in my project, it means that you will be asked to take part in at least two interviews. I will be doing the interviewing. Each interview will be

tape recorded and will take about 30 - 40 minutes to complete. All interviews will focus on questions relating to your experience with cancer and cancer symptoms. If there are specific questions that you do not want to answer, you will not have to answer them. In addition to the interviews, I will be spending time with you during certain situations such as when you attend the cancer clinic. During these times, I may ask you questions (e.g., "What is the best thing about the clinic?") and I may make a few brief notes. If any situation arises where you would prefer not to have me present, you may ask me to leave. I will also have access to your hospital record in order to get information related to the type of care you are receiving. At no time would my presence interfere with your nursing and medical care. None of your medications for symptom control will be withheld during the study.

I will replace your name with a pretend name so that know one, except me, will know what you said or did during the course of the project. I will not let your doctors or nurses know what you tell me. However, if you become very sad or upset, I will talk to your parents and you would get some help with your parents' permission.

Taking part in my project is entirely up to you, and even if you first decide to participate, you can still quit at any time. If you refuse to take part in the project, this will not affect the health care that you receive.

My project poses no danger to you. However, you may become more aware of some of your feelings about having cancer. My project also offers no direct rewards to you. However, information discovered in my project may help nurses and doctors better care for other children and adolescents who have cancer. I hope to print the information in a health journal or book for other nurses and doctors to read. Again your name would not be printed in the journal or book. A summary of the results will be provided to you, if requested.

If you have any questions about the project at any time, you are free to contact Roberta or Roberta's teacher, Dr. L. Degner, at the following numbers:
Roberta Woodgate (--------); Dr. L. Degner (--------)

Thank you very much for considering to take part in my study.
Roberta Woodgate

APPENDIX M: ASSENT FORM FOR CHILDREN
Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

Assent form for younger children:

I,_____, state that I am _____years of age and wish to take part in a Roberta Woodgate's project. Roberta is a student wanting to learn from kids what it is like to have cancer. This project may help other kids with cancer.

Taking part in the project means that Roberta will come to talk to me about my cancer. She will ask me questions such as "what it is like to come to the cancer clinic to get medicine?" She will tape record my answers and I may listen to the tape recorder. Roberta also may spend time with me when I go to the cancer clinic or if I go to the hospital. She may ask me some questions about the hospital and how I feel. I have been told that I do not have to answer any questions that I do not want to. I may also ask Roberta to leave any time that I do not want her around.

I know my name will be replaced with a pretend name so that no one, except Roberta, will know what I said or did. Roberta will not even tell my doctors or nurses what she and I talk about. If I become very sad or upset, Roberta will talk to my parents and get me help from someone in the clinic like a nurse.

I know it is up to me if I want to take part in Roberta's project. If I say no, no one will be mad at me. If I have any questions about the study at any time, I may ask Roberta or my parents.

I_____ have read this page or had Roberta read to me and I agree to take part in the project.

_____
Signature:

_____
Researcher's Signature
Date_____

.....

I would like a copy of the project:

____ ____
YES NO

Please mail a summary of the project to:
Name:_____
Address:_____
Postal Code:_____

Assent form for older children and adolescents:

I,_____, state that I am _____years of age and wish to take part in a research project that is being carried out by Roberta Woodgate. Roberta is a student from the University of Manitoba. She wants to learn more about what it is like to be a child or teen with cancer and how cancer and cancer- symptoms affects children and teenagers and their families. Roberta's project has been judged to be safe and acceptable for children and teenagers to take part in it, if they decide to do so.

Taking part in Roberta's project means that I will be asked to participate in at least two interviews. Each interview will be tape recorded and will take about 30 - 40 minutes to complete. All interviews will focus on questions relating to my experience with cancer and cancer symptoms. If there are some questions that I do not want to answer, I understand that I do not have to answer them. In addition to the interviews, I understand that Roberta will be spending time with me during certain situations such as when I attend the cancer clinic. During these times, I understand she may be asking me questions and may make a few brief notes. I understand that if any situation arises where I would prefer not to have her present, I could ask her to leave. I understand that at no time would her presence interfere with my nursing and medical treatment. As well, I understand that medications for any symptoms that I may have, would never be refused during the project. Also, I understand that Roberta will have access to my hospital record.

I understand that my name will be replaced with a pretend name so that know one, except me and Roberta, will know what I said or did during the course of the project. Even my doctors or nurses will not know what I have shared with Roberta. However, I understand that if I become very sad or upset, Roberta will talk to my parents and I would get some help with my parents' permission.

I understand that taking part in the project is entirely up to me, and even if I first decide to participate, I understand that I can still quit the project at any time. If I refuse to take part in the project, I understand that this will not affect the health care that I receive.

I understand that the project is of no danger to me. However, I understand that I may become more aware of certain feelings about having cancer. I understand that the project also offers no direct rewards to me. However, I understand that the information discovered in this project may help nurses and doctors better care for other children and adolescents who have cancer. I understand that information from this project may be printed in a health journal or book for other nurses and doctors to read. Again I understand my name would not be printed in the journal or book. A summary of the project will be provided to me, if I ask for a copy.

I understand that if I have any questions about the project at any time, I am free to contact Roberta or Roberta's teacher, Dr. L. Degner, at the following numbers: Roberta Woodgate (-------); Dr. L. Degner (--------)

I_____ have read the information and agree to participate in the project.

_____
Signature:

_____
Researcher's Signature

_____
Date

.....

I would like a copy of the project:

____ ____
YES NO

Please mail a summary of the project to:

Name:_____

Address:_____

Postal Code:_____

APPENDIX N: EXPLANATION OF THE STUDY FOR SIBLINGS

Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

Explanation for younger children:

Hi, my name is Roberta and I am a student doing a project about cancer. I would like to learn from you what it is like to have a sister or brother who has cancer. This project may help other kids who have a brother or sister with cancer.

If you agree to help me with my project, I will be spending time with you and asking you questions about having a sister or brother with cancer such as "When your brother or sister gets sick, how does that make you feel?" I will tape record your answers and you may listen to the tape recorder. I also would like to spend time with you when you go to the cancer clinic with your brother or sister or if you go to visit your brother or sister in the hospital. I may ask you some questions and you may also ask me any question. You do not have to answer any question that you do not want to. You may also ask me to leave any time that you do not want me around.

I will replace your name with a pretend name so that know one, except me, will know what you said or did. If you become very sad or upset, I will talk to your parents and get you some help from someone in the clinic like a nurse.

You only have to be in my project if you really want to. If you say no, no one will get mad at you.

If you have any questions about the project, you may at any time, ask Roberta or your parents.

Thank you

Explanation for older children and adolescents:

Hello, my name is Roberta Woodgate and I am a student from the University of Manitoba. I am doing a research project to learn more about what it is like to have a brother or sister with cancer and how cancer affects you and your family. My project has been judged to be safe and acceptable for you to take part in it, if you decide to do so.

If you agree to take part in my project, it means that you will be asked to participate in at least two interviews. I will be doing the interviewing. Each interview will be tape recorded and will take about 30 - 40 minutes of your time to complete. All interviews will focus on questions relating to your experience with your brother's or

sister's cancer. If there are specific questions that you do not want to answer, you do not have to answer them. In addition to the interviews, I will be spending time with you during certain situations such as when you attend the cancer clinic with your brother or sister. During these times, I may ask you questions and I may make a few brief notes. If any situation arises where you would prefer not to have me present, you may ask me to leave. At no time would my presence interfere with your brother's or sister's nursing and medical care. No medications for your brother's or sister's symptom control will be withheld during the project.

I will replace your name with a pretend name so that know one, except me, will know what you said or did during the course of the project. I will not let your brother's or sister's doctors or nurses know what you tell me. If you become very sad or upset, I will talk to your parents and you would get some help with your parents' permission.

Taking part in my project is entirely up to you, and even if you first decide to participate, you can still quit at any time. If you refuse to take part in the project, this will not affect the health care that your brother or sister receives.

My project poses no danger to you. However, you may become more aware of some of your feelings about having a brother or sister with cancer. My project also offers no direct rewards to you. However, information discovered in my project may help nurses and doctors better care for other children who have cancer and their families. I hope to print the information in a health journal or book for other nurses and doctors to read. Again your name would not be printed in the journal or book. A summary of the results will be provided to you, if requested.

If you have any questions about my project at any time, you are free to contact me or my teacher, Dr. L. Degner, at the following numbers: Roberta Woodgate (-------); Dr. L. Degner (--------)

Thank you very much for considering to take part in my project.

Roberta Woodgate

APPENDIX O: ASSENT FORM FOR SIBLINGS
Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

Assent form for younger children:

I,_____, state that I am _____years of age and wish to take part in a Roberta Woodgate's project. Roberta is a student who wants to learn from kids what it is like to have a brother or sister with cancer. This project may help other kids who have a brother or sister with cancer.

Taking part in the project means that Roberta will come to talk to me about having a brother or sister with cancer. She will ask me questions such as "how do you feel when your brother or sister go to the cancer clinic to get medicine?" She will tape record my answers and I may listen to the tape recorder. Roberta also may spend time with me like when I go to the cancer clinic with my brother or sister or if I go to visit my brother or sister in the hospital. She may ask me some questions about the hospital and how I feel. I have been told that I do not have to answer any question that I do not want to. I may also ask Roberta to leave any time that I do not want her around.

I know my name will be replaced with a pretend name so that know one, except Roberta, will know what I said or did. If I become very sad or upset, Roberta will talk to my parents and get me help from someone in the clinic like a nurse.

I know that I only have to be in Roberta's project if I really want to. If I say no, no one will be mad at me.

If I have any questions about the project at any time, I may ask Roberta or my parents.

I_____ have read this page or had Roberta read to me and I agree to take part in the project.

_____

Signature:

_____

Researcher's Signature

_____ Date

.....

I would like a copy of the project:

____ ____

YES NO

Please mail a summary of the project to: Name:_____

Address:_____:Postal Code:_____

Assent form for older children and adolescents:

I,_____, state that I am _____years of age and wish to take part in a research project that is being carried out by Roberta Woodgate. Roberta is a student from the University of Manitoba. Roberta wants to learn more about what it is like to have a brother or sister with cancer. Roberta's project has been judged to be safe and acceptable for adolescents to take part in it, if they decide to do so.

I understand that I will be asked to participate in at least two interviews. Each interview is tape recorded and is expected to take approximately 30 - 40 minutes of my time. I understand that All interviews will focus on questions relating to my experience with my brother's or sister's cancer and cancer-symptoms. If there are specific questions that I do not want to answer, I understand that I do not have to answer them. In addition to the interviews, I understand that Roberta will be spending time with me during certain situations such as when I attend the cancer clinic with my brother or sister. During these times, I understand she may be asking me questions and may make a few brief notes. I understand that if any situation arises where I would prefer not to have her present, I could ask her to leave. I understand that at no time would her presence interfere with my brother's or sister's nursing and medical treatment. As well, I understand that brother's or sister's medicine for symptom control would never be withheld during the project.

I understand that my name will be replaced with a pretend name so that know one, except me and Roberta, will know what I said or did during the course of the project. I understand that my brother's or sister's doctors and nurses will not be told what I talk to Roberta about. If I become very sad or upset, I understand Roberta will talk to my parents and I would get some help with my parents' permission.

I understand that taking part in this project is entirely up to me, and even if I first decide to participate, I can still quit at any time. If I decide not to take part in the project, this will not affect the health care that my brother or sister receives.

I understand that this project poses no danger to me. However, I understand that I may become more aware of some of my feelings about having a brother or sister with cancer. I understand that the project also offers no direct rewards to me. However, I understand that the information discovered in Roberta's project may help nurses and doctors better care for other children who have cancer and their families. I understand Roberta plans to print the information from this project in a health journal or book for other nurses and doctors to read. Again, I understand that my name would not be printed in the journal or book. A copy of the project will be provided to me, if I ask.

I understand that if I have any questions about the project at any time, I am free to contact Roberta or Roberta's teacher, Dr. L. Degner, at the following numbers: Roberta Woodgate (-------); Dr. L. Degner (--------)

I_____ have read the information and agree to participate in the project.

_____
Signature:

_____
Researcher's Signature

_____
Date

.....

I would like a copy of the project:

____ ____
YES NO

Please mail a summary of the project to:

Name:_____

Address:_____

Postal Code:_____

APPENDIX P: DISCLAIMER FOR HEALTH PROFESSIONALS

Study: Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families

You are being asked to voluntarily participate in a study entitled,"Symptom Experiences in the Illness Trajectory of Children with Cancer and their Families." The study will explore the types of symptoms children with cancer experience and how children and their families respond to the symptoms. Health professionals who care for children with cancer and who work either in Manitoba Treatment Cancer Research and Treatment Foundation (MCTRF) or on CK5, Children's Hospital pediatric inpatient cancer unit, are being asked to participate. Children (ages 5 years to 18 years) who have or had cancer and their parents and siblings are also being invited to take part in my study. The study is conducted by Roberta Woodgate, RN, a doctoral student at the University of Manitoba, under the direction of Dr. Lesley Degner, Professor, Faculty of Nursing. As well, Drs. Rochelle Yanofsky, D. Albas, and W. Eaton from the University of Manitoba are also supervisors for her study. This study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba and the Ethical Review Committee of Children's Hospital. Isobel Boyle, Director of Patient's Services at Children's Hospital and Vivian Painter, Director of Nursing at MCTRF also give their consent.

To understand what children and their families are going through, Roberta will be going with them to MCTRF and to CK5. Your participation in the study would mean that during such times Roberta may ask you questions about their care. The questions would relate to the children's cancer and cancer-symptom experiences. All your responses to questions would be recorded in brief notes. Roberta will be asking you questions during times when it would not interfere with your work activities. Also, if any situation arises where you would prefer not to have her present, she will respect your request and withdraw from the situation. By responding to my questions during Roberta's visits to MCTRF and CK5, means you give consent to participate in the study.

The decision to participate is entirely your own. If you do not wish to participate, it will not affect your employment status with the cancer clinic or Children's Hospital. The information gathered will be descriptive in nature, with emphasis on the children's symptom experiences. It will not be used for the purposes of an evaluation of your work performance by your supervisors. During the study, your supervisors will not have access to any information that you share with Roberta. Although it is not expected that there will be any benefits to you, the study may produce some valuable information that in the future, will help health professionals understand and care for children with cancer. If requested, you may also get a copy of the study's findings once the study is completed.

All information collected will be for the purpose of Roberta's doctoral study. The results may be published in journal articles or a book. In all instances your identity would not be revealed to anyone; confidentiality will be maintained. Only Roberta will have access to your name, and she will replace your name with a number so that no one will be able to identify that you participated in the study. Roberta's supervisors will have access to the data obtained during the study, but your name will not be identified on the data. During the study all data will be stored in a locked cupboard and computer protected by a password known only to Roberta. Once the study is completed, all data will be stored under lock and key in a filing cabinet at the Cancer Nursing Research Group Office at the St. Boniface Hospital Research Centre for a period of 7-10 years as recommended by the Medical Research Council. After the seven years, all data contained on computer discs and tape recorded material will be erased. Notes contained on paper material will be shredded.

If you have any questions about the study at any time or would like a copy of the study's findings once the study is completed, you are free to contact Roberta or the Roberta's PhD supervisor, Dr. L. Degner, at the following numbers:
Roberta Woodgate (-------); Dr. L. Degner (--------).

Thank you very much for your consideration.
Roberta Woodgate

APPENDIX Q: Table 2. RISK ANALYSES BASED ON CHILDREN"S DEVELOPMENT

Developmental Period	Developmental Concerns	Special Risks	Recommendations
Preschool	•Magical thinking •Predictability •Limited understanding of cause & effect; egocentric thinking; distorted sense of time •Fears of mutilation •Self-awareness, socialization about adult & peer expectations	•May not differentiate reality from fantasy •Disruptions in routines •Feelings of shame; "hurts" seen as punishment for misbehavior •Frightened by changes in appearance •Self-blame, confusion about peer & adult roles and behavior	•Avoid adult-initiated frightening make-believe & unfamiliar sights & sounds •Respect child's schedule. •Repeatedly assure child that procedures are not due to child's "bad" behavior •Support the presence of a significant caregiver; allow parents to comfort child in distress •Use intact dolls, puppets •Avoid deception because child cannot easily reinterpret situation
School-age	•Industry •Newly emerging skills related to self-control & independence •Peer acceptance •Rule conformity	•Feelings of failure or incompetence •Fear of loss of control •Embarrassment, peer coercion, rejection, & group labeling •Vulnerable to coercion due to respect for authority •Deceptions & betrayals by people child trusted	•Avoid putting child in losing position, especially in public •Allow child to participate in decisions relating to research methods/process •Avoid public discredit of child - privately ask for child's participation, maintain confidentiality, conceal refusals or group membership •Minimize power position, avoid using authority figures to recruit subjects, approach child with parent present, reinforce right to decline to participate •Avoid deceptions **Table 2. continued ➔**

Table 2. RISK ANALYSES BASED ON CHILDREN'S DEVELOPMENT continued

Developmental Period	Developmental Concerns	Special Risks	Recommendations
Adolescence	•Identity •Self-esteem •Peer approval •Sexuality	•Alienation, limit-testing •Embarrassment & humiliation •Peer pressure •Confusion related to gender roles & sexuality	•Ensure protocols do not undermine adolescent's relationships with parents & significant others; institute procedures to verify adolescent's status pertaining to consent; clarify adolescent's evaluation of consequence •Protect confidentiality & prevent public embarrassment of failure •Avoid peer pressure to convince adolescents to participate •Respect boundaries of personal space & emotional distance

***adapted from Conrad & Horner (1997, p. 167), Morrow & Richards, (1996) & Wender (1994)**
It must be acknowledged that all the risks listed in this table could pertain to children of all ages, however, they are indicated under the period for which they are most salient.

APPENDIX R: ILLNESS NARRATIVES

The Illness Narratives of Two Families

(1) The Preschool Child's Story: Waiting for that Beautiful Child to Return!

Introduction to the Preschool Child and Her Family:

This story depicts the narrative of a preschooler, named Jamie, and her family that consisted of her father, Dan, and mother, Denise. When I had first met Jamie in July of 1998, she had just turned 5 years old. In December 1997 Jamie was diagnosed with acute lymphoblastic leukemia. Up until the diagnosis, life was viewed by the parents as something almost idyllic. At that point prior to cancer entering their lives, they would not have really changed anything in their lives. They lived in a moderate size home in a comfortable, child-friendly area of the city. Denise's mother who had heart problems also lived with them. The parents talked about how prior to the cancer diagnosis they would go for long walks in the neighborhood and that one of Jamie's favorite places was a community playground nearby their residence.

While they had experienced present and past stressors they nonetheless described their life as enriching and full of many good fortunes. They described their life as almost perfect at the time of diagnosis. The only traumatic event that stood out was the Jamie's premature birth. However, except for getting through the birth and the period surrounding the birth, Dan and Denise saw their child grow up healthy and happy through the years prior to the cancer diagnosis. Understandably, like all other families the news of the cancer diagnosis hit them really hard and it hit them hard because something had shattered their almost safe, secure, and happy world.

For Jamie, Denise, and Dan, their world was focused their on nurturing their family unit, and maintaining strong ties with their "*good friends and family.*" To Denise and Dan, raising Jamie meant everything to them. They approached life from a "family oriented model" as Dan put it, which included doing only what was "*best for their daughter, Jamie.*" It would be an understatement to suggest that Dan's and Denise's world would not have been complete without Jamie. They got a lot of pleasure and strength from her, just like she had gotten from them. They described her as their "*beautiful child,*" and from their accounts, Jamie had led a life up until the cancer diagnosis that was described also as beautiful. In addition to valuing each other in their family, they also valued and found great pleasure in their relationships with their friends and extended family members. It was not uncommon for them to invite friends and family over or have them drop-in at least once a week. Friends and family members were always welcomed. Jamie's two cousins would come over as well, or Jamie would spent a day or night at their house. Jamie also had made some friends in the nursery school that she attended. Denise and Dan, as well as their friends and family members always made sure all their children were enjoying life and had a chance to experience many of the good things of life. Indeed, Jamie's parents tried to provide as many opportunities as they could for her. There were Jamie's favorite toys in every room of the house. She also had her own special couch in the livingroom where she often sat to watch her favorite child-related video. Recently, they had gotten a pet dog named "Spot." The dog was treated as

part of the family. In addition to Jamie, Dan and Denise in the past had fostered older children who required help dealing with behavioral and family problems. Both Denise and Dan thought it was very important to help out others especially children who were not as fortunate. Their love of seeing children happy and healthy was important to them. It was as Denise and Dan noted, important "*to have some compassion for somebody else.*" Although Dan described Denise and himself as "family oriented," I thought a more accurate description of them would be child-family oriented..

When I first met Jamie and her family, Jamie was in kindergarten. Both Dan and Denise shared equal responsibility in raising their daughter. Additionally, Dan worked as a school guidance counselor. Denise had just sold her own business, and was looking into starting a new business. As is the case for many mothers of children with cancer, her career plans were put on hold with Jamie's diagnosis. With the diagnosis, Denise centred her life on Jamie's meeting illness and care needs. Dan, however, unlike most fathers, eventually took a leave from his job in order to be more involved in Jamie's care, and more importantly in her life. In addition to changes related to their careers, Dan and Denise experienced many other changes throughout the cancer-symptom trajectory. As Denise stressed upon hearing the diagnosis of her daughter's cancer, she knew "*that their life (the family's life) was changed forever!*" She did not even have to experience any of the changes to understand and accept that life was never going to quite the same. Yet Denise and Dan realized that their beautiful child and her beautiful life were now going to change.

I followed Jamie and her family from July 1998 to December 1999. At the time I had ended the researcher relationship with this family, Jamie was six years of age and was in grade one. For the first year, I had maintained a connection with Jamie and her family through visiting them at the cancer clinic. The clinic visits lasted anywhere from two to eight hours. The clinic visits for the most part occurred on a weekly basis. She was also hospitalized on and off during the period that I was following them. Her hospitalization's stays were mainly brief, for the purpose of receiving certain chemotherapy agents. She also required a couple of hospital stays for the monitoring and investigation of fever and infection. I also maintained contact with them by making four home visits. Although the family was formally interviewed numerous times, it was my time spent in clinic, observing and interacting with the family that I really got to know this family and their narrative. The last six months of contact with Jamie and her family was through phone calls and few brief visits in the clinic. At the time of closure with Jamie and her family, Jamie was still in remission and was nearing her final stages of treatment.

Overview of Jamie's and her Family's Narrative
Waiting for the Beautiful Child to Return!:

Jamie's narrative is about the struggle of a young child waiting for a chance to once again experience life as a "girl kid." It is a story of Jamie and her family having to wait and wanting to move on. Jamie was waiting to live life like she did prior to being diagnosed with cancer where there was more happiness and less pain. She was waiting to be in that kid's world once again and not in a world where their was a lot of pain and

hurt. Her family was waiting for Jamie to have a chance of being that beautiful kid again! As Denise commented "*we (Dan and Denise) always enjoyed her...we always enjoyed doing things...and to be able to give those moments to her...,*" they were once again waiting to give her more of those "kid" moments. The parents were waiting to regain being that family who used to go for long walks and would at night often sit outside watching Jamie play. The cancer diagnosis and the cancer-symptom trajectory had put a hold on Jamie and her family experiencing a life that could only be described as beautiful. Despite not being a stranger to sadness and suffering, their world prior to the cancer diagnosis was a safe and secure world with much joy and pleasure in it. Moreover, while the parents were waiting to regain that beautiful world, they realized it never be completely the same as evident by Denise's comment:

> *She was diagnosed in December so, and the summer before she was diagnosed we used to sit outside at night and Dan and I would have coffee and Jamie would play and it was just so relaxing. It was wonderful. It was never the same again. I never sat outside again.*

For the parents the cancer diagnosis brought to them a sense of uncertainty to their happy life that they had never experienced in the past. The variability of the symptom course and as ambiguity to what the symptoms meant only reinforced their feelings of uncertainty. As Denise noted, both her and Dan "*now realized how everything is so fragile...I mean I always knew, but yet...*" They now realized that life was no longer that safe, trustful and secure place for their child to grow up in, as it should be for children:

> *Life has been shattered. You learn never to trust any one or mom to the point, yourself. You lose trust in the world!*
> *I'll never feel safe, I'll never feel safe...your whole safety net is gone, it's gone... (Denise)*

Denise and Dan now experienced a world that had less joy and pleasure in it:

> *Um, that's gone, my sense of delight in the world is gone to a certain extent... You know we just bought this home, we had such hopes and dreams here and I mean I stopped doing any renovations here, I just lost interest. (Denise)*

Jamie also now experienced a world where things were no longer as safe or secure. Dan and Denise talked about their beautiful child being more reluctant to play in their backyard and was described by her parents as being afraid at times to go outside since the diagnosis.

Jamie's parents also were angry and upset that their beautiful child was diagnosed with cancer. Like many parents they felt betrayed. While they felt they were luckier than most families with cancer, they nonetheless felt that the diagnosis was so unfair. They viewed it to be unfair due to all the losses Jamie had to experience that made her a

beautiful child. Any direct loss that Jamie felt, they too experienced. The greatest loss was losing their beautiful child. Jamie also was angry relation to not being her beautiful self or living in a world that was supposed to be safe and secure for children. Denise recalled to me a story of Jamie that took place in a fast food restaurant. Denise was there with Jamie and some friends of Denise and Jamie. At one point Denise was observing Jamie and her friend and witnessed Jamie getting really angry and upset when her friend made a comment about her short hair. Denise recalled that Jamie looked extremely upset and started screaming:

> *How would you like to have to be sick, be in the hospital and have to take all these medicines, how would like that to happen to you, how would you like it to lose your hair...*

Denise expressed that she had:

> *Never seen her so mad, or seen her react like that. She felt attacked because her hair is a big part of her.*

Yet despite their pain and anger, this family overall persevered and continued on. But like they said, they had no choice as if they did not, they would lose their beautiful child forever. The parents continued on for their own sanity, but more importantly for maintaining their child's and family's sense of self.

They focused on getting through life and maintaining their spirits by doing *"whatever was the best thing for Jamie."* Trying to provide Jamie a life that was as "*normal*" as possible, was what the parents worked on. Although Jamie would protest every time when she had to return to the cancer clinic, she nonetheless after protesting would give in and return to clinic with her parents. Just like the parents had no choice, Jamie knew she had no choice if she wanted to get better. She was aware that although the medicine made her feel sick, she needed to get better. In response to my question what she would say to other children with cancer "to convince them to go the hospital?" she expressed: *"So you can feel better!"*

The waiting also helped the family to focus more in on what they always felt was important: being a family that focused on raising a happy child. Although raising a happy, beautiful child was important to Jamie's family before the cancer-symptom trajectory, it became even more important after the cancer was diagnosed. There was more of an urgency to it now as her parents noted. Moreover, with each setback to securing a happy childhood for Jamie, they only became adamant in providing everything that was congruent to a happy childhood. They fought hard in keeping the spirit alive. The good times were even more cherished and appreciated. The parents and Jamie experienced greater joy now in the routine things of life. Although Dan and Denise expressed that they now experienced in life much fragility and loss, I also found them to be strong because they were able to hold things together. While the cancer brought them all a lot of pain and hurt, it also made them stronger as a family experiencing even more love for one another.

Doing so, however, was difficult and depended on them maintaining some childhood and family life that was away from the cancer:

> *Cancer can either make your family stronger or tear you apart. Those who become stronger do not let the cancer totally consume them, they keep it separate. It is so important you...(Denise)*

At the time I ended my interactions with this family, Jamie was receiving maintenance treatment once a month. For Jamie and her family, the routines of life were in fact returning and did have meaning, although the meanings were different now. Denise expressed that *"they had to redefine what normal was!"* They were as the Denise noted "*learning to live life again!*" Dan was slowly returning to work full-time and Denise was contemplating when it would be a good time, or more to the point a right time for her to return to work. Although they were making plans now, it was nonetheless hard for them as expressed by Dan:

> *Exactly, exactly where we are right now...there is pressure, pressure on you when you work full time and this weighs heavily on your mind...you can't throw yourself into 100% into anything. You know it is hard.*

Although Jamie was in remission, her parents never completely regained their sense of peace or security of raising a child that they experienced prior to the cancer diagnosis. Like all the parents in this study, they would always feel that the cancer was never completely gone and that it could show up anytime. Not only could it return as cancer itself, but it could return to haunt them in the form of long-term cancer treatment effects that had an affect on Jamie to be that happy child or "kid.". Both parents wondered how the cancer treatment would affect Jamie over her life as a child. While they had hoped there were no long-term effects, they never felt completely confident:

> *I (Dan) think there definitely are some long-term effects of the steroids on Jamie. We are pretty sure, but can never say for sure. But um, hopefully it will not be permanent.*

For Jamie, she was now entering grade one and was experiencing life as a "girl kid" again. She was experiencing more childhood experiences like her peers, but still experienced hurt that was a direct result of the cancer-symptom experience. Denise has noted that Jamie was in fact thinking and talking more about her cancer experience and was sharing with her some of the past and present painful moments she experienced because of the cancer-symptom trajectory. And while she was able to join her peers at school and learn and play with them, she still had to be more careful at play and also required a teacher's assistant during class time. She also would only go to school half days instead of full days. The parents now had a chance of seeing their child experience childhood again, yet their excitement of seeing her happy was balanced with threatening

feelings:

> *It was an exciting time to go back (to school) because she (Jamie) never had them (peers) and she really made connections, a lot of people were incredible, you know parents and the kids, everybody was wonderful, and she, you know, she loves it. But next year it will be challenging as she has to go a whole day, and we don't know how much she'll be able to do.*

So while she regaining her beautiful life back, it was not completely the same as her peers. Although Jamie and her family were moving on, they were still waiting to some extent. However, upon leaving them, I knew whatever the final outcome would be, the parents would still strive to provide those special moments for Jamie that would allow Jamie the opportunity to be a "kid" again. They were all now beginning as a family to go into their backyard:

> *We just waited till she got back into school, and between last summer when I (Dan) was able to start taking her outside and we flew the kite and she just ran around with it...so she could enjoy* (continued below)

But just as life was becoming more like a dream, a part of the nightmare was still with them:

> *...but she wasn't able to and it was because of her development again.*

The Core Narrative: Main Themes:

A Dream Turned into a Nightmare: Unlike many of the children, Jamie's pre-cancer diagnosis was brief lasting approximately a couple of weeks. Yet like the other children, it was initially assumed by her parents and physician that she was experiencing the flu:

> *Tons of energy...but then she was sleeping in the afternoon and you know we thought maybe she was getting the flu. Really for one day that she was at home we know she was really low and she looked really pale and she just, we thought she was coming down...we thought she was getting something. Yeah! We even had her to the doctors...the doctor checked her out and everything was fine.(Denise and Dan)*

The feeling that it was only the flu was supported by Jamie's sudden bursts of energy during the few weeks leading up to the diagnosis. She still had energy to play although she did stay away from school for a couple of days. It was not until Jamie had fainted that the parents knew that it was more than the flu as expressed by Denise:

> *She just collapsed, she was unconscious...I knew something was terribly wrong.*

Denise immediately called for ambulance to take Jamie to the hospital's pediatric emergency. At the emergency department, things happened or seemed to take place really fast as perceived by the parents. Both parents talked about getting "*a number of different diagnoses*" including different types of cancer all within a time frame of two hours. Having arrived at emergency before seven o'clock in the evening, Dan expressed that "*by nine o'clock at night they (the doctors as well as Denise and himself) were pretty sure it was some type of cancer.*"

But like other parents, Dan and Denise never expected at least up until the time that they arrived at the emergency department, that it was or would be cancer. Everything happened so fast as Denise described, that the cancer diagnosis was a complete shock:

> *You know it is a strange thing just, everything happened so fast, escalated so fast that it's not, you know it was a shock.*

Morever, both Dan and Denise concurred that as soon as they heard the diagnosis of acute lymphoblastic leukemia, their life changed instantly. In fact, life as they described it and continued to describe it, changed from a pleasant dream to a horrendous nightmare:

> *It was a nightmare. It was like within a few minutes the doctor knew right away. She was white, and her lips were white. Her blood count was so low, I think it was thirty-five...They told us right away. It was a nightmare!*
>
> *I mean we had such dreams, such...its not that anymore. After all this...means nothing. But I mean just as far as now, the future, you know...Well its just goes right to the core of your being. When you have such hopes, you know we bought this house. Its not the same ...and we had so many hopes and dreams and they're gone.*

The nightmare that they were referring to, was the potential that they could lose their beautiful child. Their child had looked like she was dying, lying listlessly on the stretcher, and the diagnosis only made it more real to them. Her pale appearance and lack of energy now represented a sign of death to Dan and Denise. From that very moment the urgency to save Jamie their beautiful child, was all that truly matter to Dan and Denise:

> *Anything else has, at best, diminished meaning...Routines of life are meaningless! (Dan)*

A Month Lost: As soon as Jamie was diagnosed, life truly changed for Jamie and her parents. In fact, for Denise the change was instantaneously:

> *It's a change. You look at the world different...the only way I can explain is the day she was diagnosed that day's a blur. Its like in a second! You open your eyes and you don't see the same, you don't see anything the way you did the day*

before.

Although they immediately experienced feelings of change, the parents nonetheless during the first couple of weeks to a month, experienced numbness. Like other parents, life was experienced as a blur. When asked, they really could not describe how they felt:

> *I was blank, yeah I knew that my life was changed forever. We had, we didn't know. I mean I didn't know how to feel. I didn't feel anything unusual...You know it is a strange thing it just, everything happened so fast, escalated so fast that it is not. You know it was a shock, I mean, I think ... (Denise)*

The parents continued to describe everything as happening really fast between the diagnosis and the commencement of treatment which further led them to feel in a state of confusion or more to the point in a deep trance-like state:

> *The next day she was transfused and uh (pause) and uh (pause) so I (pause) it was just uh (pause). It was like everything is rushing you don't even (pause) it is like an out of body experience. (Denise)*

The out of body experience was due to the shock and trauma in realizing that their child had cancer. They never once expected or suspected cancer even though to some extent they expected their child would acquire some type of health problem. Denise noted that Dan and her were "*always waiting for the bomb to drop*" because of the dramatic nature of Jamie's birth. However, even with such thoughts they nonetheless were still felt they were caught off guard:

> *It was all very surreal, I mean it was all very surreal...I feel too a big part of this whole thing which is why Dan and I felt this so traumatic is that Jamie had a very stressful birth. She was in intensive care for three weeks, we didn't bring her home, she had an emergency cesarian, she seizured constantly...she had two central lines, um she wasn't eating...we really took the first year like, you know not knowing if she'd seizure again, being careful...You don't have a child so dramatically and not think that anything scary or serious would ever be down the road. So I think this (cancer) was a double blow to us, because we'd been reassured everything's fine and nothing's wrong and she's thriving no problem, nothing. It's like you don't have a child so dramatically that you never let your guard down. (Denise)*

The seriousness of their daughter's birth only made their daughter's cancer diagnosis more unexpected. It was almost as if they felt that because they had already experienced the most stressful event any parent could experience in relation to their child,

they should not have to go through anything else that could be more scary or serious. They also talked about not being prepared for the diagnosis. Not expecting or being prepared for the cancer made it difficult for them to think straight or even respond to anything:

> *It was a shock. Yes, it was a shock...You know what, nothing went through my mind. I was blank...Nobody prepares you for this. Nobody, I mean we came home seven days from the hospital with the most earthshattering news of our lives. And we're home in seven days and you can't gauge how to react. I don't know whether, what's an emergency and what's not. I had lost my whole perspective. (Denise)*

The parents also described Jamie as experiencing the shock and trauma in relation to her life suddenly and dramatically changing:

> *And then I think too, we went through, we went through quite a, I mean it is psychologically traumatic for a child that has gone through from going to school everyday to all of a sudden a whirlwind of hospitals, procedures and how do you prepare a child for that? (Denise)*

Although Dan and Denise experienced life as a blur when they first made aware of the diagnosis, they experienced life as a blur to varying degrees throughout the cancer-symptom trajectory especially when they were uncertain of some of their daughter's symptom experiences. As Dan noted: *"There were always these episodes that you can't possibly anticipate that you dread."*

As well, Denise and Dan throughout the cancer-symptom experience had sometimes difficulty focusing on anything not specific to the cancer:

> *You know a lot of times the light goes on and you have to pay bills. I mean I couldn't even focus for awhile about paying bills, I didn't know what I was doing. I was a scatter brain, your mind is never the same. You don't remember, I forget. I'm not as organized as I used to be, I forget. I have no memory anymore, I have short term memory, I have to write everything down or I'll forget. My mind just isn't focused...(Denise)*

A Child Lost: Dan's and Denise's nightmare was of losing their beautiful child in relation to all the qualities that in their eyes made her unique and beautiful. Dan and Denise throughout their narrative would talk about all her unique qualities and how Jamie was so special to them:

> *It's always been good, she always spoke clear, never trouble. People were astounded. At nine months she was talking. She couldn't walk she could talk (Dan laughs with pride and joy). People couldn't believe how clear, she never mispronounced anything. (Denise)*

> *Denise: Every night (prior to the cancer diagnosis) we talked about what she did...*
> *Dan: We talked about what she was like as a baby like when she took her first steps...We have always been very Jamie-focused.*
> *Denise: And not like in a sick, obsessed, just in a very you know, fascinated way from the minute she was born. It has just been a complete fascination.*

From the moment of hearing the diagnosis Dan and Denise felt constantly threatened about their child losing all her unique qualities or even possibly dying, the ultimate loss:

> *Denise: You don't want it in your face all the time, yet it is always there. And it is like a thing you can't get rid of...*
> *Dan: And it threatens the most important thing in life, every moment, every moment.*

Dan and Denise always took great pride in their daughter and to see Jamie lose many of her beautiful qualities was devastating to them. To Dan and Denise the loss of all Jamie's unique characteristics was an attack on Jamie's spirit as evidenced by the following conversation that Dan and Denise shared with me:

> *Dan: When everything you see is horrible, a deterioration and all the symbols of her beauty are falling away, her looks, her hair, her spirit, her physical prowess it is hard to sit there and say "oh, did you see what she did today..."*
> *Denise: The spirit and the life, and the zest of her life (interrupted)*
> *Dan: Yeah!*
> *Denise: everything that she was all about, the personality is altered when you are tired, you don't eat ...*
> *Dan: She wasn't Jamie, she was a sick child! Oh, I am not saying that, but I am saying that it is harder (pause) you know, it is one thing to say that she scored a goal in soccer against the boy's team, then to say, "Oh she didn't throw up as often (interrupted)*
> *Denise: Her fever didn't go up*

Dan: the diarrhea stopped for 45 minutes today!"

The loss of their beautiful child became even more real to them with each new symptom and side effect that Jamie experienced in response to the cancer-symptom trajectory. The symptoms and side effects resulted in changes to how Jamie thought and responded to life. For Dan and Denise the changes were almost unbearable to watch, and indeed they had to watch and experience many changes. Most notable was the physical pain: *Her joints swelled. Her knee, just she couldn't, she was in so much pain, I'd give her Tylenol and uh...(Denise)*

> *And that is my hardest thing that I had, knowing that I am inflicting pain (in relation to medical and nursing staff not giving analgesics or sedatives for painful procedures). I, I couldn't live with myself. I mean it was almost barbaric to me (pause) and even a spinal, she's used to now, but she's hysterical. I mean it's not a pleasant experience...(Dan)*

Even more difficult to witness were the changes in Jamie's behavior that resulted because of the side effects of the treatment especially from the steroids. The parents had to see her respond in ways they never expected from such a beautiful child:

> *I mean the first time on steroids she was just* ***nuts*** *from the sleep, she had food cravings which were tearing her apart...and there she was stripping her room of the furniture. Things she's never done before. (Dan and Denise)*

The loss was also in relation to how the symptoms changed Jamie's life. She no longer had a control over her body or her way of life. Many aspects of her life that existed and made her happy prior to the cancer were now no longer part of her life:

> *She won't be playing in her kiddy pool out there. She won't be exposed to mosquito bites or we don't take her to the public pool. She won't be going to shopping centres and stuff like that. It will be very insular until her blood counts go back up. And that was really tough during the winter in the beginning, just terrible. Cause you couldn't even take her in your own yard for a walk. (Dan)*

Perhaps one of the hardest loss for Dan and Denise to deal with was the loss of Jamie's hair. The parents described Jamie as once having the most beautiful long curly blond hair and took time to show me pictures of Jamie when she had hair. Wherever they would go people would comment on her head. Just as Jamie's hair was a big part of her sense of self, so too was it for Dan and Denise:

> *She had the nicest hair (pause) of any human being ever...That was a big part of her identity, everywhere we went everybody stopped us, everywhere we went, as a baby...(Denise)*
> *That's (Jamie's hair) a very big part of (pause) you know my (pause) pride was*

that she was, her physical beautiful, is her physical beauty. (Dan)

From Denise's perspective she felt that loss of Jamie's hair caused Jamie to have a lot of pain and sadness into her once happy life:

> *But when we got to the point when there wasn't much there (hair) she became very self-conscious (pause). We went to "name of restaurant," she (pause) would hide in the bathroom.*

From Dan's perspective, he thought Jamie was more confused with her sense of self:

> *She was toying with the idea of "what's my identity...uh, does this mean I'm a boy? Should I experiment with more boy things for awhile?" (Pause) Wore boys' clothes for awhile. She identified only with boy animals but it wasn't in a sad or frightened way it was well this "is happening to me, let's see where this take me."*

From Jamie's perspective I think she viewed the hair loss as sadness and confusion. Her crying out "*how would you like to lose your hair*" to one of her friends, as well as her comment that she "*still was a boy*" in response to complementing her on her hair regrowth, suggested so. In addition to hair loss, Jamie's losses were in relation to no longer experiencing a world without intense pain or frequent sickness. She like her parents, had a hard time not being able to do all the things that made her happy.

The loss of their child's hair and everything else was hard not only because it was hard for them to see their child suffer, but also because it was an attack on their sense of self. At times, the parents expressed feeling self-embarrassment about the changes:

> *People look at you, "how can you let your daughter be like that (in reference to her behavior)...They don't understand. It is very embarrassing and very doubting situation...It happens all the time to us! People just don't, it bothers me. I find sometimes there is a big change when she is on steroids and with friends, going places, and sometimes it is embarrassing cause I can't control the situation or things escalate you know, and sometimes it is embarrassing, and sometimes it is not. (Denise)*

Part of their embarrassment was that they felt they no longer had control over their child and that they lacked proper parenting skills.

Moving Forward; Forgetting about the Routines of Life and Regaining the Beautiful Child: Once the parents no longer experienced life as blur or fog, they then began to really focus on getting through and more to the point, getting their child through the cancer-symptom experience. They did this by trying to regain their beautiful child and the beautiful life for their child. Dan and Denise both felt regaining their child back was the only thing that gave meaning to them living. It became their only true purpose in life:

I mean nothing is important other than Jamie...(Dan)

We're completely devoted to get through this. Its our only focus in life. I have no other goals. Nothing. Dan doesn't either. There's nothing. No money goals, no um, no kind of getting me getting back to work goals, my career. Dan too. This is our only focus is to get through this. (Denise)

It was at this point that the parents like all parents recognized they had to work at getting through it. They had to go on:

We have been through traumatic family trouble and you learn to deal or you don't. You don't carry a grudge and we learn to live and move on. (Denise)

I mean we only think of tomorrow, we can only move forward. We don't live in what happened because our life is different now...(Denise)

As in the past, they did whatever was best for her. However, in comparison to the past they did it with even greater urgency and vigor. In short, this meant doing anything that would make Jamie's life beautiful again. As the mom noted she and Dan *"would move the world for her..."*

Well we wanted to exploit every service that was available to us. Yeah, everything that was good for her to help her. (Dan and Denise)

Just as Dan and Denise described the fear and worry to be constant, they also described having to get through cancer-symptom experience as constant. To them this meant not only living day-by-day, but also "*living every moment*":

We live every moment, like I'm telling you. Enjoy with her and um, we do things. We don't care what time she goes to sleep sometimes we, we just enjoy it, you know? (Denise)

This included coming to know everything about cancer:

You are thirsting for information, you read everything, you know. You are reading everything. You gather whatever information to make sense out of it. (Denise)

Taking care by comforting Jamie was important:

We do the best we can to make Jamie comfortable and we do whatever we can to make her comfortable. We bring her quilt, we bring her sheets, the whole room is full of all her favorite toys, everything (in relation to Jamie's hospitalizations). (Denise)

Protecting Jamie as best as they could was also important. Like other parents, they were always watching for changes in her. Part of the protection also involved encouraging an increase in Jamie's strength in herself:

> *Without trying to, you know being discompassionate, we haven't done anything (pause) tried not to undermine her confidence, tried to (pause) get her to be tough about the things she has to be tough about, and wavering about the, the pill-taking and the hygienic procedures when they're necessary...(Dan)*

Dan and Denise also would look out for each other:

> *The only thing that I could control was how Denis and Jamie see me. My job in fact is to be as controlled and in control as possible because I felt that I would inspire confidence and um, it didn't give me any benefit but um, it felt good to be able to put up a front like that. (Dan)*

Although the parents expressed that routines became meaningless, they nonetheless tried to regain some of the routines that made Jamie's life happy such as inviting her cousins over to spend the weekend with Jamie. It was their way of providing some sense of normalcy for Jamie. Involving Jamie in activities appropriate for her age was stressed:

> *...we do our crafts, you know she doesn't just sit in front of the T.V. all day you know. We would play computer games together and she dresses up all day long, she is every different character and you know we bake and we cook together you know. (Denise)*

The parents also tried to make life normal for Jamie by never using the word "cancer" in front of her. In fact, when they gave me permission to talk to Jamie it was with the stipulation that I should not mention the "cancer word" to her. The parents also did not talk to Jamie about dying, nor did she ever ask about it, unlike other preschoolers who participated in this study. When around Jamie, Dan and Denise tried not to emphasize the seriousness of what was taking place:

> *And like we've never said to Jamie "you are sick." We've never, we've always told her "you are well" and it's (the treatment) just to keep you to stay well." (Denise)*

This is not to say that they were not honest about the treatment. Part of protecting her was to appropriately prepare her for her treatment:

> *I think we have given her certain skills to because we have been honest with her*

because we've had her face what it is, which is not an easy thing to do, the parents, you can barely do it yourself. Like Dan has been amazing with the treatments and he's been amazing getting her to cope with this and then it's over for her, it's ***over*** *and she just talks coherently after Friday (treatment day) and you know, I know you have seen that. (Denise)*

Despite the losses they experienced in relation to Jamie, the parents also would try to deal with losses by looking for everything in Jamie that demonstrated to them that she was still beautiful. It was important to her parents to tell me of all the "amazing things" that Jamie had done in between our visits. As well, in any of my conversations with the parents, it was not uncommon to hear the parents describe Jamie as amazing, smart, and so on:

And the way she talks, her vocabulary, it's like it ain't bad!...She is very curious and she remembers everything, it's amazing! (Denise)

Additionally although parents talked of loss they also reinforced that deep down inside Jamie had not really changed:

She's always had an unique personality and that hasn't changed...Certain aspects of her interests have changed ...But those were, you know, temporal things, temporary things...I don't think there's been any fundamental damage to her personality by any means.(Dan)

The parents also put the cancer in its proper place by rationalizing that as "*hellish*" as this experience was, it could had been a lot worse if Jamie had been older:

And she is lucky that she was young. OK she could go to school but she doesn't have to. She was at the end of prenursery into kindergarten. You know just imagine if it was her graduating year from high school or her grade six or seven transitional year to a new school, it would have been devastating, missing a year with her peers. (Dan)

Yet at the same time Dan and Denise acknowledged that over the last year, Jamie has had a lot of missed opportunities that someone her age normally gets to experience. Most important was the loss of potential friendships:

There hasn't been a lot of kids for her, from being in the social situations for two years from prenursery to kindergarten, learning about sharing, waiting your turn, those really important things...(Dan)

Jamie too worked at regaining her beautiful life. Often this meant learning to accept that she could not always do a lot of her favorite things like going shopping to the mall or out for dinner with her parents because her blood counts were too low. She had to

adjust to the restrictions on her life and be satisfied with activities that kept her inside for the most part. to school or to Whenever she got a chance and more to the point when she was feeling well, she would do the things that she had in the past always like doing like swimming in a wading pool. Both her parents said that this activity gave her such joy. Perhaps of all the things that helped Jamie was her imaginary "*kid's world*" that she had created and would sometimes retreat to especially when she would go to clinic:

> *She was very imaginable and she has an imaginary friend, she brings along to the clinic and never takes him home, he just comes with us. And some days when she goes to the clinic and she is very nervous about it, she sleeps in her bed, she will get an extra pillow there for him and she holds his hand like this and asks me what he should wear and she buckles him in the seat belt in the car. It's all her own, but yet when we get to the clinic and it's over, he's gone you don't take him home, she says "she doesn't need him anymore."...Yeah, somebody her own, because she always says to me "my kid's world you wouldn't understand" and she has her own kids world she tells me which is amazing. We've never said anything like that, it's all coming from her. She has told me you know "in my world, you wouldn't understand." (Denise)*

For Denise and Dan it was very important not to invade her private "kids world" because they feel that is what keeps her going. It gave her some control. Additionally, Denise and Dan tried or focused even more on connecting as a family and keeping the family together. It was important that the family worked together:

> *Denise: We are a very strong couple in a lot of ways. (Dan: In a lot of ways!) And we work together with this, we live together, we enjoy together. Our lives are not without pain and that's a big thing...*

In fact Denise at one point expressed that even during the diagnosis things were not that bad because they experienced the cancer as a family unit:

> *Because it's all been good for us as a family even during the diagnosis, but because we just made, whatever we could do with her we did...*

At the same time, Dan and Denise still had to work at keeping the family together. Because of all the changes they both realized that they "*had to re-establish themselves as a family.*" Part of this involved recognizing the importance of taking time for themselves, as well as giving time to Jamie to be in her own world:

> *I don't know, but I think it's really important for her to have that (her own special world) on her own.*

It was also important that both accepted each other's ways of approaching the cancer-symptom trajectory:

Denise: You have to deal with together and you have to allow the other person to also deal with it in their own way separately as well. You don't have to know everything, you don't have to talk about it all the time, you don't have to, you got to realize that the other person, and Dan and I have really given each other room
Dan: Yeah, I think we have very different ways of dealing with it.
Denise: We do and we are very conscious of that.....

In addition to having to work at regaining their beautiful child and life and keeping the family together, the family also had to deal with other stressors. For Denise she experienced stressors that included not being able to take part as much in simple pleasures like going to the hairdresser, and not being able to go out with her friends as much. But even more stressful were responses by some of her friends and family members. While Dan and Denise did describe many of their friends as helpful and supportive as well as important to getting themselves through it, they nonetheless experienced negative support experiences. Most notable were in relation to others questioning Jamie's acting out behavior and the parents ability to control her behavior. Denise expressed that at times her friends just had no idea how they could be helpful and therefore, would avoid them:

People don't know what to do, and it is hard and it is hard because people don't, like I said it is a major change in all of your relationships you know because people don't want to tell you that their kid did this and that or that they just whatever or may be bought a new car or they just you know, or they don't want to complain about anything as they'll say "what I have to complain about is nothing compared to what..." You know it changes everything, everything, (pause) at every level. (Denise)

Both Dan and Denise felt that the cancer changed many of their relationships with some of their friends and family. They experienced some people not really understanding or not wanting to understand what Jamie and themselves were experiencing. Both parents lost relationships that they felt they never would regain. At the same time they made new friendships because of the cancer-symptom trajectory. In contrast, Jamie unlike her peers, was not having the opportunity to build her circle of friends because of the cancer.

Dan also experienced stress in relation to having to work while thinking constantly about Jamie and her having to go through the cancer treatment. The stress became too much for Dan and accordingly, he took a leave of absence from his job. Returning to work once Jamie was getting better was even more difficult because he was having a hard time putting the cancer diagnosis in its proper place.

Despite the work and stressors, the family did have their "*periods of spiritualization*" as Dan put it. One such period occurred during the summer of 1998. Dan talked about how Jamie had a real chance to grow as a child during 40 days of that

particular summer. He talked about all the parties she had gone to and how she was able to play a lot more with her cousins, and how they had a lot of relatives from out-of-town visit them. This was all possible because during such times when Jamie was receiving less treatment, and consequently experiencing fewer symptoms. Denise described Jamie as viewing "life as an adventure" during the good periods. Indeed, when she came to clinic for check-ups during this period, she was full of energy and had a smile on her face. She would dance in the clinic's hallway with her dolls. It was almost like a victory dance as she would fling her arms up into the air. Dan and Denise were so pleased to see Jamie regain her spirit.

Siege Mentality and Going Crazy by the End: Even though Dan and Denise worked hard at regaining a beautiful life for Jamie, there were times when it became more difficult for them. Even when they experienced periods of spiritual wakening, both Dan and Denise anticipated difficult times ahead:

> *When she's feeling stronger, when she looks healthy that helps a little bit (pause) but then (pause) you know coming up is a very tough ride with chemotherapy (pause). You know, you're almost guaranteed she is gonna be in the hospital again. (Dan)*

While Jamie did not experience any relapse or major complication, the family nonetheless experienced events that they deemed to be very stressful. Most notably were the times when Jamie had to be admitted for chemotherapy that required monitoring for a couple of days:

> *What it's like when you are not there (the hospital), you try some normalcy in your life, you know, having a meal together, go outside and play, go for a walk, but when she is in the hospital, you realize how serious this really is. I mean it doesn't really hit home until you are there, when she is there and you hear of stories and everybody is talking and everybody's horror stories and it is very difficult and it really hits home but it's just something that isn't just going to go away...The hospital stays are very difficult, very stressful and very isolated. (Denise)*

A particularly hard part of the hospitalizations as well as the clinic visits for Jamie and her parents were all the needle pokes and traumatic intravenous (I.V.) insertions that Jamie had to have for treatment:

> *They give me lots of needles. A million. It hurts. The I.V. hurts too. The I.V. is a needle too. (Interviewer/Researcher: Doesn't anything help to make it feel better?)* ***Nothing!*** *Only when they take it out my hand feels better. (Jamie at 5 years)*

Every time she would get the I.V. insertion she would display the same pattern of

behavior of initial protest leading to the realization that she could not fight it and therefore, giving in but still screaming to the nurse who had to insert the needle: *"I hate you! I hate the poke! I thought I did not have to come here anymore. I want to go home." Don't leave the owie in!"* As physically painful as it was for Jamie, it was equally mentally painful for Dan and Denise. By the time it was all over, Denise would be sweating from having to hold and trying to comfort Jamie during the procedure. Yet both knew it had to be done, that it was necessary. Also stressful were the few times when she was admitted for treatment of infection. Although Jamie would physically get over such events, the family nonetheless found them difficult. It was like the cancer was coming back. They were reliving the initial cancer diagnosis all over again:

> *She was definitely ill with infections...which was scary with the Infectious Disease's doctors and she was listless and white, it was terrifying, we didn't...it brings it home, how serious it is. (Dan and Denise)*

But perhaps even more stressful were the unexpected symptoms and not knowing what they meant:

> *I've just had certain things that you know like with this rash and joint pain really set her back and I mean, and things change. Just a little. Like this morning she had, she was up till 10:30. She never has, and we kept checking on her which normally you wouldn't but you know these things go through your mind...You know I gave her this, I gave her that, she poked her stomach yesterday when she was playing. Maybe something, you know I don't know. I mean you wonder...Even childhood accidents aren't little childhood accidents and little, you know what I mean. Like falls and...Like before, you knew she had an ear infection she had an ear infection. Cause now you're waiting for another bomb to drop. You never relax. (Denise)*

It became even more difficult for Dan and Denise to hear from the physicians that certain symptoms do not mean anything, especially when in fact the symptoms were an indication that some illness was brewing:

> *We both knew all a long it was not nothing...it is frustrating cause you can't control it. You say this is the problem but (Dan)*

Symptoms that went undiagnosed despite being carefully checked out were for the parents difficult to accept. The not knowing caused a lot of frustration and anxiety on their part:

> *We still don't have an explanation to this day...That is what you are going through all the time! You don't know if they are going to be able to find anything or treat it. (Denise)*

But perhaps the most difficult or stressful aspect of the cancer-symptom trajectory to Jamie and her parents was the relentless nature of cancer and having to deal with the day to day aspects of it:

> *That's a lot of responsibility and being worn down and being emotionally drained after you know a day's events and watching her have a bone marrow or a...or a spinal you know for a spinal you have to sit here at night and give her pills, it doesn't end. You know for parents after it wears you down to have to do that as well. You make sure if the kid doesn't want to take the pills you try and...you know it's very difficult. (Denise)*

Moreover, the stress resulting from the cancer was compounded by other stressors. While they were focusing on dealing with the cancer, the families began to experience additional stressors or crises within the major crisis of cancer. Denise's mother had to be hospitalized and had major surgery. Once discharged, Denise and Dan now had to care for her and were having a great deal of difficulty trying to get some home care assistance. Understandably Dan and Denise experienced stressors in their relationships.

The unexpected symptoms, hospitalizations and so on were also difficult for Dan and Denise because it meant to them that they felt they had no overall control in regaining their child:

> *Every time. Every time. We really realize how we've lost control as a parent and we can't control this at all, or protect her from it as when she's in the hospital and there's nothing you can do. Um...that is...that...you get the same sick feelings that started. Days like this and when you go through the (pause). (Denise)*

> *Infinitesimal (in relation to the amount of control the parents feel that they have)! We can keep her happy and show her that she's loved. We can not let her know our fear, we can keep her healthy (pause), we can get her into a regime about taking her medication. We can explain things to her, to her level so that it takes away some of the fear and mystery. We can guard her from a certain degree of external exposure to things especially when she's most sensitive, we can be particularly careful about our hygiene and who we bring into the house. But really I think those are really tiny things compared to the big picture. (Dan)*

However, although on one hand the parents felt they had minimal control, they also felt in the end that it was up to the parents to get the children through the experience:

> *Some kids don't survive because the parents just can't keep up with it (Dan)*

While at times Dan and Denise expressed their feelings of helplessness, they also

recognized they had abilities to get through that many families may not have:

> *Yeah, because I think there are many ways we've had ideal circumstances to deal with such a horror. We are both able to leave our jobs and still support ourselves, we have a therapeutic model of family behaviour happening in the house already and in a lot of ways we...In many ways, if God forbid that to happen to anyone, I think in a lot of ways we are the ideal couple for it to happen to, however crazy that sounds. (Dan)*

To deal with the more difficult times the parents became even more vigilant in their approach:

> *But we had a **SIEGE MENTALITY**, we were going crazy by the end of the winter. (Dan)*

Being under siege involved the parents not only becoming even more vigilant and unified, but retreating almost completely into their own world where only Jamie and themselves were the concern:

> *Dan: That whole year was like living in a bunker!...Denise: You are afraid to go out and do anything, you know, it is just that kind of situation.*

Jamie as young as she was, had her own term for retreating into her own world: *Zoning out.* She would "zone out" when things got particular tough for her. During her "zone out" times she would be present physically yet on all other levels was in her own space and time. She would not talk to those around her, nor even look at them but instead stare into space. She even sometimes would "zone out" around her parents.

For Dan, Denise, and Jamie all interactions with others were limited during the really "crappy" periods. They lost social and emotional ties with some of their family and friends. Moreover, some of these ties were never regained.

Resolution: Now I am almost a "Girl Kid" Again:

At the time of ending my relationship with this family, Jamie had gone through the most intensive aspects of her treatment and was at the point of only requiring monthly treatments. The family was beginning to regain more of the life they had prior to the cancer diagnosis. They were no longer mainly just surviving, but as Denise put it: *"We are learning to live again."* Dan had returned to work although not full-time and Denise was looking into job prospects. Jamie was attending school half days and more and more was able to play with her peers. Dan's and Denise's dream to get their beautiful child back was now more of a reality to them. Although they both agreed that Jamie would never completely be the same beautiful child, they reconciled this by acknowledging she would have changed any ways as she was young when her cancer developed and therefore, her spirit and her sense of self had not yet fully emerged. Moreover, they

acknowledged that although she experienced many losses, she also experienced some gains, most notably they felt she became even wiser. She was in reality and always their beautiful child. They also saw a future for her. Yet for themselves, things were still not as secure. While they felt things were back on track for Jamie, they did not think this was the case for themselves:

> *(Dan)...things are back on track in some ways, with her (Jamie) but personally, not in my life...it is related to her being sick...*
> *(Denise) You never regain*
> *(Dan joins in) Once it happens you never look at life the same way*
> *(Dan alone)...What I am finding the things that are starting to normalize are my feelings about Jamie and her future, but in terms of my future or Denise's and our future, the family's future as a whole has changed quite a bit from before we found out about this.*

Additionally though Dan and Denise felt lucky that Jamie was a survivor in comparison to other children, they nonetheless experienced some bitterness just for the very fact that they and their child did have to go through the cancer-symptom experience. They had to experience the possibility of Jamie dying:

> *Well to see what the eclipse of her life might have been like and to say that she was lucky (slight laugh), well I guess everything is relative. (Dan)*

While Dan and Denise still felt like an united couple who cared for each other and while they got pleasure in seeing their beautiful child slowly return, they both were still grieving the loss of certain qualities of their child. Even though Jamie had gone through the most difficult parts of the treatment regimen and was now in the maintenance phase, both parents still viewed cancer as a horrible experience and they were still suffering because of it. They both agreed that it really did not matter what stage of the treatment Jamie was in because all of it was hard. Moreover, while Dan and Denise appreciated that Jamie now once again was able to take joy in many of life's simple pleasures, they themselves did not necessarily appreciate or enjoy those things for themselves. As they saw it, it was not there for them anymore.

Jamie too still experienced cancer as a horrible experience. Denise noted that the last time they attended clinic, Jamie had expressed "*the horror of it all!*" in response to Denise telling her they were going to clinic that day. Denise noted that it was very hard for her in adjusting to going to school. Physically and emotionally it was challenging. She only had enough energy to attend school in the morning, and at times she got easily frustrated while at school.

So while the family had moved on to some extent they were still waiting. Part of the child was renewed, part of the child, the innocence of life, was gone forever. Moreover, Denise noted that with the treatment becoming less frequent, Jamie is now even talking more about what has happened to her. The cancer was a part of her like all the other children and families:

> *It is right there on the surface for her and it could come out any time...out of the blue she'll just say something like when she told me the other day "I got that butterfly needle and it hurt so much. Um she, that was a long time ago when they took blood from her...she remembers but it is just, I don't know what associated it with the thought of it, but she had just mentioned. (Denise)*

More importantly there would always be reminders:

> *She was watching a certain show and she stopped watching you know, and she really enjoyed it and the other day it came on and she said this "is the episode that I had to go to the hospital." She was watching this show when it happened and she remembered. She said "see!" (pause) And you know she wouldn't watch it. She really enjoyed watching it but she stopped watching it for months about 6 months ago and she just started watching it again when it came on and she said oh "I remember this one, this is when I fainted". (fainting represented sickness to Jamie when I asked Jamie). She knows that she fainted, we explained it to her and she said that's "why I have to go to the clinic all the time and she said this was the episode," this is what she was watching in my room. (Denise)*

Although Jamie and her parents became stronger because of all the difficult times that they had experienced, there was still a fragility about them. To some extent the nightmare for Dan and Denise would never be completely over because the cancer could always come back to claim their beautiful child:

> *Five years. She has to be five years (in reference to years in remission) after the treatment, after everything and it is a nightmare for us.*

Just like after the traumatic birth of their daughter, they were waiting for another bomb to drop someday as well as waiting for the beautiful child to become a beautiful adolescent:

> *It'll be that five years waiting. And then up until then we've got another seven years to go here. Until then six and half years to go. Until then we won't breathe. I won't breathe until she's fifteen years old. (Denise)*

Like all families, their narrative was still in progress.

(2) The Adolescent Child's Story: Sweet Sixteen and Never Been Kissed

Introduction to the Adolescent Child and Her Family:

This story depicts the narrative of an adolescent referred to as Ann, and her family that consisted of her father, mother, one sister, and two brothers. When I had first met Ann in June of 1998, she had just turned 16 years. In April 1998 Ann was diagnosed with acute lymphoblastic leukemia, the "*high risk kind*" as Ann put it. In addition to the cancer diagnosis, this family had many other major stressors to contend with in their lives. As Ann viewed it, her diagnosis of cancer was just "*one more thing her poor family had to deal with.*"

Ann was the second youngest child of a family of five including her parents, Tom and Gail. She had one younger brother, Roger, 11 years of age and another brother, Eric, 19 years of age. She also had an older sister, Lynn, 20-years-old. Ann's father, Tom, worked in a machine shop and during most of the 18 months that I followed Ann, her mother, Gail, stayed at home to care for Ann. Previously Gail worked in a hotel as a kitchen staff supervisor. In addition to Gail having to quit her job to care for Ann, this family had like all families experienced numerous changes since the cancer was diagnosed. Ann herself had gone through many physical transformations in appearance over the time that I spent with her. However, as was with all the other children in this study, she always retained the qualities that made her unique. Ann especially was an outgoing adolescent who valued her friends and loved hanging out with them. She had a special look about her that suggested she was here and ready to try anything in life. Her grin and twinkle in here eyes suggested "I am here world, don't try to stop me!"

Ann and her family all lived in a small bungalow. From a financial standpoint this family was not well off and next to the cancer, the major concern for this family was being able to get by financially on a weekly basis. Ann's father always seemed worried and expressed his concerns about being able to pay all the bills. During the time I visited Ann and her family, there was always a lot of movement or action going on in their house. It was usually noisy and alive, at times chaotic, and very rarely quiet even during the times when Ann was not feeling well. There were numerous pets in this house. Friends of the Ann, her parents, and her siblings were always coming and going. The phone was always ringing.

Most of the family action occurred in the kitchen and livingroom that were closely connected due to each other. The family was always in these rooms and at time numerous different interactions or plots could be occurring at the same time. The interactions that occurred amongst family members and others did not stop, even during our interview sessions. Moreover, all the action did not stop even when the livingroom became a temporary bedroom for Ann during the time when she was too weak to climb the stairs to her own bedroom. As Ann laid on the couch with her tube feeding machine beside her, the family would continue on in the ways. Medical supplies took up even more of the livingroom's limited space, however, the family was still able to continue on. As chaotic as the living arrangements appeared to be, this family seemed for the most part to know what was important to them: staying together as a family.

Ann and her family were especially close to the parents of Gail. Although Gail's parents resided in another province they nonetheless would take turns visiting each other. Ann would travel with her family about every month or second month to see her grandparents. Sometimes they would travel a day after Ann had completed her weekly chemotherapy treatment. Sometimes her grandparents would come down for a week and stay with them. They always got together on holidays. Although this family was "poor" from a financial standpoint, they were "rich" in another way through the closeness they had developed as a family over the years. As well, despite the limited resources that Ann and her family had, this family was always involved in helping their friends and family members. Gail and Tom would not hesitate to take in any children's friends who were in trouble and needed a place to stay. The coffee was always brewing for anyone who happened to come by.

I followed Ann and her family throughout their cancer-symptom trajectory until Ann was 18 years of age. For the first year and half, I maintained a connection with Ann and her family through visiting them at clinic and in the hospital. The clinic and hospital visits lasted anywhere from two to eight hours. The clinic visits for the most part occurred on a weekly basis. She was hospitalized for chemotherapy treatments during the period that I was following them. I also maintained contact with them through home visits which involved a total of ten visits. The last six months of contact with Ann and her family was through phone calls and some visits in the clinic. At the time of closure with Ann and her family, Ann was still in remission and was nearing her final stages of treatment.

Overview of Ann's and her Family's Narrative: Waiting for Some Fun, Waiting to be Sweet Sixteen:

Ann's narrative is about the struggle of a young girl waiting for a chance at life as a teenager embarking onto adulthood. Like the other families, it is a story of Ann and her family having to wait and wanting to move on. Ann was waiting to live life like a typical adolescent wanting to grow up "just enough" and her family was waiting for Ann to have a chance of being that adolescent. Ann's suffering stemmed from waiting to turn "sweet sixteen" with all the good things associated with coming of age such as all the entitlements, promises, and enthusiasm, and then once having turned sixteen years never seeing most of the good things transpire. The cancer diagnosis had put a hold on Ann experiencing what it truly felt like to be sixteen years of age. She expressed frequently that for two and half years of treatment she would not have control of her life. Moreover, she was not going to have a "*normal teenage life like most of her friends.*" She reinforced "*they'll be partying or hanging out while I'm getting sick from my treatment. Leukemia sucks!*" She feared death and moreover, feared not having a chance at getting married, having children, or ever being an aunt. To Ann, it was like having the wind kicked out of her. It was like she was betrayed:

> *I waited all my life this day (16th birthday). It is so important to a girl and well I don't know if I'll now be in the partying mood.*

Her family also felt the same way, like they were kicked in their guts. This family had already been through so much, a lot more than most families. In fact, having a crisis in their lives was the norm for them. Each crisis always kept them waiting, waiting for an easier life and this crisis with cancer was no different. It was a real blow to them. They felt betrayed because they had already had their fair share of life's misfortunes to deal with. And this cancer experience involved many crises or rough times for this family such as the times when they thought Ann had relapsed. At times Ann's mother would express *"how much can one family take*?" In addition to the cancer stressors, they experienced other non-cancer crises during Ann's illness. Understandably, at times this family felt like finally throwing the towel in:

> *All she's (Ann) ever had is the occasional rough day or a long day. She'll come home and cry a little bit, she will cry and she'll go "mom I can't do this anymore, you know mommy I just can't" and I'd let her of course, let her cry it out but you know...(Gail)*

Yet overall this family persevered and continued on. They continued on for their own sense of self, but more importantly for their family's:

> *This being sick makes me very angry and sad. Sometimes I just want to end everything but I know I can't do that because my family needs me and that would be a wrong thing to do. (Ann)*
> *I would never do it (stop treatment) because I have such a good family, and I couldn't do that to them. (Ann)*

Moving on was important to this family regardless of the situation:

> *My aunt has talked with us a few times and she has a wonderful outlook and it's one big question, can you change it? If I can change it then you change it. If you can't change it, deal with it and move on. (Gail)*

As in the past, this family approached life and life's problems head on. It was important to be able to say that they dealt with a particular problem and were able to move on. Ann persevered so she could have a real chance of teenage life and growing older. She was waiting to survive but also waiting for "*payback time"* as she put it. She was waiting to do all the things that she perceived was part of being a 16-year-old. Interestingly though the things she was waiting for changed and the change stemmed from her having to experience the cancer-symptom trajectory. While she'll was still waiting to grow up, what she was waiting for had changed to some degree. In short she changed her future life plans. Yet, while she was still waiting to have some fun and "really party," she also now had a real career goal. She wanted to do something that would make a difference in life. Cancer helped to give her more direction in life or helped her to carve out more of clear path in life.

The waiting also helped the family to focus more in on what they always felt was important: maintaining a strong family. Although maintaining a strong family was important to Ann's family before the cancer-symptom trajectory, it became even more important after the cancer was diagnosed. With each blow to them as a family unit, they only became stronger. While difficult at times, they tried to remain fairly positive throughout the time I spent with them. Although the cancer brought them all a lot more heartache, it also made them stronger as a family experiencing even more love for one another.

At the time I ended my interactions with this family, Ann was still receiving treatment. Although she was in remission, there was still some uncertainty if she would truly survive. She was now waiting to reach the age of 21 years of age and all the things that came with it such moving in to her own apartment, being at university or college, and having her own car, yet still being close to her family. For her family, although things in life had settled down and life was not as hard, they were also waiting. While they were more relaxed, they were waiting for their next crisis. However, upon leaving them, I knew whatever the final outcome would be, this family yet would one more time get through another crisis and survive as a caring, loving family.

The Core Narrative: Main Themes

Sweet Sixteen and Cancer to Boot: Ann's cancer took awhile to be diagnosed and when it was, it was just like the other families, the least thing that Ann and her family expected. Ann's pre-diagnosis illness trajectory was especially lengthy, commencing about eight months prior to her turning 16 years of age, the age when she was diagnosed with cancer. Prior to being diagnosed with cancer, Ann was attending high school. She was in grade ten. While she described herself as being fairly smart, she was not too interested in her studies. She was much more interested in the extracurricular activities especially cheerleading practice. She loved going to school, because it was a time to socialize with her friends. Ann was really outgoing and had many friends from school and from outside of school. Tara, was her very best friend who had been friends with her for years. She loved going out with her friends to such places or events as parties, the local mall, or movies. She and her friends did not have much money to spend but some how they managed to get into places where they wanted to go. Ann and her friends could be described as adventurous and would always like to try new things and go to new places. They would at times crash parties and Ann admitted to attending "raves" with her friends.

Her parents were well aware of Ann's "*going-ons,*" and although always worried about her, they were able to deal with Ann's behavior. Moreover, Ann had respect for her parents and always knew when she crossed the line. Ann had learned from the mistakes her older siblings had made such as them quitting school. She was not going to quit school like they did because she knew it was important to her parents that she complete school. Both Ann and her younger brother needed to succeed where her older siblings failed. Not that her older siblings were "*bad*" according to Ann, but it was just that they made mistakes that only caused her parents to worry more. Ann noted that her "*older brother and sister gave my parents a lot of headaches.*"

Ann got along well with her parents. She referred to her father as "*pappa*" and would enjoy going out with her father especially to a restaurant. Ann also spent time with her mom. Her relationship with her siblings prior to the cancer diagnosis was described by Ann as "*typical.*" They got along at times but also would have their typical fights and arguments. Ann at times would "*boss around*" her younger brother. Ann was especially close to her two brothers. She would share things with her older sister, but because here sister had moved away from home approximately two years ago, she was not as close to her sister as she was to her brothers. Ann was also close to her best friend, Tara who spent a great deal of time at Ann's house. At times, she would even describe Tara as her sister.

Ann's parents described their life as "*busy.*" Prior to the diagnosis, both parents worked, Tom in a machine shop, and Gail at a hotel. Just before being diagnosed, Tom was promoted to supervisor which meant he could now get off of shift work and work days although it involved a lot of overtime. Gail worked days and evenings so at times Gail and Tom were not able to spend a lot of time together. However, Gail would always try to make sure that daily everyone sat down for supper even if it meant having a late supper. Gail and Tom would also try to go out every Saturday evening. Gail maintained a close relationship with her parents. Even though they lived in another province, Ann's family would frequently get together with Gail's parents. Ann especially had a fondness for her grandfather. Ann's parents also participated in a lot of volunteer work. Even though Ann's family had little with respect to material wealth, they always felt they were better off than most, and wanted to share whatever they had with others. Ironically this included working with agencies that focused on improving the life of children experiencing chronic illness and disabilities. Ann's parents thought it was important that their children learn to respect other children and people in general especially for those children and families who had a harder time in life. Ann's parents also got their children involved in their volunteer work. In a way, the parents' experience with volunteering helped the family prepare for Ann's cancer experience although that was not their original intent in volunteering. They knew that it was important to try to deal with life's hard times. After all, if disabled children and their families were able to get through the rough times, so could they. They could deal with getting through the cancer-symptom trajectory.

Even before Ann's diagnosis, Ann's family had experienced a lot of stressful or hard times, from major financial concerns to loss of close relatives. As Ann reinforced "*my family and poor parents already had to go through a lot!*" It was perhaps for this reason that made the cancer diagnosis difficult for the family to accept, yet at the same time helped them to get through the cancer-symptom trajectory. As well, despite all the stressors in this family's life they nonetheless were able to continue on as a family.

Ann's and her life family's life started to take a turn of direction early in February 1998. Prior to that time around December 1997, Ann started to feel "*not well.*" Yet she did not think much of it. Life continued on as is for Ann and her family. There was no need to direct extra attention to keeping her spirit alive. But Ann did not get over the flu and she continued to feel unwell. Like her parents, it was not until February that she felt it was more than the flu:

> *Back in December she was, she was sick flu-like, cold like...basically at that point it was just a cold...It goes to February, the first week of February That I had taken her to Children's Hospital Emergency and they sent her home, saying that "she had the flu, let it run its course..." and at that time, I knew there was more than the flu. I believed that she had the flu because she definitely had the symptoms. But, she was blacking out...and blacking out a lot, she was weak, she couldn't stand up. She's got a...she's got a nineteen year old brother who was taking her to the bathroom. You know, assisting her, carrying her into the bathroom because I'm at work. You know, sixteen year old girls just don't do that. (Gail)*

Accordingly, life started changing for them in February. Ann could no longer do everything that she wanted to do such as cheerleading, one of her most favorite activities. There were more doctor appointments, Ann missed more school, and Gail had to take time off for work. Ann was not acting like herself. Her energy for life was not the same. More to the point, it was not pleasant to be around her:

> *She was moody...she would just turn off anyone! (Gail)*

Things started to become more stressful for the family. The siblings would fight more. It was at this time that Ann's physicians began to agree with Ann's parents that it was more than the flu. They thought may be it was severe migraines or epilepsy as her symptoms supported such diagnoses and plus the fact that the family had a history of epilepsy. Cancer was never entertained. In fact, as Gail emphasized, it was not until nearly three months later that cancer was diagnosed:

> *March 31st Ann was diagnosed with high-risk A.L. L. (Gail)*

The date was significant in many ways. First it was a day near many of Ann's family members' birthdays including her father's. As well, it was a month before Ann's sixteen birthday; the birthday that Ann had planned forever. Well, cancer ended all her and her family's plans. Not only did Ann joke "*some birthday present for me!* ", she also expressed in a sarcastic tone that "*it was some gift that she gave to her parents!*"

The timing of the diagnosis and her birthday was even made more significant because at the time of diagnosis, Ann's condition was deemed critical and she had to be admitted to the intensive care unit. Had it been made a few days later, she may have not survived. Instead of celebrating a birthday, they would have been mourning a death. As it

was, it took sometime for Ann's family to really believe that she did have a chance to experience life as a sixteen year old. The news was devastating for everyone in the family. For Ann it resulted in many thoughts including perhaps the most poignant of all:

Here I am sweet sixteen and I have never been kissed!

A Month Lost; Birthdays Lost: As soon as Ann was diagnosed, life truly changed for Ann and her family. As chaotic as life was before the cancer diagnosis, life became even more topsy-turvy or upside-down for them. So much so, that for the first two weeks , Ann's parents described the experience like being in "*limbo*." Life was one big blur for them. As Gail noted it took her and her husband time to digest the news. However, considering their past experience with hard times, they were at least able to see part of the cloud or fog lifting within two weeks. For Ann, however, this took longer as for the first month Ann was so sick she basically slept her way through the first month. And then after waking up, she required further time to digest the news. For Ann, it was a *"total blur..April was a blur...I don't remember much of it!"* She noted:

> *See, like, okay...At first I didn't, like, everything from the first couple of days when I was in the hospital it was a total blur. Like, I remember parts of it and stuff like that? I don't know...I guess it was because my hemoglobin was so low? Like, I remember some things but very little? And I just remember...like it's, like it's coming back to me I know that sounds kind of weird but...*

Moving Forward and Trying to be Sweet Sixteen: Once the first month had passed, Ann and her family focused on moving forward and getting through the cancer-symptom trajectory. Moving forward and on was important to them, but as they soon found out, it was not so easy to. That is, within the big crisis of cancer there were many other crises contained, waiting to come out. Nonetheless, Ann and her family approached the cancer like they did with other crises. Once the family got over the initial shock they moved on in their usual manner. Although looking from afar one would get the impression that this family responded to the cancer crisis in a disorganized manner, this was not the case. Gail with the help of Tom, tried to keep things on track, including trying to maintain much of their old lifestyle as was possible. They tried as much as was possible to reduce the amount of change in their lives including not getting rid of the family's pet cat and parrot, both considered to be a source of infection for Ann.

All family members knew what their responsibilities were in order to get through it. Gail would become the primary care giver and Tom the sole breadwinner. Ann's siblings were to continue on as before without trying to cause additional stress for Ann and her parents. They were to be supportive to Ann without Ann knowing otherwise. Ann's main responsibility was to concentrate on getting well. Gail and Tom also encouraged the family to try to continue on as before. However, there was now a greater focus on Ann which was sometimes at the expense of the other family members especially Ann's siblings.

For Ann's parents dealing with the cancer meant keeping Ann well and alive. An important sign to them that they were dealing with it was Ann not having to be hospitalized. Except during the initial diagnosis, Ann only required hospitalization for specific treatments and not for complications related to the cancer-symptom trajectory. Ann's parents were proud that they were able to keep Ann out of the hospital:

> *She has done a good job, we have done a good job...Ann has never been hospitalized except when she was first diagnosed...**WE** are keeping her out of the hospital! (Gail)*

Part of keeping her out of the hospital, was learning about the cancer and its treatment. Gail assumed the major responsibility for this while Tom worked in order to pay the bills. Both assumed these roles as they felt it was the best way to prevent the family from falling apart. Throughout the initial first six months and throughout the cancer-symptom trajectory, Gail developed a knowledge base that resulted in her becoming an expert in caring for the child with cancer:

Moreover, Gail and Tom became even more of an expert of keeping the family together. This included paying attention to their other children's needs where possible, still visiting Gail's parents, and when they could afford to, going out to dinner. Tom was even able to take his youngest son hunting with him one weekend. Most important of all was having dinner together as a family. Dinnertime would take place around 7:30 PM after Tom got home from work. Most of the time, all the children and the parents would all be there, except when the older siblings went out with their friends. Tom and Gail also thought it was important not to treat Ann like a "*glass doll.*" This meant being there for her during the times she needed help, but also not giving in to her every wish or yearning.

Yet even though they were able to continue to move forward, doing so was not without experiencing any stressors or losses. Gail experienced stressors that included a temporary loss of her job, not being able to take part as much in simple pleasures like going to the hairdresser, and not being able to go out with her friends as much. Tom had to work more overtime in order to pay for the additional expenses related to having to get through the cancer-symptom trajectory. Accordingly, Tom was not able to get too much involved in such aspects of Ann's care such as not being able to attend Ann's cancer clinic appointments. Gail was his informer; his main source of information. He had to rely on Gail who at times was too tired to give every single detail. Tom's lack of involvement in Ann's care became a real sore spot for him. He wanted to be involved but could not because like he said *"the bills still had to be paid, it doesn't matter to the bill collectors that someone in your family has cancer..."* Not only did he feel a loss, but he also felt inadequate at times or more to the point like an outsider. This was especially evident during the times when he was fortunately able to attend his daughter's appointment. Such feelings were only compounded by some of the clinic staff pointing out to Tom that he ha not attended clinic in a long time. Most telling was the helpless, lost look on his face while watching his daughter undergo a bone marrow test. While Gail encouraged Ann to breathe and held her hand, Tom stood there like an outsider wanting

to become an insider.

For Ann dealing with the cancer meant being able to try to be a "*regular*" teenager. Although she realized she could never feel the same or experience being a teenager like her friends until her cancer was cured, she nonetheless tried to live some of her life as a teenager. She had a lot of "chutzpa" such as not giving up wearing her high platform shoes despite her muscles weakening in her legs. She would try to go to school once a week and when she was unable to she tried to keep up her studies at home. In fact, she even took a greater interest in her studies at this point in her life. She was really excited about her school giving her a computer to use at home. The day she got the computer was a major event for the family. For the first couple of weeks of having the computer at home, part of their conversations would include talk in relation to the computer. Especially important to Ann was that she was able to still go out with her close friends even during the times when she was not feeling well. This included going out to parties.

Most important of all activities, was Ann hanging out a the local mall with her friends. She tried to do this almost every second day of the week.

Her good friends stuck by her, and most of them treated her in the same way as before her cancer was diagnosed. Tara was especially supportive of Ann. She treated her like she did prior to the cancer-symptom trajectory; she treated her like her peer and very best friend. In fact at times, Ann felt that Tara had "it worse" compared to what she was going through. This was because Tara came from a broken home and received minimal support from either of her parents.

Ann's sister and brothers managed to continue on with their daily routines, although they also experienced changes. For example, Roger spent less time in school as he would often go with Ann and his mother to Ann's clinic appointments. Both Eric and Lynn continued to hang out with their friends, but at the same time had to pick up the slack so to speak, that is, assume more responsibilities. The older siblings became even more self-reliant. No matter how hard the parents tried, they realized that the other children had to give up some things. While Eric and Lynn could deal with by just getting away from their house, it was more difficult for Roger to deal with. At times he would get into fights with Ann, and then would feel really bad afterwards. He would also display more aggressive behavior at school when Ann was especially not feeling well. Lynn would also become angry at times because she felt her parents were not concerned about her relationship with her boyfriend. Eric also had a hard time accepting his sister's illness and in fact when Ann was initially hospitalized, was unable to see her because he was so upset. Watching his sister suffer through the cancer and feeling that he could not do anything to help her was in fact as he noted harder to deal with than if he had been diagnosed with cancer. Gail noted that if it was possible he would gladly trade places with her or wished that he was the one diagnosed with cancer.

Accordingly, as Ann and her family were moving on they still nonetheless were waiting. Although Ann's parents were pleased with how Ann was progressing, they still were waiting for "*the other shoe to drop...*," or for the other crises:

> *It is not really a true remission till all the treatment is over...the bone marrow aspiration could possibly not show everything...those cancer cells could be.*

For Ann she was also waiting as she moved on. Like her parents she feared the possibility of dying and more to the point of not having a chance to be a truly, real teenager. Accordingly as they moved forward they also still experienced waiting.

One Step Forward, Two Steps Back or the Spiral Effect: During the first eight months Ann and her family continued to approach cancer and life's difficulties head on, and managed to deal with all the setbacks. Even with these stressors and losses, the family was getting through it. They were getting through it because Ann despite feeling sick, felt she was not "*really sick*" with respect to the cancer. She was remaining in remission and her symptom distress had not totally overcome her lifestyle. Up until this point, despite all the non-cancer and cancer stressors that the family continued to experience, the stressors were not strong enough to pull their family apart and Ann was less able to be a "*regular*" teenager. The family was able to move forward to some extent. However, slowly the crises became more frequent and more intense. The setbacks were becoming more frequent and the family was spending less and less time together as a family unit. They had less time to do things that they liked doing. Instead of taking small steps forward, the family appeared to be on a downward spiral course.

While they were focusing on dealing with the cancer, the families began to experience crises within the major crisis of cancer. In addition to feeling sick because of the chemotherapy, one of the first and hardest things for Ann to deal with just as was the case for most of the children, was losing her hair due to the effects of the chemotherapy.

Although on reflection she felt she was the same person, she nonetheless felt different at times especially when she compared her present sense of self to the past, and when she compared her life to her peers. Showing me and others pictures of what she once looked like with hair was important to her. Feeling not quite herself was further compounded by other temporary physical changes such as her on and off experience with bloating or her inability to do minor tasks like in hold a pencil without her hands shaking. Changes in her mood also caused her to feel different and to feel out of control. She was now becoming aware of her body because of all the changes.

Ann also was going out less often with her friends because she felt too sick or weak. In fact her desire to go out was lessening.

She also would get behind in her studies and worried that she would not be able to graduate from high school with friends. These losses and potential losses only reinforced to her that she was still waiting to be that 16 year old.

The siblings also were facing more challenges. This included Eric's best friend being beaten up in bar and Lynn becoming pregnant. While Lynn became more of a sister to Ann, Eric was still having a tough time accepting the fact that his "baby" sister was

sick. For Ann, she longed for a hug from Eric. However, ever since the time he accidently hurt Ann by hugging her after she had just had surgery for a central line insertion, Eric was reluctant to approach her in fear of hurting her or as Gail put it: *breaking her now!*

Roger was also not doing well in school. He was becoming more rebellious. Moreover, it was about this time that Roger became sick with pneumonia. It was at this point that Ann's mother was having a hard time getting through the cancer-symptom trajectory. It was during that time in the hospital that Ann's mother while waiting the results of Roger's blood tests cried:

This is too much, how much more can I take!

Although Roger recovered without experiencing any complications, it was nonetheless difficult and was further compounded by the deterioration of Ann's health just as Roger was recovering. Ann became so weak she would fall often in her attempts at any physical activity. Ann was getting tired of the treatments and the way the treatments made her feel as well as look. Her parents were also getting tired of having to keep on top of things, and more and more they would argue. While Ann learned to live with the pain of certain symptoms, her increasing fatigue subsequently reduced her ability to keep up with her friends. Luckily, her best friend, Tara, stuck by her throughout the cancer-symptom trajectory. Instead of going to every parties, Tara would spend time with Ann or when she did go to parties, would make sure Ann experienced some of the party through Tara's retelling of her experiences.

Ann was experiencing weight loss and despite all her hard efforts to eat, she would come to clinic weekly only to discover that her weight was decreasing. At the same time, Ann's blood count was remaining low for weeks on end. Ann herself was not feeling well, although she was quiet about just exactly how unwell she felt. Both her and her mom feared the possibility that the cancer may have come back, although they kept quiet about their feelings. Sometimes as Gail explained, "*it was better not to know to...better not to go there...*!"

The final blow for Ann was having to have a nasogastric feeding tube inserted for supplemental tube feedings. This was traumatic for both Ann and her family, especially her mother who had to observe the tube being inserted. Gail felt that she had not succeeded in helping her child get through the cancer. She wished that cancer had never entered their lives. Where she always liked to be the one to deal with problems, she had no control in this situation. For Ann the tube represented one more sign that showed others she was not a "*normal*" 16 year old teenager. Although she adjusted to using a wheelchair from time to time, the tube was just too difficult to accept. Yet at the same time she realized she needed it. As weak as she was she was still fighting.

The tube feedings further resulted in changes to the family unit. Gail became more of a care giver and less of a mother and wife in order to care for Ann during this period. Moreover, the living room was converted to a hospital room in that Ann due to weakness now slept on the couch in the living room. A big cart containing the necessary medical

care supplies as well as medication was adjacent to the couch. Extra work , restrictions, and losses resulted. For Ann especially, she missed going out for dinner with her friends and family. The feelings experienced by Ann and other family members were in particular described as a "*roller-coaster*" experience during this time. The siblings especially felt detached from their sister and family. The younger sibling expressed that his family was not like the family he once knew. And yes, week after week there was no improvement in Ann's blood counts. Although Ann's physician felt that most likely her low blood count was the side-effect of one of Ann's other medications and would resolve itself, Ann and her family could not shake the feeling that it was something more serious.

The seriousness of the situation was reinforced when Ann's physician decided it was time to do another bone marrow test. On the day of the test, both parents came to the clinic. They were very quiet and somber like individuals waiting to hear bad news. After the test was done the family were waiting once again. This time they were waiting to hear that the cancer had relapsed. To their surprise, however, it had not, and eventually both the problems with Ann's weight and blood count resolved themselves.

Resolution; Now I am Truly Sweet Sixteen: The news that Ann's cancer had not relapsed brought on a renewal of the family's spirit; they were now able to once again focus their energies on moving forward.While they came across further crises, none compared to the time when Ann experienced the fear of relapse. Things started turning around for them. Ann was feeling better and was able to resume many more activities including acting as a cheerleading coach. Although she did not feel like her 100% old self, she felt pretty close to it and moreover, still believed she would eventually feel 100% well again.

Tom dealt with his lack of not being able to care for his daughter by taking on a new job in his workplace that involved shift work. Although he was unable to take a leave of absence from his job like Dan in the first illness narrative was able to do, he purposely changed his job in order so that he would be the one to attend all of his daughter's appointments. Like all fathers, Tom needed and more to the point, wanted to spend more time in his role as a father. This in the meantime afforded Gail the time to renew her energies. She had become exhausted caring for Ann and with Tom keeping the family together. Now she took some time to have parties at home with her "girlfriends!" She had time to reflect on what she would do in the future.

Gail's and Tom's goal was to keep the family together and for the most part this was accomplished. Slowly, the family was able to get their life back on track:

> *I think the family was pretty much on track. We had some disturbances with different things that Ann had to go through but really, I think the family was on track. (Gail)*

The family as Gail emphasized remained intact. Moreover, it became stronger. The family had to wait, but also now was moving on to other areas in life. This included Ann's desire to graduate from high school and therefore, she made plans to take

additional summer courses to upgrade herself. She had the goal to go into some health professional career in order to "*help other children going through cancer.*" Gail was now slowly returning to her old job, and Ann's brothers and sister now were feeling more at ease with Ann. Tom felt that he was getting his family back as it was before. Moreover, the family grew in that Tara had a baby boy. Ann did have her chance of becoming an aunt.

At the time I left, Ann was still on maintenance treatment. Although she still exhibited a sense of fragility about her, she and her family nonetheless demonstrated additional strength. Moreover, they felt the cancer experience had brought them closer together as a family.