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CONQUERING HEROES:
PARENTS' PERSPECTIVES OF THEIR CHILD'S SCHOOLING EXPERIENCES AFTER THE CHILD'S DIAGNOSIS OF CANCER

BY

MARIANNE C. GAREAU ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
DOCTOR OF PHILOSOPHY
in
COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA
SPRING 1996

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ISBN 0-612-10590-3

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **CONQUERING HEROES: PARENTS' PERSPECTIVES OF THEIR CHILD'S SCHOOLING EXPERIENCES AFTER THE CHILD'S DIAGNOSIS OF CANCER**

submitted by **Marianne C. Gareau** in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

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Date: November 9, 1995

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DEGREE:	Doctor of Philosophy
YEAR THIS DEGREE GRANTED:	1996

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ABSTRACT

This is a qualitative study of parents' perspectives of their child's schooling experiences after the child has been diagnosed with cancer. Interviews were conducted with 11 parents of children who ranged from 6 to 13 years of age. All of the children were considered survivors of childhood cancer, having been diagnosed from 2 to 9 years before these interviews were held. Data indicated that although the parents expressed a range of satisfaction or dissatisfaction with respect to their children's schooling experiences, there were several themes that were consistent among all participants. These themes included the importance of parents being strong advocates for their children vis-a-vis the school system; the continued importance of schooling in the lives of these children and their families (mainly as the normalizing factor in a child's life); the lack of liaison between the medical world and the school; and the importance of schools being better informed about the psychological, emotional, and cognitive sequelae of childhood cancer and its treatment.

ACKNOWLEDGEMENTS

I would like to thank the many people who contributed to this dissertation:

First and foremost, thank you to the eleven parents who so generously and honestly participated in the study, and to their children - Chester, Frank, Robert, James, Elizabeth, and Roger.

Thank you to my supervisor, Don Sawatzky. Your thoughtful support and encouragement throughout the last three years have helped to make my graduate school experience very rewarding. I look forward to a continued working relationship with you.

Thank you to MaryAnn Bibby and to Norah Keating, for your support and invaluable assistance in planning and writing the results of this study. To Michael Handman, the fourth member of my supervisory committee, and my internship supervisor for this past year, thank you also for your support and many helpful comments. To Lorraine Wilgosh and Joyce Epstein, thank you for your supportive comments, and for your valuable editorial suggestions.

Thank you to my dear friend, Colleen Kennedy, for your unfailing love and the countless hours you spent discussing the study with me, helping me with the data analysis, and reading the numerous drafts of this document. Thank you also to my mother, Thérèse Gareau, and to my friend Evelyne Gaudet, for all your help in editing this dissertation.

Thank you to my daughters, Elène and Lise, for encouraging me, and for tolerating a mother who wrote her Ph.D. dissertation at the kitchen table - and for turning down the volume of the television set whenever it became too distracting for me!

Finally, to my husband, Herb, thank you for making the past three years possible. I know that, without you, I would not even have considered undertaking a Ph. D. This is as much your accomplishment as it is my own.

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CHAPTER ONE

INTRODUCTION

"The real art of poker... isn't winning with a winning hand -- anybody can win with a full house. It's winning with a losing hand. We had a losing hand, all of us. And in some way we won."
-Actor André Gregory

No parent ever asks for or chooses to have a child diagnosed with cancer. However, the parents in this study have all been handed this challenge, and the stories they told me are indeed the stories of people who "win with a losing hand." It is for this reason, among many others that will become evident throughout this work, that I have chosen the title of "Conquering Heroes." The heroes in this case are the parents as well as the children whom they love so dearly.

I set out wanting to learn about parents' perspectives of their child's schooling experiences after the children's diagnoses with cancer. What I learned included not only these parents' perspectives with respect to their child's schooling experiences; I also learned about how these parents had taken the challenge of cancer, and had turned it into an experience that became meaningful to them and to their entire families.

Overview to the Study

The purpose of this investigation was to study **parents' perspectives of their children's schooling experiences since the child's diagnosis of cancer.** Since my objective was to focus solely on the **parents'** perspectives, and since this is a topic that has not received much research attention until this time, a discovery-oriented approach was used, as opposed to a "verification" approach. At this stage in our knowledge, it would even be difficult to know specifically which questions should be asked, so I decided to rely on open-ended interviews to gather data. Strauss & Corbin

(1990) suggest that qualitative methodology is best suited for understanding what "lies behind" something that is little understood, and for examining the experience in-depth from the perspectives of those experiencing the investigated phenomenon. The study, therefore, can best be characterized as a descriptive study using a thematic analysis to describe and interpret the data.

The sample for this study consisted of eleven parents (five fathers and six mothers) of six children who had been diagnosed with various types of cancer (five boys and one girl). These children ranged in age from six to 13 years old, from kindergarten to grade seven. All of the parents lived in north and central Alberta, and participated in face-to-face, in-depth interviews with the researcher. All of the children were now in remission, and were attending school on a regular basis. The parents' stories, and my understanding of their thoughts, form the basis of this thesis.

In order to limit the study, I decided at the outset to focus on parents of children at the elementary school level, since children of this age have a greater dependence on their parents and are more likely to be affected by their parents' attitudes and behavior. Furthermore, rather than focusing merely on "school re-entry," I also decided to study parents' perspectives on their child's entire "schooling experience." The reason for taking this position is that "schooling" is an on-going element in the lives of most children with cancer, even though actual attendance at school may be interrupted for periods of time.

The main question that I asked of all the participants was, "Tell me about your child's schooling experiences since he/she has been diagnosed with cancer...?". After this initial question, the participants' responses basically determined the direction of the interview. Nevertheless, there were three questions that I that I made sure to ask everyone:

(1) What importance does your child's schooling have for you as parents?

(2) How do you think <u>your</u> attitudes, your actions and reactions, have affected your child's schooling experiences?

(3) What "advice" would you like to give to the schools, based on your experiences of having a child with cancer?

I was curious to learn about what it "meant" to parents that their child be attending school, and be successful both from an academic and a social-emotional perspective.

General Background for the Study

Childhood cancer has gradually evolved from an inevitably fatal illness to a life-threatening chronic disease (Katz, Varni, Rubenstein, Blew, & Hubert, 1992). Advances in medical treatment of childhood cancer over the past decades have dramatically increased survival rates (Peckham, 1989). For example, a child diagnosed before 1960 with the most common form of childhood cancer, acute lymphocytic leukemia (ALL), had a 1% chance of surviving. Today, 70% of children treated for ALL can expect long-term survival and cure (Bearison & Mulhern, 1994). Children with other types of cancer now have between a 50% and 90% chance of survival, depending on the type of cancer. The result of this medical success is an ever-increasing number of children who have had cancer progressing through school and entering adulthood. In fact, most children treated with cancer today do survive in the long term; they can be expected to go to school, and to grow up with their peers. However, these children and their families have had a very special experience in coping with this life-threatening disease, complicated and often painful medical treatments or tests, and living with an unknown future for at least some period of time (Koocher & O'Malley, 1981). Besides the major issue of survival, however, there are many potential problems likely to be encountered in long-term survivors of childhood cancer. Some of these problems are reflections of the physical and psycho-social consequences of the disease, but many others are related to the therapeutic modalities employed in achieving these successful outcomes (Meadows & Hobbie, 1986).

Although not all children with cancer will survive, each child has rehabilitative potential, if only for a short time. Achieving a state of remission, however temporary, is a realistic goal for all children, allowing for a return to school and resumption of normal activities for at least some period of time. Furthermore, the possibility of a biological cure for cancer now forces both parents and caregivers to be concerned about facilitating normal emotional, social, and intellectual development during the child's treatment (Koocher & O'Malley, 1981). It stands to reason that a diagnosis of childhood cancer is not individual; in a very real sense, the whole family "gets it" (Carpenter & Levant, 1994; Northouse, 1984). The implications of childhood cancer for the child and his or her family are many, and affect every area of their lives, physically, socially, emotionally, and academically (Bracken, 1986).

The quality of a child's school life is also vital to his/her mental health, which in turn significantly affects his/her physical health. Quality of life for children and their families is to some extent dependent upon the characteristics and sensitivity of the schools that the children attend (Kirten & Liverman, 1977). The function of the school in the child's response to the disease has been described (Lansky, Cairns, & Zwartjes, 1983) as the setting for the most frequent encounters with the community, school in our society being "the work of children." It is generally considered important for the child with cancer to be made to feel as "normal" as possible, and successful school experiences are a strong factor in providing a child with a normal life. At the same time, much current research supports the belief that successful school experiences require the combined efforts of parents and teachers (Epstein, 1992; Henderson, 1989).

According to Kaplan, Smith, and Grobstein (1974), a child's ability to cope with a serious illness is largely dependent on the behavior of adults in his/her immediate environment. Like all human behavior, the behavior of adults is largely shaped by their perspectives of a given situation. For the majority of children, the most significant adults in their lives are their parents and their teachers. However, when a child is diagnosed with cancer, much of the impact of adjustment is on the parent, and parents are often faced with the responsibility for "bridging" the medical world and the school. Therefore, studying parents' perspectives of their child's school experiences is important since these perspectives inevitably shape both the parents' and the children's behavior.

There is also general agreement in the professional literature that school and family connections are important for schools, children, and families (Epstein, 1992). The relationship between schools and parents is a factor widely discussed by educators and psychologists as important in the effectiveness of educational programs for children. In the literature, schooling issues for children with cancer are most frequently addressed by health care personnel. Many needs of these children have been identified, particularly physical, social/emotional concerns, and in many cases, learning difficulties related to the cancer or its treatment. However, there are few references that represent the perspectives of parents with respect to their children's schooling experiences. An exception to this is a recent study by Niles (1992) at the University of Alberta, which focused on the schooling needs of children with cancer from the parents' perspective. A teacher at a large urban hospital, Niles introduced her study by quoting a charge nurse who once said to her: "There is no quicker way to give a kid the message that he is going to die than to tell him he does not need to go to school anymore." Since schooling was clearly not optional, she said she decided to take a closer look at the specific educational needs of children with cancer, and to do this by talking to the parents of these children. However, Niles did not report on these parents' perspectives of their children's actual schooling experiences. In this study, my intention was to expand on Niles' study by talking to parents about their views on their child's schooling experiences since the diagnosis of cancer.

Significance of the Study

This is a particularly important area of research at this time for two main reasons. First of all, developments in scientific medical knowledge and treatment have resulted in changing childhood cancer from an illness that was inevitably fatal to one where at least half of the total number diagnosed can enjoy a permanently controlled disease along with a "normal life" (Charlton, Pearson, & Morris-Jones, 1986; Hughes & Lieberman, 1990; Katz et al., 1992). Each year in Canada, approximately 845 children are diagnosed with cancer, and approximately 630 of these children will survive this diagnosis (Canadian Cancer Statistics, 1994). Secondly, there have been dramatic increases in at-home care rather than long-term hospitalization, and in the integration of students with special needs into regular schools and classrooms. Until the 1980s, children with special health care needs were frequently cared for in hospitals or other institutions. Since that time, children with all types of special needs have been increasingly moved from institutions and special education centers, and placed in regular schools.

Both of these factors have resulted in increasing numbers of children who have been diagnosed with cancer attending their community schools. Since these changes have occurred over the past twenty years, it is not surprising that many teachers may not have been adequately prepared to meet the needs of these children and their parents (Charlton et al., 1986). One recent American survey of public school teachers found that only 38% of the respondents reported any coursework in their teacher education programs related to chronic health conditions, although over 40% reported having one or more children with chronic health conditions in their classrooms (American Federation of Teachers, 1992).

Furthermore, the school children who are the focus of this study, the survivors of childhood cancer, are not generally included in the "special needs" category, and thus they have not been given as much research attention from the educational community as other groups of children with special needs. In fact, it has been estimated that at least one in every 1,000 children in the general population is now a survivor of childhood cancer (Granowetter, 1994; Meadows & Hobbie, 1986). This figure exceeds the number of students with severe hearing impairments or visual impairments, or those with severe to profound mental retardation.

As increasing numbers of children experience longer survival, and return to their regular schools, new problems arise for both the patients and their families. It has been well-documented that the child's emotional response to cancer and treatment is directly related to the parents' reactions (Gibbons, 1988). There is also substantial evidence that schools affect children's general adjustment, and that families affect children's school adjustment (Rotheram, 1989).

I believe that this is an important area of research, and one that can help in terms of facilitating communication between families and schools. One of the objectives of this research is to assist schools to better meet the needs of children who have been diagnosed with cancer. The study also has practical implications for psychologists and counsellors who work with the families of children with cancer.

Organization of this Thesis

In this first chapter, I have addressed the background to the study. The problem is stated, along with the purpose and significance of the study. In Chapter Two, the relevance of the question is addressed in the context of a literature review and an outline of the conceptual or theoretical framework that has guided my inquiry.

Chapter Three explores the theoretical perspective contained in the method of study, which is basically descriptive and exploratory in nature. I also describe in detail the methods and procedures that I employed to carry out this investigation.

Chapter Four is the presentation and interpretation of the findings of this study, the main themes that emerged from the analysis of the data. In Chapter Five, I discuss some of these findings, and compare them with current professional literature in the area. Chapter Six is a summary of the implications that have emerged from this study.

CHAPTER TWO

CONTEXT

Theoretical Approaches and Assumptions

Theory is central in qualitative family research (Gilgun, 1992). Not only is development of theory a major goal, but data analysis and interpretation are organized by theory. Qualitative methods also offer ways to demystify theory development, by inviting others to scrutinize the processes as well as the products.

Over the past 30 years, psychosocial functioning in children with cancer and their families has been the subject of a significant number of studies. Since the 1960s there have been over 200 psychosocial studies of coping, adjustment, or adaptation to pediatric cancer (Kupst, 1994). Most of these studies have been more concerned with description than with theoretical perspectives. Kupst (1994) notes that there is a notable lack of theory-driven research in pediatric cancer. Few investigators have explicitly identified a theory or paradigm that guides them in their work, and even fewer have provided a link between theory and research. Since this field is still in a descriptive phase, "theory" as such may be premature; however, every study proceeds from some basic assumptions that affect the choice of research question, methodology employed, and interpretation of results.

In a recent review of current literature, Kupst (1994) describes the main orientations that have been used in psychological research with pediatric cancer patients and their families. She suggests that some of the underlying assumptions about the population of children with cancer and their families also guide this research. In a pathology-oriented model, children with cancer and their families are seen as being at risk for significant psychological problems, and studies attempt to compare them to "normal" families. In a normative-based model, children with cancer and their families are viewed as normal individuals who are facing a series of stressful situations. Here the emphasis is on the process of coping with an abnormal situation. Within this normative model, children and families are often viewed as a sample of the population of patients with chronic illnesses and their families.

"Coping" has been defined as the efforts one makes to deal with situational demands (Kupst, 1994). Thus, coping strategy is an intervening variable between stress and adaptation. Kupst (1994) describes a number of theoretical perspectives that have been used in the coping research with childhood cancer patients and their families. She notes that these models are not necessarily mutually exclusive, and some researchers may use more than one orientation:

(1) Grief and Loss Model. Until the early 1970s, most studies employed a grief and loss paradigm, since the prognosis for pediatric cancer was almost uniformly poor. One of the important concepts in many of these studies was that of "anticipatory grief." This paradigm assumed that parents could be expected to exhibit psychosocial problems, and that intensive psychosocial intervention with the family would probably be necessary to help them work through their grief. However, the model provided little opportunity to discover healthy forms of coping, and was not as relevant for understanding how children and families cope with 2 to 3 years of intensive treatment, the late effects of treatment, and coping with survival. As children with cancer began living longer and even being cured, and as more studies began to emerge (Koocher & O'Malley, 1981; Spinetta & Deasy-Spinetta, 1981), it became clearer that a pathological orientation did not fit. Instead, these families appeared to be basically normal people who, while they might experience significant stressful situations and losses, did not develop serious psychopathology.

(2) Stress and Coping Model. This model was based on the work of Lazarus (1991), and emphasizes situational characteristics (coping tasks) and what people actually do to deal with them (coping strategies). Thus, coping is not seen as a state or a disposition, but it is what people actually do in a specific situation. According to Lazarus, coping strategies are not good or bad in themselves; they have to be appraised in light of the outcome and in relation to adaptation in specific situations. In addition, what works at

one time may not work later. Two of the basic assumptions of this model are that the expected outcome is adaptation rather than psychopathology, and that coping is a process that is enacted over time.

(3) Development Model. This model emphasizes that children with cancer and their families are normal people undergoing a stressful situation, and that basic normal developmental processes continue in spite of the disease. Thus, some basic assumptions of the developmental model are that the impact of cancer must be considered in light of the child's developmental level, that normal developmental issues and needs (i.e., school, peer relationships) should be acknowledged, and that a process approach is necessary. The family's stage of development also needs to be taken into consideration.

(4) Cognitive-Behavioral Model. This model is generally espoused by those who are more interested in intervention in pediatric cancer, and helps us to understand such problems as anxiety, distress behavior, pain, nausea and vomiting, anticipatory reactions, and social withdrawal. Common interventions include distraction, relaxation, hypnosis, guided imagery, providing information, behavioral rehearsal, and modeling. The assumptions of this model are similar to those of the stress and coping model, where children with cancer and their parents are seen as essentially normal people in an abnormal situation.

(5) Social Ecology Model. The basic premise of this model is that the child with cancer must be studied in the context of transactions that occur with social and environmental systems. This model is derived from Bronfenbrenner's (1979, 1986) theory in which development co-occurs within different contexts that constitute a series of concentric rings radiating outward from the child: the microsystem (family), the mesosystem (interactions among family, school, hospital, agencies), the exosystem (social support networks, agencies with indirectly affect the child), and the macrosystem (culture and policy). The child and family members are not viewed as isolated individuals, but as

they interact with other persons and systems. These interactions are both multidirectional and dynamic.

This social ecology orientation emphasizes a nonpathological, developmental perspective, including the developmental level of the family. It also reflects the most comprehensive approach to understanding that a child's coping is related to his or her social context, and supports the need to consider the parents' perspectives. Kupst (1994) states that according to the social ecology model, intervention studies should go beyond those that target the individual child to include parents, siblings, peers, schools and medical settings (p. 45). This contextual approach to the study of childhood cancer survival requires consideration of other systems that relate to survivors and their families.

It is estimated (Libow, 1989) that between 6% and 12% of all children in North America have a serious chronic illness. The impact of a child's illness on the family is related to the major dimensions of onset (acute or gradual), course of illness (progressive, constant, or relapsing), outcome (fatal or nonfatal), and degree of incapacitation. Three other dimensions -- pain, deformity, and treatment ambiguity -- are also relevant to the emotional impact of a child's illness on the family system. The age of onset of the illness is significant, not only because it determines the young patient's level of understanding and degree of dependency on parents, but because it also determines the stage of the family life cycle at which the family first confronts the challenge of illness. As Carter and McGoldrick (1980) point out, if chronic illness happens to surface during an already stressful period in the family life cycle, greater difficulties can be predicted.

Van Dongen-Melman, Pruyn, Van Zanen, and Sanders-Woudstra (1986) present a conceptual framework for studying the impact of childhood cancer on the psychological and social functioning of the patient and the family. Their model is based on the literature relevant to coping with stress, especially with respect to cancer, and on two psychosocial theories of human behavior, the attribution theory and the social comparison theory. According to Van Dongen-Melman et al. (1986), childhood cancer presents a complex of potential stressors to a family. These stressors include the life-threatening nature of the disease, the side effects of the medical treatment, the number of hospitalizations, and the reactions of family, friends, and others. Any stimulus is perceived as a stressor when it causes (1) uncertainty, (2) loss of control, (3) threat to self-esteem, and (4) negative feelings. These four aspects of stress can vary in intensity, and they can also occur simultaneously. Van Dongen-Melman et al. (1986) point out that uncertainty is one of the most striking features of childhood cancer. As a result of progress in medical treatment, the course of the disease has a much increased chance of disease-free survival and cure; consequently, the course of the disease has become extremely difficult to predict.

> The psychological dilemma of children with cancer and their families has been transformed from one of adapting to the imminence of death to one of coping with uncertain survival. Because individuals in this situation do not know whether to prepare for death or for life, living with the disease, by definition, means living with uncertainty. (van Dongen-Melman et al., p. 149)

Loss of control, threats to self-esteem, and negative feelings are also very common factors in childhood cancer.

When individuals are faced with problems, they are motivated to use coping strategies to lessen or eliminate those problems. The most important coping strategies are: (1) seeking information, (2) seeking support and comfort (for example, patients from families that openly discuss the illness seem to have fewer problems and are more satisfied with themselves), (3) attributing events to causes (attributing the cause of the illness to an external agent can have positive effects because it allows one to maintain self-esteem), (4) attempting to change the situation, (5) using denial and avoidance (denial often permits the child with cancer to live with the illness, resulting in better psychosocial adjustment and a more positive outlook on the future), and (6) accepting the situation (Van Dongen-Melman et al., 1986).

This proposed model is very helpful in our understanding of the stresses that are most specific to childhood cancer (for the child and the family), as well as the common coping strategies that families use to deal with these stressors. However, it fails to explain why some people would choose certain strategies over others, and it does not necessarily account for the impact of other systems outside the family, such as the school or the medical system.

Historically, family coping with childhood cancer has been viewed as a problem requiring intervention, but more recent studies have reported that families coped well (Kazak, 1994). However, many of these studies were using non-standardized instruments to measure family coping with childhood cancer (Birenbaum, 1990). Birenbaum's 1990 study described parents' coping in 45 families where a child had cancer, using the scales of a standardized instrument, the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin, & Cauble, 1981). Birenbaum began this study with an assumption that illness is a subjective perception of a symptom and the evaluation of that symptom. In childhood cancer, families construct an "illness representation," and develop an illness perspective as they learn to live with the effects of the cancer and its treatment. Birenbaum's review of the childhood cancer research resulted in identifying two levels of "illness representation" in the family, **encapsulation** and **at-risk**. Both encapsulation and at-risk are evidenced in family coping strategies.

Encapsulation within a family is manifested in the coping strategies of normalization and controlling the meaning of the experience. Although cancer limits activity and even longevity, many children with cancer engage in normal age-appropriate behaviors, and many families attempt to function as normally as possible. Normalization has become the "watchword" for medical professionals in prescribing parenting for the chronically ill child. However, in childhood cancer, parents must assume responsibility for many of the daily problems, such as symptom control, regimen compliance, and crisis management. How parents manage these daily problems influences the entire family.

A second way to encapsulate the illness is by controlling the meaning of this experience. Strategies that control the meaning can be grouped into cognitive functions or behaviors. Some examples of cognitive functions are a realistic appraisal, an optimistic viewpoint, affirming life, and endowing the illness with meaning. Parents' behaviors that function to encapsulate the illness include living day-to-day, open communication, shielding (withholding information), role obligations, reorganization of life, treating the child as normal, and keeping the child's spirits up.

For parents, the **at-risk** role involves acting to overcome the illness and to block its recurrence. This is primarily done by complying with treatment and protecting the child. Parents' ways of monitoring signs, symptoms, and infection prevention communicates an attitude about illness to the child as well as to all family members. Particularly in young children newly diagnosed with cancer, parents play a major role in interpretation of this experience.

Birenbaum's (1990) study was an attempt to document whether families successfully encapsulate the illness, engage in predominantly at-risk behavior, or use some combination of these strategies. Her findings suggest that most families coped well while living with childhood cancer, and that the concepts of encapsulation and at-risk behaviors are conceptually good descriptors of parents' coping strategies.

Others have suggested that the way a family manages stress is determined to a large extent by the meaning that the family attaches to the event (Boss, 1988). Figley (1989) described the creation of a system of meaning for families of children with cancer as the family's "healing theory." In developing this healing theory, the family members, both individually and jointly, form a perception of the situation that incorporates their understanding of the situation, as well as acceptance and affirmation of their responses and the reasons behind them. Families (and parents) can be viewed as groups that construct both individual and shared meanings (Daly, 1992b). In qualitative research on families, one of the things we do is seek to understand how families (and in this case, parents) give insight into the meanings of their experience. These family meanings can often become more understandable when we study the "problematics," the disruptions, or the non-normative transitions, in family experience. It is my hope that studying parents' perspectives of their child's schooling experiences after the child has been diagnosed with cancer can offer insight into the everyday meaning of children's schooling experiences, as well as of parents' perspectives regarding these experiences.

I undertook this study based on the following "assumptions":

(1) that parents of children with cancer would have "thoughts and perspectives" regarding their child's schooling, and that they are likely to have encountered some challenges and difficulties in this area,

(2) that parent perspectives are an important factor in the child's overall school experience and achievement, and

(3) that "schooling" can be defined broadly as all of the formal educational experiences that the child receives.

Characteristics of Childhood Cancer, Diagnosis and Treatment

Childhood cancer is a relatively rare disease, accounting for less than 2% of all cancers. The risk of developing cancer between birth and age 15 is about 1 in 600 (Granowetter, 1994). Each year in Canada, approximately 845 children are diagnosed with cancer (Canadian Cancer Statistics, 1994); of these children, it is anticipated that the overall survival rate will be over 60%.

Advances in medical treatment of childhood cancer over the past two or three decades have dramatically increased survival rates (Peckham, 1989). Recent treatment advances including chemotherapy, radiotherapy, and surgery, as well as improved diagnostic expertise and effective drugs to combat infections, have all dramatically changed both the longevity and quality of life for these children. Whereas a diagnosis of childhood cancer used to imply a rapidly progressing fatal disease, long-term, disease-free survival is now a fact for close to two-thirds of the total number diagnosed. Along with these developments, the quality of life for the child becomes a far more pressing consideration.

Cancer is an abnormal, uncontrolled proliferation of cells, which can occur in any organ system of the body. However, the "why" of cancer for most individuals remains a largely unanswered question. For most childhood cancers, the etiology is most likely due to a complex interaction of environmental factors and genetic susceptibility (Granowetter, 1994). The most common form of childhood cancer is leukemia (cancer of the bone marrow), followed by brain tumor, and then lymphoma (cancer of the lymph glands). Other typical childhood cancers are Wilms' tumor (a cancer of the kidney), neuroblastoma (a tumor of sympathetic nervous tissue), and a variety of solid tumors involving muscle, bone, the eye, ovarian and germ cell tumors, and the liver (Granowetter, 1994). The age of onset of childhood cancer also varies with the specific disease. For example, bone tumors usually occur in the second decade of life, while Wilms' tumor and neuroblastoma most commonly occur in children between the ages of 2 and 3 years of age. The peak incidence of acute lymphocytic leukemia (ALL), the most common pediatric cancer, is between ages 3 and 6 (Granowetter, 1994).

Childhood cancer is sometimes difficult to diagnose at first. This is partly due to its relative rarity, and the fact that diagnosis is usually suggested by a constellation of symptoms rather than any specific symptom in particular. The manifestations of cancer relate to its organ of origin. For example, children with leukemia may be anemic, have a tendency to fever or infections, or experience bone pain due to expansion of the bone marrow filled with leukemia cells. With brain tumors, there may be headaches or vomiting, changes in personality or cognitive function or motor control, and other neurologic changes. Other solid tumors may be detected through a growth, which may be visible or may cause pain.

Once cancer is suspected, the child undergoes a variety of interventions to determine the specific diagnosis and the extent of the disease. Once again, these interventions are related to the suspected illness. For leukemia, diagnostic tests include blood counts and examination of the bone marrow; while for tumors, X-rays and biopsies of the tumor tissue are required. Bone marrow aspiration is done by inserting a needle into a marrow-bearing bone, most often the hip bone. A second procedure, called a lumbar puncture (LP), or spinal tap, is required to determine if the leukemia has spread to the central nervous system. Once again, this test is done by inserting a needle in the spinal column to remove some spinal fluid. Both the bone marrow aspirates and the lumbar punctures are done intermittently through the course of treatment, to evaluate the state of the disease and, in the case of the lumbar punctures, to give medicine directly into the spinal fluid.

For most brain tumors, the primary treatment is surgery, followed by radiation and chemotherapy. Recent treatment programs employ chemotherapy after surgery, in order to delay the administration of radiation as long as possible with young children, where the neuropsychological sequelae of radiation can be severe. Current treatment programs for lymphoma, depending on the subtype of lymphoma, include chemotherapy with multiple medications given directly into the spinal fluid. For patients with central nervous system (CNS) disease at diagnosis, cranial radiation may also be used.

After diagnosis, treatment is usually started right away, since cancer is invariably fatal if untreated. The first goal of treatment is to obtain a remission, which is a realistic goal for almost all children with cancer. Further therapy serves to consolidate and maintain this remission. The initial phase of treatment is called *induction*, indicating that treatment is planned to induce a remission, or to obtain a state of no obvious disease. The term "remission" implies that although there is no obvious disease, microscopic disease still exists, and thus further treatment is required. Most leukemia treatment plans include *consolidation* treatment, which is usually geared at preventing the occurrence of central nervous system disease. Afterwards, *maintenance* treatment continues for 2 to 3 years.

The initial induction period of therapy usually takes place in the hospital, and requires about two to three weeks of treatment. Once the child is in remission, therapy continues on an outpatient basis, with intermittent admissions to the hospital for possible infectious complications or for administration of medications which require hospital observation. Most children with cancer respond to initial therapy, but relapse or recurrence of the disease may occur during or after therapy. Relapse is usually not a good sign, although most cancers will respond to treatment for relapse, and some children may be cured even after relapse. Unfortunately, death still occurs in about 35-40% of children, due to either relapsed disease or as a consequence of therapy complications. *Cure* is defined as the absence of the cancer, off treatment, for a period of time based on the natural history of the specific disease. For example, a child free of leukemia 4 or 5 years after initial completion of therapy is generally considered cured, because later relapses are rare.

There are three primary treatment modalities for cancer: chemotherapy, surgery, and radiation therapy. Most leukemias are treated only with chemotherapy, although radiation therapy may also be used. Most solid tumors require combined-modality therapy, that is, chemotherapy used in combination with surgery and/or radiation therapy.

Some chemotherapy is given intravenously, some by mouth, and some by injection into a muscle or directly into the spinal fluid. Since the effects of chemotherapy are not completely selective, there are some unavoidable side effects on normal tissues. The most common side effects are temporary low blood counts, resulting in susceptibility to infection, bleeding tendency, and anemia. Other common side effects include temporary hair loss, nausea and vomiting, general malaise, mouth sores, or changes in appetite or ability to eat. There may also be short and long-term damage to internal organs, particularly the heart, kidneys, and liver (Granowetter, 1994).

Radiation therapy is used when surgery and/or chemotherapy cannot completely remove the tumor, or when there is residual microscopic tumor. Most radiation treatments are a form of external beam radiation, delivered by a machine to the patient (outside the body). Each treatment generally takes only a few minutes, and is not painful, but it must be delivered to a completely still patient. For very young children, this usually requires either strong sedation or anesthesia. Side-effects of radiotherapy include reddening and irritation of the skin areas receiving radiation, loss of appetite, and malaise, as well as specific effects related to the site of the tumor (headache if the head is irradiated, diarrhea if the abdomen is irradiated). Radiation in high doses will also prevent normal growth of the areas irradiated, and may be associated with secondary malignancies (Granowetter, 1994). In treating children, radiation is generally used only when required for cure, and the lowest effective total dosage is used.

Bone marrow transplantation is now also being increasingly used as a treatment for leukemia and in the treatment of solid tumors. A bone marrow transplant is not a surgical procedure; it consists of an intravenous transfusion of bone marrow, that is, the cells which are capable of forming blood, and not the bone itself. The source of marrow for transplantation may be a donor or the patient, from whom marrow is collected during a remission. The donated marrow enters by vein, but then finds its way to the bone marrow, and repopulates the marrow with the cells necessary to regenerate all the blood-forming elements. Before bone marrow transplantation, chemotherapy (and often radiation therapy) is given in doses so high that normal bone marrow function would not recover without the transfusion of marrow replacement. After the bone marrow is infused, it takes several weeks before the patient has normal bone marrow function. During this time, there is a high risk of infection or other complications, and the patient needs to be kept in protective isolation.

Late Effects of Childhood Cancer and Treatment

As significant numbers of children are surviving cancer, the long-term and sometimes late-appearing effects of therapy have become increasingly important. Although the goal of the medical specialists is to cure without creating long-term disabilities, current treatment programs seem to result in late effects for many children (Granowetter, 1994). Late effects of cancer among children are usually defined as occurring after the successful completion of medical therapy, usually two or more years from the time of diagnosis (Mulhern, 1994). It is generally assumed that these late effects are chronic, if not progressive; this separates late effects from those effects of disease and treatment which are acute and time-limited, such as chemotherapy-induced nausea, vomiting, or hair loss. Neuropsychological late effects are related to pathological changes in the child's central nervous system (CNS) secondary to cancer or its treatment, and are manifested by changes in the child's behavior. The most frequently studied behavior correlates include intellectual and cognitive functioning, as well as academic performance. However, all research designs are quasi-experimental at best, since the researcher cannot control for essential features of the child's disease and therapy.

Peckham (1989; 1993) suggests that the price of long-term survival and cure for some children with cancer may be the long-term effects of the treatment that saved their lives. Naturally, the most feared late effect is a second malignancy or cancer. Brain surgery, cranial radiation, and some chemotherapeutic agents can also compromise cognitive or sensory functions. Some families who face life-threatening disease with their child subsequently face school problems and learning difficulties created by the cure. These children and their families have already had a very special experience of surviving a life-threatening disease with its psychosocial, emotional, and physical consequences. Some cancer survivors return to school with few effects of treatment, but most experience acute short-term effects of treatment while undergoing chemotherapy. Others experience long-term effects such as the development of growth and hormone failure, or of learning disabilities subsequent to radiation treatments (Peckham, 1989).

Studies have also shown neuropsychological sequelae in children who receive radiation therapy to the cranium, or chemotherapy with significant entry into the CNS (Granowetter, 1994; Meadows & Hobbie, 1986). Not surprisingly, neuropsychological difficulties are closely associated with difficulties in academic achievement. Special education placements and retention in a grade were common in one study of long-term survivors (Peckham, Meadows, Bartel, & Marrero, 1988). The younger the age at time of treatment, and the higher the dose of radiation, the higher the risk.

Loss of fertility is an important late effect for children who have received radiation which involves the ovaries or testicles, or who have received certain classes of chemotherapy. Other treatment-related late effects include growth problems and disturbances in organ function due to specific chemotherapeutic agents. These can include kidney dysfunction and hearing loss, heart failure and pulmonary problems. Because of these possible late effects, children who survive cancer must be carefully monitored throughout their life, and many institutions have started "long-term survivor" clinics to meet the needs of these children and their families (Granowetter, 1994). One other significant late effect is related to the possible stigma of being a cancer survivor (Granowetter, 1994), which may have ramifications in school admissions, employment opportunities, and accessing various types of insurance protection plans.

Many of the potential problems likely to be encountered in long-term survivors of childhood cancer are reflections of the therapeutic modalities employed in achieving these successful outcomes. Meadows and Hobbie (1986) conducted a study of 200 long-term survivors (i.e., over five years since diagnosis or last evidence of disease). The most common effect of treatment found in the patients treated for leukemia was severe learning problems, necessitating special education. Other problems included obesity, extremely short stature and gonadal failure, and the risk of secondary neoplasms.

The psychosocial consequences of cure have also been documented. Lansky, List, and Ritter-Sterr (1986) state that:

> Surviving cancer itself does not necessarily signal an end to the difficulties and stresses faced by young patients and their families. The late medical sequelae of cancer and its treatments can be frightening and restrictive, and

> the financial burdens incurred during treatment can be prohibitive, extending beyond the time of illness. Equally significant are the alterations in life-style, relationships, future plans, and intrapsychic equilibrium consequent to living with a life-threatening disease. (p. 529)

Psychosocial problems may also be a direct result of the disease and its treatment, or of the family's capacity to deal with the difficult and complicated experiences they have faced. Sometimes parents will develop patterns of over-protection for their child, which may be appropriate at the onset of the illness but become inappropriate as the child becomes well (Peckham, 1989).

School activities make up a large part of a child's world. Return to school is thus important to the successful psychosocial rehabilitation of the child with cancer. Children newly diagnosed with cancer are now being recommended to return to pre-illness activities and environments as soon as medically feasible (Katz et al., 1992). However, studies have shown high rates of absenteeism among these children (Lansky, Cairns, & Zwartges, 1983) and a higher than average rate of school phobia (Deasy-Spinetta, 1981). These phenomena appear to be connected to psychosocial late effects of cancer, as well as to some of the physical/medical late effects. These psychosocial late effects include depression, and difficulties re-establishing previous activities and lifestyle. The disruption of school participation and accompanying social experiences because of cancer and its treatment have been related to major problems in adjustment and adaptation to the disease (Katz et al., 1992).

Several recent studies have found evidence of difficulties in cognitive functioning and academic achievement for pediatric cancer patients (Greenberg, Kazak, & Meadows, 1989; Sanger, Copeland, & Davidson, 1991; Sawyer, Toogood, Rice, Haskell, & Baghurst, 1989). However, Kupst and Schulman (1988) found that most children coped well overall with treatment and long-term remission, in spite of the fact that at least one-fourth of the children did indeed have some academic problems.

Studies have shown that there are declines in IQ scores and evidence of learning disabilities in children who received cranial radiation therapy (Meadows & Hobbie, 1986; Mulhern, 1994; Rubenstein, Varni, & Katz, 1990). The drop in IQ score appeared to be greatest in younger children and those with initially high IQ's, but did not become evident until three or more years after diagnosis. Other studies (described by Mulhern, 1994) have suggested that children irradiated at younger ages (under five years) are more likely to exhibit deficits than are older children. Ross (1984) states that learning problems have been observed not only in children with brain tumors, but also in those who received radiation treatments to the brain to prevent central nervous system leukemia. Memory loss, sequencing difficulties, inattentiveness, and trouble concentrating are among the observed problems affecting academic achievement in this group.

Peckham (1989) states that it is now clear that there are significant residual effects of some chemotherapeutic agents. For example, certain anti-cancer drugs may cause hearing loss, while others may affect vision. The price of survival for some children may be the loss of specific sensory function, which may have direct impact on the child's learning ability. It is also becoming clear that the effects of cranial irradiation do not appear immediately after treatment, but two or three years after the radiation treatments are finished. Work with parents and teachers of long-term survivors of childhood cancer has shown that each child is an individual, and that the degree of late effects differ from child to child. The kinds of problems encountered by these children in school are similar to those of other children with special learning disabilities (Peckham, 1989). Peckham concludes that:

> Any child who received cranial irradiation as part of cancer treatment should be considered to be at academic risk. An awareness by parents, teachers, and other educational professionals that there may be late effects of medical treatment is imperative. (p. 323)

Because treatment with chemotherapy alone has become increasingly successful, most children diagnosed with leukemia today receive no radiation. But there are still many children who do receive cranial radiation--for relapse, central nervous system disease, or bone marrow transplantation--and those children will probably experience at least some school difficulties as a result (Peckham, 1993). However, the degree of these late effects differs from child to child, and is very difficult to predict.

I began this research with the assumption that various late effects of cancer and its treatment would quite likely have an impact on the schooling experiences of these childhood cancer survivors. Since many of these late effects are so difficult to predict, and since they would naturally not be obvious for a number of years after diagnosis and treatment, I speculated that these may be contributing factors in shaping the parents' perspectives with respect to their children's schooling experiences.

The Child with Cancer and the Family

Until 1970, the psychological literature on children with cancer was largely devoted to helping professionals and parents to cope with a "fatal illness" (Spinetta & Deasy-Spinetta, 1981). By the mid-1970s, with increased survival rate, there came a gradual change in focus from death to life, and an increased interest in the quality of the ill child's life. The focus of both medical and psychosocial concerns shifted from preparing for an inevitable death to helping the child and family prepare for an increased chance of long-term survival.

The first psychological study of long-term survivors, The Damocles Syndrome (Koocher & O'Malley, 1981) was a comprehensive study of 117 survivors. Koocher and O'Malley document how changes in cancer treatment, as well as changes in prognosis, have raised new issues for patients and their families. Success in treatment for many forms of childhood cancer have come at a rather high cost to the patients themselves; frequently the "cure" seems worse than the disease. Losses in self-esteem and self-confidence can have a negative effect on children's peer relationships and willingness to attend school, thus further affecting their emotional and academic development. The patient's age is also an important factor in this respect. For example, hair loss may not be much of a problem to a five-year-old, but may be very disturbing to an older child. Koocher and O'Malley (1981) describe the experience of cancer patients and their families as "living in limbo," as they cope with long-term uncertainty and balancing an awareness of the possibility of death with a realistic hope for cure.

By the late 1980s, several studies of long-term survivors were published (Chang, Nesbit, Youngren, & Robison, 1987; Greenberg, Kazak, & Meadows, 1989; Kazak, 1994); most of these studies were about survivors of ALL or lymphoma, and tended to utilize samples across a broad age range. From these studies, strong support for generally normal levels of psychosocial adjustment among long-term survivors of childhood cancer emerges. However, despite an overall picture of normal adjustment, there is also consistent evidence for psychological difficulties, especially subclinical anxiety or depression, for a significant percentage of survivors (Kazak, 1994).

There is general agreement that a chronic or life-threatening illness such as cancer exerts a powerful impact on children and their families (Rolland, 1987). Although it is likely that there are commonalities in the impact of chronic childhood illness on families, different illnesses and treatments do have specific and unique impacts as well. Rolland (1987) has outlined four characteristics of illnesses (onset, course, outcome, and degree of incapacitation) that may affect psychological outcome differentially.

Several early clinical studies cited a high frequency of emotional disturbances in families, generally parents, of children with cancer; others failed to replicate these findings and even noted positive functioning in many cases (Kupst, 1994). Kupst and Schulman (1988) describe a project that followed 64 families of children with pediatric leukemia for six years, and found that parental coping was normal, and that indeed there were no instances of serious psychological dysfunction. These findings support Kazak and

Meadows' (1989) suggestion that it is time to accept the null hypothesis of no important differences between these families and "normal" families. Kupst (1994) proposes that rather than continue to focus on finding differences, it would be more useful to determine what children and their families do when faced with cancer, and to determine what variables are related to good coping and adjustment to childhood cancer.

Family development includes identifiable stages in the life cycle, and childhood chronic illness can disrupt family development, interpersonal relations, and allocation of resources. For example, in the case of childhood cancer, anxieties about the future may disrupt the child's ability to individuate from the family according to societal expectations. For this reason, psychological problems of chronically ill children often present at critical times in development, such as the beginning of school or onset of adolescence, both of which require increased demands for independence. The contribution to development demanded by parents of school-age children is "letting go" comfortably. Since the child in his/her school years needs to become more autonomous and move into relationships with teachers and peers, those same parents from whom so much nurturance was recently required must now "surrender" some of their involvement with their child (Drotar, Crawford, & Bush, 1984).

Drotar, Crawford, and Bush (1984) state that since chronically ill children (like all children) learn strategies of coping and adaptation from their transactions with family members, the quality of intrafamilial coping is a critical component of the child's ability to negotiate the stressful demands of disease-related regimens, socialize with physically healthy peers, and function effectively in school and at work. Therefore, a family systems perspective is critical in planning mental health interventions for chronically ill children who are initially identified as having individual adjustment problems that are more properly construed as related to family functioning.

General systems theory has been applied to the study of families by many other researchers. Wright and Leahey (1984) outlined the contributions of general systems theory to their development of a family assessment and intervention model for nurses. They identified several concepts stemming from this perspective, starting with the concept that individuals and family systems are part of a larger suprasystem, as well as being composed of subsystems. Another concept is that change in one or more family members affects all other family members. A third concept is related to a family's ability to create balance between change and stability, so that both can coexist at the same time. Finally, the last concept states that behavior is best understood from the point of view of circular causality rather than linear causality. For example, a parent's behavior influences that of the child, and the child's behavior in turn influences the parent (Northouse, 1984).

Adopting a systemic perspective, Northouse (1984) outlined how cancer impacts upon the entire family system, as cancer patients both affect and are affected by family members. She describes three general phases in the course of cancer: the initial phase, where family members have to deal with the diagnosis and early treatment; the adaptation phase, where concerns are more related to changes in lifestyles, meeting the needs of well family members, and living with uncertainty; and the terminal phase, where families are called upon to deal with the death of the person with cancer. As she reviewed the literature, Northouse noted that the majority of family-oriented studies focused on families of patients who were dying, and that very little research was conducted on families of patients who have completed treatment and are considered "survivors," or what she terms the "adaptation phase." This emphasis is not surprising, since cancer is often equated with death; however, the increasing survival rates among children diagnosed with cancer has resulted in greater research emphasis, in the past 10 years, on the survivors and their families.

A study by Adams (1992), entitled Parents of children with cancer speak out, was commissioned by the Candlelighters Childhood Cancer Foundation Canada. Candlelighters is a new (1985) national organization serving families of children with cancer through assistance to parent support groups, and the purpose of the study was to gather information about its clientele. The survey was completed by 166 parents. (The percentage of responses from mothers was 86%, compared to 14% for fathers.) The parents said that children were helped most by clinic (72%) and ward staff (67%); this was closely followed by school involvement (40%), professional counselling (39%), and other children with cancer (35%). However, parents felt that they were the ones who helped their children with cancer the most (89%). They also commented that school re-entry programs were not available in some regions, and that some school personnel lacked experience in meeting the needs of children with cancer. Adams (1992) concluded:

> We are living in a time of increased medical improvements and new developments with the focus on long-term survival and cure. However, there remains a tremendous strain on children and families because of the uncertainty of the outcome, the intensity of the treatment, and the prolonged course of the illness. (p. 6)

Adams (1992) states that, over the last four decades, there has been a change from focus on death and bereavement to long-term survival and cure. Cancer has moved from a fatal illness to a life-threatening chronic disease of children. This has resulted in a change from concerns only about medical care to concerns about parents, then the child with cancer, then the family including siblings. Services have become multidisciplinary, with a greater focus on self-help groups, the social adaptation of children and families, and introduction of camp and school reintegration programs in the 1980s.

Greenberg and Meadows (1991) studied 118 children who were long-term survivors of cancer, and 120 of their parents. This study addressed the impact of surviving childhood cancer, based on the assumption that of these survivors, as many as three-fourths could be expected to experience at least some late effects of the disease or its treatment by chemotherapy, radiation, or surgery. These effects may include damage to specific organ systems, impairment in cognitive functioning, and reduction in linear growth or severe cosmetic changes in appearance. Half of the parents in Greenberg and Meadows' study expressed concerns about the late effects of cancer and its treatment on their children.

The majority of these parents said that they "worried" about their child's school performance, and that they noted subtle learning or memory problems.

Another study (Overholser & Fritz, 1991) explored the relationship between various facets of adaptation to cancer and psychosocial outcome variables assessed in "survivorhood." Even in survivorhood, the diagnosis of cancer in a child is associated with a variety of persistent and pervasive stressors for the family. When examining the stress of cancer on the family, at least three important domains of impact can be identified: personal distress, marital discord, and financial burden. Parents' distress is particularly associated with higher levels of hopelessness in the child. When examining any stressor, Overholser & Fritz (1991) claim that one can also identify variables that protect a person from the adverse effects of stress. Two important moderating variables are (1) social supports, and (2) coping styles. In relation to cancer, the availability of socially supportive relationships has been associated with better adjustment in parents of children who are in remission or in treatment for cancer. Coping styles are the cognitive and behavioral response patterns used to manage life's problems. Researchers have begun to emphasize the importance of individual and family coping styles in relation to medical and psychological treatments. The study by Overholser and Fritz (1991) assessed 44 children and their parents, two to seven years after the successful completion of treatment during a period of continuous remission. The study found that parental coping styles during the child's treatment can have important implications for the psychological and social functioning of both child and parents long after treatment ends. Therefore, helping parents of children with cancer to develop illness-related coping skills is an appropriate intervention.

Because a diagnosis of childhood cancer is a crisis that poses significant challenges to the stability and adaptive functioning of the entire family system (Carpenter & Levant, 1994), a number of research studies have chosen to focus on the impact of childhood cancer on the psychosocial functioning of siblings of the child with cancer. Several studies have reported that approximately 50% of the siblings of children who have cancer experience adjustment problems (Carpenter & Levant, 1994); however, most of these studies did not take into account the rate of adjustment problems among these children prior to the cancer diagnosis. Feelings of guilt, loneliness, rejection, jealousy, anger, sadness, and depression were among emotional symptoms of distress found among siblings (Spinetta & Deasy-Spinetta, 1981). There is also some evidence of externalized behavioral distress such as decreases in school performance, increased acting out at school, isolation from friends and family, acting out at home, and anger directed at parents and the child with cancer (Carpenter & Sahler, 1991).

Following a diagnosis of childhood cancer, parents begin a journey into what, for many, is personally uncharted territory. Uncertainty and a loss of control are inevitably involved. In fact, parents of children with cancer have to live with uncertainty at every step from the time of diagnosis onward (Maguire, 1983). Even when the child survives the first two-three years of active treatment, parents then have to decide whether or not they should take the risk of deciding that their child is now cured. In addition to this constant uncertainty, there are all the strains on parents that inevitably accompany the pain and discomfort associated with the cancer treatment, the cost of travelling to the hospital for treatment and getting time off work, and the difficulties associated with child-care for other children in the family.

Developmental Issues

Several developmental issues that warrant consideration for survivors of childhood cancer also have methodological implications for research in this area. The first is the developmental stage of the survivor. Survivors who are preschoolers, young children, and adolescents all face different developmental tasks. The age of the survivor when the cancer is first diagnosed is also of significance, since cancer is inevitably disruptive of normal experiences. Psychological problems of chronically ill children often present at critical times in development, such as the beginning of school or onset of adolescence, which require increased demands for independence (Drotar, Crawford, & Bush, 1984). The long-term differential impact of minor or substantial arrests in development has not been well-researched until now. Similarly, the extent to which treatment occurred at an age when memories can be accurately recalled is another developmental issue. The developmental stage of the child's family is also of interest, since the ways in which parents facilitate normal development hinges on the family's stage of development as well. Kazak (1994) suggests that one of the most obvious omissions in the research on childhood cancer survivors is that of a developmental perspective on the entire process of diagnosis, treatment and survival. Central to this is consideration of the experience of the disease for the child and the family, and the quality of the relationships formed with the medical team and the school personnel.

The psychological concerns that arise at diagnosis and during treatment also become part of the family's history, and are integrated into family development in subtle ways. Every family of a child with cancer faces the fear that their child might die, and such major issues cannot help but influence the survivor of cancer and his/her family. A key issue in the long-term relationships of the family and outside agencies (i.e., the medical team and the school) concerns the way in which the cancer diagnosis is communicated. Open communication with the child and family about the diagnosis is a relatively recent phenomenon (Kazak, 1994). Another developmental concern pertains to the period of transition from treatment, and the process of becoming an "ex"-cancer patient. Kazak (1994) discusses how the status of "survivor of childhood cancer" even lacks an appropriate term, and how we have no appropriate way to characterize children who have ended treatment but have not reached the five-year disease-free point to be called cured. "Survivor" in these cases may carry some sense of impermanence or feel somehow undeserved. Also, the label of survivor may also inhibit children and parents from voicing their uncertainties and troublesome memories (Kazak, 1994).

Childhood Cancer, the Family and the School

Most literature on school issues and childhood cancer focuses on school re-entry after treatment commences, or on concerns about an increased rate of absences by children in treatment. Far less has been written about survivors outside of the neuropsychological literature (Kazak, 1994). With some children, the question of learning problems may be raised by the school or by the parents. Often school personnel may be unaware of the potential academic impact of treatment that a child received many years earlier. Also, the types of subtle learning difficulties that some childhood cancer survivors evidence are often similar to behavioral difficulties (Kazak, 1994). Thus, difficulties with attention and memory, or a generally discouraged attitude toward school performance, may be attributed to laziness, depression, family problems, or other nonspecific emotional distress. Kazak (1994) has recently suggested that:

> Examination of the academic histories of childhood cancer survivors is an area ripe for psychological research. Such research would necessitate investigations of several different aspects of the survival experience. One aspect is the impact on the individual survivor of school difficulties related to treatment... A second aspect is *parental perceptions of learning difficulties in survivors and the ways in which parents process these difficulties for themselves, their children, and the school.* [italics added] (p. 175)

In one study of parental perceptions by Williams, Ochs, Williams, and Mulhern (1991), survivors of leukemia were perceived by their parents as having poor academic skills, which they often attributed to school absences.

Since school and peers are a major part of a child's normal development in our society, school adjustment has been viewed as an important indicator of functioning in children with cancer (Kupst, 1994). However, the school systems, as extensions of the larger society, are essentially designed to provide services to the average, healthy children who are able to attend and participate on a regular basis. Chronically ill children often fall "between the cracks," because the child's educational needs vary with the changing circumstances of the illness. Because of frequent or long absences due to treatment or illness, children with cancer often experience disruptions in their schooling. In addition, cancer and treatment-related problems in cognitive, academic, and emotional areas have been well documented. Cairns, Klopovich, Hearne, and Lansky (1982) state that:

> Despite recent improvements in medical technology, cancer remains a very stressful illness for a child and his/her family... Treatment is prolonged, often uncomfortable, and makes great demands on the families' time and emotional and financial resources. In addition, some children are left with physical handicaps resulting from the disease and/or treatment. It is becoming increasingly apparent that total treatment and successful rehabilitation of a child with cancer demand attention to all aspects of the child's and family's life. (p. 152)

School is a crucial area of concern in the child's treatment and rehabilitation for many reasons. First, academic achievement may be particularly crucial in enabling children to become productive adults. Secondly, children need the normal peer contacts and social life that occur in school to help them become socially mature. Finally, participation in normal school activities effectively counters the anxiety and depression that many children experience when diagnosed with a life-threatening illness (Cairns et al., 1982). For the child with cancer, school attendance takes on added significance as a "normalizing" factor. According to Deasy-Spinetta (1981), "the importance to the seriously ill children *and their families* (italics added) of the children continuing to find satisfaction and fulfillment in school cannot be overestimated" (p. 153).

Major advances in the medical management of cancer have resulted in increased long-term survival and potential for cure of children who have the disease (Spinetta &

Deasy-Spinetta, 1981). This has led to a shift in psychosocial emphasis from that of coping with imminent death to helping the patient and his/her family live with a chronic illness, with an increased emphasis on psychosocial rehabilitation and reintegration (Katz et al., 1988). Pediatric cancer patients are encouraged to return to their pre-illness activities and environments as soon as is medically feasible. One essential pre-illness environment is school. The disruption of school participation and intrinsic social experiences caused by the diagnosis and treatment of cancer has been related to major problems in adjustment and adaptation to illness (Spinetta & Deasy-Spinetta, 1981). As early as 1977, Katz, Kellerman, Rigler, Williams, and Siegel noted four general categories of school problems experienced by children with cancer:

> (1) The child exhibits school anxiety because of the illness or its treatment-induced physical side effects, such as hair loss, weight gain or loss, nausea and vomiting, and surgical disfigurement.
>
> (2) The child, parents, and school have difficulty reintegrating the patient into school after a prolonged absence.
>
> (3) The child has illness-related learning disabilities requiring psychological evaluation and possible special school arrangements.
>
> (4) The newly diagnosed child needs preventive intervention and guidance to be reintegrated into school.

A report of a three-year study of how children with cancer functioned in the regular classroom (Deasy-Spinetta, 1981) found that these children were viewed by their teachers as exhibiting school-related behaviors that vary significantly from those of the typical child in the classroom. These differences tended to be in the area of school attendance and academically-related issues, such as difficulty concentrating, and signs of learning disabilities. Teachers also said that student-patients appeared underactive and lacking in energy. However, a study conducted by Feldman (1980) concluded that the roles of teachers and counsellors, and the support of fellow students, were more important determinants of whether a school-age patient would continue with school than was the patient's state of health and the effects of treatment.

School Re-entry and Reintegration Programs

Many of the articles on the topic of children with cancer are reviews of "school re-entry" programs that have been established to assist children and their families as the children return to school after having been diagnosed with cancer. Research indicates that children who do not return to school in the early stages of their illness have more difficulty becoming reintegrated at a later time (Katz et al., 1988; Katz et al., 1992). Social acceptance by peers is a major developmental concern for all school-age children; when a child has cancer, this need for peer acceptance is intensified by the child's awareness that he/she is different from peers (McCormick, 1986). Furthermore, childhood cancer often causes frequent absences from school for treatment, and the time away from this important social arena can interfere with peer relationships and interactions (Spinetta & Deasy-Spinetta, 1981). Studies have shown that children with cancer often fear peer rejection, and feel isolated from their classmates. School personnel also describe social adjustment problems similar to those reported by the children (McCormick, 1986), but the perspectives of parents are not referred to. Clinical practice with children who have cancer has shown that they feel more hopeful about recovery when they are able to maintain normalcy in their everyday lives. Since school is a major part of a child's growing years, reintegration into the classroom is an important concern.

A number of "school re-entry programs" have been developed to help children with this transitional period (McCormick, 1986). These programs are usually highly individualized to address the special needs and concerns of each child. Emphasis is placed on providing classmates and school personnel with honest, straightforward explanations of the child's disease, its treatment and externally obvious side effects such as hair loss and weight gain. Other psychosocial factors of childhood cancer, such as frequent school absences and the issue of isolation, are also discussed. Re-entry programs generally consist of the following components: preparation of the child with cancer and the school personnel for the return to school, a classroom presentation, and a program follow-up. Children with cancer and their parents have responded very positively to such re-entry programs (McCormick, 1986).

Katz, Varni, Rubenstein, Blew, and Hubert (1992) conducted a study of children's, parents', and teachers' subjective evaluations of the benefits of a comprehensive school reintegration program. The program consisted of supportive counselling, educational presentations, systematic liaison between the hospital and the school, and periodic follow-ups. One of the main findings of this study was that although "generic" workshops for teachers and other school personnel serve a useful educational goal, such workshops are not viable substitutes for more patient-specific school reintegration interventions.

In a study of a school re-entry program conducted by Charlton, Pearson, and Morris-Jones (1986), it was found that the parents were closely involved in the child's return to school, and that the parents' outlook affected the whole process. The study was a small pilot study, consisting of 16 children who had been off treatment for at least two years, along with their parents and teachers. In this study, both teachers and parents talked about experiencing uncertainty, and wishing for more support at the "pre-return" stage. Teachers said they would have appreciated more in the way of "medical guidelines," as well as better guidance in preparing the other children in the class.

From the teachers' perspective, successful reintegration included three important elements: (1) the stability of the child, which they saw as strongly related to the home; (2) contact with the school throughout the illness; and (3) a normal relationship with his or her peers. It was also found that children at the "junior" school age (grades 2 to 5) seemed to have the least problem in returning to school (Charlton et al., 1986).

Another study by Chekryn, Deegan, and Reid (1987) looked at the impact on teachers when a child with cancer returns to school. In-depth interviews were carried out with nine children, their parents, and their primary teacher; the interviews were conducted four to six weeks after the child's return to the classroom. Two predominant themes emerged: (1) the dilemmas the teachers faced as they attempted to normalize the school experience for these children, and (2) the personal impact teachers experienced from having a child with cancer in the classroom. Chekryn et al. (1987) concluded that teachers needed to be included in planning for school reintegration in a concrete way, and that the strongest need was for information that is "continuous, appropriate, education-related, and child-specific." It appeared that in spite of dramatic improvements in survival and cure, childhood cancer is still perceived as a dreaded disease.

School Attendance among Children with Cancer

There is a general acceptance in our society that school attendance is important for all children. Lansky et al. (1983) state:

> "School is the work of children. It is the setting for their most frequent encounters with the community and the vehicle through which they develop mentally, physically, and socially. School children not only acquire knowledge and skills; they also make peer contacts and develop a social life that contributes to their emotional growth. For children with a chronic disease, school often counteracts the anxiety and depression that accompany a long illness. Finally, school plays an important part in normalizing these patients' lives. Just as the success of psychosocial rehabilitation of adult patients with chronic diseases is measured by their return to work, so can the rehabilitation of pediatric patients be assessed by their return to school. (p. 75)

Lansky et al. (1983) examined the school attendance of a large group (239) of pediatric cancer patients in Kansas and in Colorado. They found that children with cancer had a high rate of absenteeism, and concluded that resuming regular school attendance after a diagnosis of cancer is a difficult task for the child, family, and the teacher. The side effects of treatment and the disease process itself may reduce the child's energy for, and interest in, the usual activities of childhood. In addition, the child may fear ridicule or rejection by teachers or peers, especially if his or her appearance has changed because of hair loss, weight gain, or amputation of a limb. Lansky et al. (1983) speculate that parents of a child with a life-threatening illness may often foster absenteeism unwittingly because of an overprotective attitude, which can lead them to try to keep the child under constant surveillance. Overprotectiveness becomes an even more intense problem when a child is expected to live for only a short time.

Many aspects of their illness may make it difficult for children with cancer to attend school regularly (Cairns et al., 1982). Doctor's appointments, clinic visits, hospitalizations, and the physical side effects of treatment lead to absences. In addition, emotional factors such as embarrassment in the classroom situation may interfere with the child's desire to attend school and with parents' willingness to allow the child to leave home, and approximately 10-12% of these children develop "school phobia" (Cairns et al., 1982). Some studies have shown that children missed an average of 41 days of school during the year they were diagnosed. Absences remained high three years after diagnosis (Cairns et al., 1982).

A study by Cairns et al. (1982) examined two years of school attendance data for 55 children who had been diagnosed with cancer, and found that school attendance patterns varied considerably. The main factors influencing school attendance were:

(1) the ultimate outcome of the child's illness: those who had progressive disease and eventually died were in school fewer days.

(2) the population of the child's home town: children living in smaller towns went to school more often that those in larger cities.

(3) patients who were firstborn in their family attended school more consistently than others.

(4) children who had received central nervous system chemotherapy spent fewer days in school than those who did not.

(5) boys attended more regularly than girls.

Cairns et al. (1982) suggest that the influence of some of these factors is easily understandable. For example, central nervous system (CNS) chemotherapy has many troublesome side effects, and is usually given at intervals for a year or more. CNS chemotherapy is given both to prevent cancer cells from proliferating in the brain and spinal cord, and to combat active disease in those sites. When such disease is present, the symptoms combined with drug side effects may produce even greater physical limitations. Furthermore, there is some evidence that CNS chemotherapy may result in perceptual problems or learning disabilities. The influence of ordinal position fits in with other reports that first-born children do better academically and are more highly motivated to achieve in school than their younger siblings. The finding that boys attend school more often than girls may reflect a cultural expectation that boys will not give in to illness, while girls may be more readily excused from normal activities when they are sick. The observation that children from small towns have better attendance may reflect the fact that a closer relationship between the school staff and the child (and parents) is likely to exist. It is particularly striking that parents' attitudes were not considered as an "independent variable" in this study. The only reference made to parents is in analyzing the reason why children from smaller cities and towns might have higher school attendance.

Conclusions

School is a focal point of achievement for all children, but for the child experiencing a life-threatening illness, school also symbolizes the possibility of a future (Ross, 1984). Some young cancer patients can return to school quite soon after the initiation of therapy, while others may be absent for weeks or months. Many pediatric cancer centers now have an educational specialist or designated person whose role is to facilitate school re-entry or to assist with school-related problems. Ross (1984) states:

> *Parents' attitudes* [italics added]... play an important part in the timing and the manner in which the child returns to school. Most parents recognize the importance of maintaining educational continuity, but after cancer is diagnosed, they regard their children as vulnerable and fear that at school they will be unprotected... Children take cues from their parents who, because of pessimism about the child's future, can no longer invest themselves in the child's school career. (p. 154)

The need for a collaborative relationship between parents and health care professionals, and between parents and the school, has been well documented in the literature. In articles and books written for educators, teachers are advised to be informed and communicate thoroughly and often with parents, patients, and the child's treatment centre. The first days and weeks after returning to school are generally considered the most significant, although it is understood that many issues are ongoing ones that go beyond mere "re-entry." Parents provide the general framework for the child's acceptance of him/herself and the illness; teachers set guidelines for the way the child will be seen and will feel about him/herself while at school (Ross, 1984).

From my perspective, this literature has several limitations. First of all, few researchers have looked specifically at the parental perspective in the schooling of children with cancer (or any other chronic illness). A second limitation concerns the perspective taken by investigators: many articles discuss parental concerns from a health care professional perspective. The specific "schooling" concerns of parents of children with cancer have not been investigated. It is possible that these concerns differ from those of parents of children with other special needs such as mental retardation, learning disabilities, sensory handicaps, and even other chronic illnesses such as asthma, diabetes, or cystic fibrosis. Thus, while disabling and chronic conditions are frequently treated synonymously in the literature, I was curious to discover what specific concerns exist for parents of children with cancer.

CHAPTER THREE

INQUIRY

The Research Question

Since the approach to inquiry should be determined by the research question itself, I will review the research purpose once again before presenting a detailed description of my chosen methodology. As indicated earlier in this document, the purpose of my research is to describe parents' perspectives of their child's schooling experiences after the child has been diagnosed with cancer.

Why Qualitative Research?

This study describes the parents' thoughts and opinions from a qualitative research perspective. I have chosen a qualitative, human science research approach (Bogdan & Biklen, 1992; Patton, 1990; Van Manen, 1990) for this study because of the basic philosophical belief system that underlies this approach, and my own personal belief that this is the best approach that can "tap directly" into the first-hand experiences of parents and allow insight into their personal perspectives. The research methods will reflect the underlying principles of a descriptive, exploratory approach (Bibby, 1993): using interviews as the main source of data, recognizing the ongoing dynamic nature of reality, and attempting to gain a holistic perspective.

Qualitative research is "contextualized," and individuals are seen as co-creating the world, having active and interactive relationships with their environments (Osborne, 1990). The qualitative research approach also has understanding as a focus (Bogdan & Biklen, 1992), and follows the tradition of descriptive rather than explanatory science. Furthermore, qualitative research depends strongly on the power of language for communication: the aim is to capture a detailed "thick" description of the phenomenon under investigation and to use direct quotations in order to capture the participants' perspectives and experiences (Patton, 1990).

The position that reality is socially constructed is basic to the framework for this study, as is the acceptance of multiple realities (Osborne, 1990). An underlying assumption is that it is possible to discover the perspectives of others through their words as they communicate with us, and through our knowledge of our own words and actions as we see them reflected in others (Bibby, 1993). This perspective is basic to a qualitative, descriptive approach to research. Qualitative research pays attention to the human consciousness, the subjective experience (Bogdan & Biklen, 1992), and it is this consciousness which shapes our behaviors, our interactions with the world. This perspective is consistent with symbolic interactionism, which relies on the meanings that people give to things. Rosenblatt and Fischer (1993) state that one of the implications of symbolic interactionism is that research should focus on subjective as well as objective data. In family research, subjective data refers to the understandings and perceptions of various family members.

Rosenblatt and Fischer (1993) also point out that qualitative strategies are especially useful for investigating matters that are sensitive or touchy for people to reveal. Nonqualitative approaches might completely miss such sensitive areas or might be abrasive or hurtful, or may be stymied by the defenses they elicit. Qualitative strategies are also advantageous in studying topics where feelings, thoughts, meanings, accounts are complex, qualified, ambivalent, situational, or different at different times.

In the search for understanding of this subjective experience, both the participants and the researcher play important roles. As Patton (1990) states, behavior cannot be understood without knowing how it is perceived and interpreted by the individuals involved. The qualitative interview then becomes one of the most creative ways of illuminating this meaning. One of my underlying assumptions as a qualitative researcher is that it is possible to discover the motives and meanings of other persons through my connections with them, through our words and actions as we communicate with one another. This perspective is basic to a qualitative, descriptive, and interpretive research approach (Giorgi, 1970; Guba, 1981).

Marton's (1981a, 1981b, 1988) descriptions of phenomenography draw our attention to "first-order" and "second-order" perspectives. In this paradigm, my research question is a second-order one, since I am asking parents to tell me about their perspectives regarding their child's (i.e., someone else's) schooling experiences since the child's diagnosis of cancer. The purpose of this second-order orientation in phenomenography is to describe how people interpret significant aspects of reality, aspects which are socially significant and which are shared (Marton, 1981a). There are two reasons for investigating such second-order (i.e., parents') perspectives in this proposed study. One is that parents' perspectives inevitably have an impact on the perspectives of their children; the second is that parents' perspectives are autonomous in the sense that they cannot be derived merely from first-order perspectives, i.e. the children's own schooling experiences (or their own perspectives of their schooling experiences). The phenomenography of "children's schooling experiences" can refer to "anything that can be said about how people perceive, experience and conceptualize [children's schooling experiences]" (Marton, 1981a, p. 181). This research is focused on the different perspectives that parents have, as much as on the commonness of these perspectives.

I am also defining this study as "family research," since it centers around experiences between families (or parts of families) and other systems (the schools). Gilgun (1992) provides the following definition of qualitative family research as

> ...research with a focus on experiences within families as well as between families and outside systems; data are words or pictures and not numbers; the data are conceptualized, collected, analyzed, and interpreted qualitatively; the subjects or informants of the research are persons who mutually define themselves as family, are in committed relationships, have a

> shared sense of personal history, and who usually but not always have legal and biological ties. (p. 24)

Rosenblatt & Fischer (1993) describe three "basic" assumptions of qualitative family research:

> (1) the focus of research should be the family, not the individual.
>
> (2) the meanings people come to as they act, speak, feel, and think in and about their families are crucial data.
>
> (3) qualitative family data consist of the details and idiosyncracies of what people communicate about their families and themselves in their families. What they communicate often comes in the form of organized accounts that could be called "family stories." These stories are not incidental to the analysis. Their interpretation is a key analytic tool. It is through the analysis of idiosyncratic materials that the qualitative family researcher can begin to understand the complexity and variability of family experiences, and to generate theoretical constructs that reflect underlying themes and variations. (p. 170)

A question that is often raised is how qualitative family research differs from literary or journalistic accounts. Rosenblatt and Fischer (1993) say that the distinction is that the qualitative researcher is accountable for her or his insights based on systematic observation and analysis of data. However, as they point out, there is always an aesthetic component to qualitative family research. The aesthetic is "partly a matter of deciding what is important, sifting information judged valuable, ignoring the dross, and choosing what and how to report" (p. 172).

Another point worth noting is that this research emphasizes the perspectives of parents, who are in many ways the "insiders" in terms of their children's experiences. Parents' perspectives have traditionally not received a great deal of research attention, particularly on the question of children's experiences. Since I like to describe myself as a feminist, and since part of the feminist tradition involves incorporating "previously unheard voices" (Allen & Walker, 1992), it seemed particularly important to me that I find a way of "giving voice" to parents of children with cancer. Furthermore, feminist research is distinguished from other types of research by worldview rather than by method (Nielsen, 1990), and has as an explicit intention to conduct research that is *useful for* women, not just about them. As a feminist researcher, one of my goals in conducting this research has been to make sure that the parent-participants would feel heard, and that I find ways of sharing the research findings with both parents and schools, with a view to improving the schooling experiences of children with cancer.

METHODS

Background to the study - A personal perspective

In qualitative methodologies, the investigator is the research instrument (Patton, 1990). As a result, both participants and researcher play very significant roles, and the subjective experiences of data-gathering and analysis must be made as explicit as possible. Patton (1990) states that the researcher's personal experiences and insights are an important part of the inquiry, and critical to understanding the phenomenon. At the same time he proposes that the qualitative researcher must strive to take on an attitude of "empathic neutrality," which he defines as a "neutral non-judgmental stance toward whatever content may emerge" (p. 41). This perspective is neither easy to acquire nor to maintain, since the researcher must "become aware of and deal with selective perception, personal biases, and theoretical predispositions" (Patton, 1990, p. 56). The process of doing this is frequently referred to as "bracketing." Sandelowski (1986) noted the importance of addressing research trustworthiness in this light. One of her steps is to inform readers about how the researcher became interested in the subject matter as one way of enabling readers to judge the study's trustworthiness. The following section is a short history of the development of my interests and values as they are related to the subject of this research; as a researcher, my interests, my values, and my experiences (both past and very recent) were the main source of inspiration and motivation for this study.

First of all, I am a parent myself, and I have experienced first-hand the intense emotions that accompany the birth and raising of children. As I spoke with the parents in this study, I became acutely aware of the places where we connected, as well as those where such a connection was impossible. When they spoke to me about their willingness to "fight" for their children, I knew that I understood that feeling. I remembered that one of my earliest thoughts after holding my newborn baby daughter was that I would "die" for this child. I remembered the fierce protectiveness that I felt at the thought of anything terrible happening to my children. Although I have not experienced the pain of hearing that my child has cancer, and I know that I can't even begin to truly understand how that would feel, I empathized with the strong feelings expressed by all of the parents in this study. My own experience as a parent also gave me an opportunity to establish rapport with the parents involved, and to develop an empathic understanding of the experiences shared during the interviews, as well as to recognize and make sense of the meanings and themes that emerged from the analysis of the interviews.

Secondly, I have worked for over twenty years in the field of education, a career that has included positions as a teacher, an elementary school consultant, a school administrator and a provincial (Alberta Education) consultant. My professional experiences have confirmed for me the importance of teachers working closely with parents. I believe that a school's "job" is not merely to work with children, and that the school's "clientele" also includes the parents and families of the children at the school. I believe that teachers and parents need to be working together as closely as possible, in order to help all children learn to the best of their ability. Thus, this topic of parent-school relationships is one to which I bring over twenty years of experience and reflection. I feel strongly about the importance of parents and schools developing truly collaborative relationships, based on my belief that children benefit greatly when the adults who have responsibility for them know each other, respect each other, and share similar goals and values for the children.

For my master's thesis, I conducted a study on the topic of parent-school collaboration, and I interviewed parents and educators to learn how each group described collaboration. One of the participants in my study was a parent of a child who had been diagnosed with cancer several years previously. I was deeply moved by her account of her child's schooling experiences, and it seemed clear that, from her perspective, her son's cancer had significantly affected his school experience. Furthermore, it seemed to me that this parent had strong beliefs that were directly related to the fact that her son was a survivor of cancer. I became intrigued with the long-term consequences for children (and their parents) of having cancer. As I began to delve into the literature on survivors of childhood cancer and schooling, I realized that this is an area that has not been researched from the perspective of these children's parents. Since I have a long-standing interest in studying parents' perspectives, I decided to pursue this area of research.

In the past two years, I have been pursuing graduate studies in counselling psychology, and have specialized in the areas of family therapy and school-family relationships. I have also been doing my practicum placement and internship year at the Cross Cancer Institute in Edmonton, and have been working closely with cancer survivors and their families. During this time, I have become convinced of the importance of truly understanding another person's perspective before one can ever begin to support and help that person during a difficult or challenging experience. Furthermore, I have a much stronger belief in the importance of viewing people from a systemic perspective. In terms of this study, I believe that we must understand parents' perspectives in order to understand children's experiences. I also began this research with the assumption that for parents of children with cancer, both encapsulation and at-risk activities (Birenbaum, 1990) would be occurring, and that these activities would in turn have an impact on the parents' perspectives of their children's schooling experiences.

Research Participants

Becker (1986) states that the most basic qualification for research participants is that they have "salient experiences of the phenomenon in their everyday worlds" (p. 105). All the parents who participated in this study had a child who had been diagnosed with cancer, and all were able and willing to share with me their thoughts concerning their child's schooling experiences since the cancer diagnosis, and to participate fully in the research process.

In choosing participants for a study, some researchers prefer their samples to be as homogeneous as possible, while others believe that more diverse single subjects are more productive in arriving at an understanding of the phenomena under investigation (Patton, 1990). I decided to use a variation of what Patton (1990) refers to as a type of purposeful sampling, *intensity sampling*. In intensity sampling, one seeks excellent or rich examples of the phenomenon of interest, but not necessarily unusual cases. At the same time, I based my selection of participants upon the assumption that diversity in experience would allow for the greatest differences in perspectives, and would therefore allow for a better understanding of the range in parents' perspectives. This diversity was accounted for in three ways: (a) the parents live in a variety of settings: urban, suburban, and rural; (b) the children vary in age from 6 to 13, and their cancer diagnosis ranges from 2 to [illegible] years in the past; and (c) there is a variation in the type of cancer, as well as the intensity and length of treatment.

I had initially decided that participants for this study would consist of parents of children who have been diagnosed with cancer within the past five years, and that all of the children would be of elementary school age (ages 5-12). Furthermore, the child's cancer diagnosis should be at least one year old, in order to eliminate from the study children who die within the first year of the cancer diagnosis (and also to get a longitudinal perspective of the child's schooling experiences). Children who are non-terminally ill were sought because of the longitudinal aspect of this study, and because schooling is more likely to be one of the considerations for these children. The selection of participants for this study was deliberately kept "open," so that I might add to the sample as required, to explore an area or an issue in greater depth.

As I began to review the literature in this area, I became aware that the term "parents" is used quite loosely in the research literature when describing study participants. Few studies even document whether the mother, the father, or both parents are actually involved in the study. In this study, I decided that I would like to talk with both fathers and mothers whenever this was possible. Whether to interview parents alone or together was another issue that I considered carefully. On the one hand, interviewing parents individually might increase the likelihood that I would really hear each person's perspective. On the other hand, understanding of the "shared constructed" perspective of the parents was more likely to occur if I interviewed parents jointly. As Daly (1992a) points out, parenthood is usually contingent on a *shared* construction of reality, and interviewing couples together is one of the best ways to try and capture this shared reality. Furthermore, conducting separate interviews might present some ethical issues, such as, do I have an obligation to maintain confidentiality between parents? I solved this dilemma by telling prospective participants that my strong preference was to speak with both parents, but to respect the couple's decision if they decided that only one parent will meet with me.

Access to the participants was facilitated by contacting the local chapter of parents of children with cancer, Kids With Cancer. A notice was placed in their bi-monthly newsletter, describing the purpose of the study, and asking for volunteers to participate in the study. Since approximately 85-90% of parents of children with cancer in the north and central Alberta area become members of this organization, I thought that this would provide a representative cross-section for the study. Seven of the participants were parents who phoned me to volunteer for the study after seeing the notice in the newsletter; the other four parents were referred to me through other contacts.

The parent-participants included 5 fathers and 6 mothers, and were the parents of 6 different children who had been diagnosed with cancer (See Table 1). All of the participants were in their thirties and forties. Each of the participants had at least one child other than the one with cancer; one couple had three children, and two other couples had four children. All of the children and their families were caucasian. I interviewed four of the couples together, one couple separately, and one mother alone.

Table 1 - Participants in the Study

Name of Child	**Age/Grade at Diagnosis**	**Age/Grade Now**	**Diagnosis**	**Rural/Urban**
Chester	6 yrs. - K	8 yrs - Grade 2	T-cell leukemia	Rural
Frank	3 yrs. -	6 yrs. - K	B-cell lymphoma	Urban
Roger	6 yrs. - Gr. 2	10 yrs. - Gr. 5	T-cell leukemia	Urban
Robert	4 yrs. -	13 yrs. - Gr. 7	Acute myelogeous leukemia (AML)	Rural/Urban
Elizabeth	4 yrs. -	8 yrs. - Gr. 2	T-cell lymphoma	Rural
James	4 yrs. -	7 yrs. - Gr. 2	Acute lymphocytic leukemia (ALL)	Urban

While purposeful sampling is advocated by most qualitative researchers (Morse, 1994; Patton, 1990), there is not the same direction when it comes to making a decision about sample size. In a discussion concerning sample size, Patton (1990) points out that "qualitative inquiry is rife with ambiguities" (p. 183), and that nowhere is this ambiguity clearer than in the matter of sample size. Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources. In qualitative studies, it has been suggested that the research needs "as many as it takes" to illuminate the phenomenon. In Bibby's (1993) words, "often the difficulty has not been in getting enough data, but in knowing when to stop" (p. 67). The number of participants is ultimately determined by the quality of information that emerges through the inquiry process. "In qualitative research, the investigator samples until repetition from multiple sources is obtained. This provides concurring and confirming data, and ensures saturation" (Morse, 1994, p. 230). In obtaining saturation in this study, I noticed that as early as the second and third interviews, many of the issues and perspectives were already repeating themselves. However, new ones continued to emerge even in the last interview, although the number of issues that supported previous themes was far more obvious than the new ones. I decided to stop gathering more data when I felt that diversity had been achieved, and a solid data base established.

Collection of Data: In-Depth Interviews

Three of the most common methods of gathering data in qualitative research are interviews, observation, and document analysis. However, one of the best ways to understand someone's "perspective" on a topic is to talk with him or her. Strauss and Corbin (1990) suggest that in order to get an in-depth understanding of a person's perspective, interviews are very effective. In fact, Patton (1990) states that the purpose of interviewing is "to find out what is in, and on, someone else's mind" (p. 278). We interview people to find out from them those things we cannot directly observe, to "allow us to enter into the other person's perspective" (p. 278). Marton (1988) also describes the interview as the primary source of data for obtaining a "second-order perspective," and says that interviews can be used effectively to find diversity in people's conceptions of a phenomenon.

Patton (1990) describes three basic approaches to collecting qualitative data from interviews, each of which involve different types of preparation, conceptualization, and instrumentation. These three approaches are:

(1) the informal conversational interview

(2) the general interview guide approach, and

(3) the standardized open-ended interview.

The informal conversational interview relies entirely on the spontaneous generation of questions in the natural flow of an interaction, and is most typical of the type of interview that occurs as part of ongoing participant observation fieldwork. The general interview guide approach is more structured, and involves outlining a set of issues that are to be explored with each participant before the interviewing begins. However, these issues do not need to be taken in any particular order, and the wording of questions is not specifically determined in advance. The interview guide serves more as a "checklist," to make sure that all the relevant topics are covered, as there is some common information that the researcher wishes to obtain from each person. The third type of interview, the standardized open-ended interview, consists of a set of questions that have been carefully worded and arranged, with the intention of taking each participant through the same sequence of questions. This approach is particulary helpful in minimizing the variation of questions that are asked, and is often used when more than one interviewer is collecting the data.

As I considered these different options, it seemed to me that the general interview guide approach was most suitable to my purposes for this study. There were some questions that I wanted to make sure I asked everyone, (such as what advice they would like to give to schools, how they felt their actions and reactions had affected their child's schooling experiences, and what their thoughts were on the relative importance of schooling in their child's life), but I also wanted to be free to explore, probe, and ask questions that would elucidate or illuminate each parent's perspectives. I also wanted the freedom to word questions spontaneously, and to establish a conversational style. As I proceeded with each of the interviews, I also wanted to be able to "test" some of the issues and themes that had emerged in previous interviews, and see if participants agreed with some viewpoints expressed by others. Consequently, I developed an interview guide (see Appendix A), but encouraged each of the participants to digress and expand on his/her thoughts. Whenever it seemed necessary, I asked some probing questions, in order to make sure that I understood each participant's thoughts on the topic clearly.

One of the difficulties that I encountered had to do with trying to limit my questions, and the participants' responses and comments, to their perspectives regarding their child's <u>schooling</u> experiences. I was very conscious of Van Manen's (1990) caution that the interview process "needs to be disciplined by the fundamental question that prompted the need for the interview in the first place" (p. 66). However, I discovered that parents found it very difficult to separate their perspectives on "their child's schooling experiences" from their perspectives on "their child's experience of having cancer." In fact, it seemed to me that it may be impossible to really make such a distinction clearly, since they are so closely connected. It also seemed to me that the parents' perspectives with regard to their child's schooling experiences were often quite connected with how they perceived their child in his/her other experiences. There were a number of instances during the interviews, where I found myself bringing participants back to issues related to their child's schooling experiences, and realizing that in doing so I was having to "not explore" other issues that were of equal or greater importance to these parents.

The opening question for each of the initial interviews was a variation of, "Tell me about your child's schooling since his/her diagnosis with cancer..." After this opening question, I tried to allow the participants to control the direction of the interview. During each interview, I was able to observe the impact of my questions on the participants; some questions were seen to be irrelevant, some were changed or modified to allow for easier communication, and often new questions came up in response to comments by the participants. I came to appreciate even more the importance of empathic listening, of using open-ended questions and probes, and making statements that allowed them to express themselves as well as they could.

The relationship between researcher and participant is also an important consideration in qualitative research. As I met with the parents in this study, I became aware that I was entering into a "complementary relationship" (Guba & Lincoln, 1981) with them. One of the essential elements of this relationship is not the objectivity of a quantitative, "objective" researcher, but rather the sensitivity and empathic understanding that allows people to share their thoughts and emotions most fully. There were times when I was surprised by the intensity of my own emotional reactions. Since all of these children were cancer "survivors," and since I was dealing with the parents' perspectives of their child's schooling experiences, I had certainly expected that there would be some strong feelings expressed. What I hadn't anticipated was my own response, and the extent to which these parents would become a part of me. Since my conversations with these participants, I have also been changed in many ways. I have felt deeply moved by the parents' ability to take some incredibly challenging circumstances, to meet them "head-on," and to turn them into very positive experiences, not only for themselves but for their entire family.

Interview Procedures

Each of the participants was interviewed twice, the first an open-ended interview, and the second a validation of my interpretations. All of the interviews were held in April, May, and June of 1995. Seven of the participants chose to be interviewed in their homes (three couples and one mother), and the other four met with me in other locations. The interviews were approximately one hour to one and a half hours in length, which seemed to be a length that was comfortable for both the interviewees and me. The interviews ended when we each felt that we had exhausted the possibilities for discussion at that time, and I was sure that we had covered the questions that I wanted to ask of each of the participants.

At the beginning of all of the first interviews, I spent about half an hour establishing rapport, obtaining some basic demographic information (See Appendix B), informing the participants about the nature of the research and answering any questions, and getting the consent forms signed. Then the tape-recorder was turned on for the main phase of the interview. The participants were assured that they would have an opportunity to review the transcripts of the interviews, and make any clarifications or additions they wished.

The second interviews, which were held after the transcribed first interviews had been analyzed, were also approximately one hour to one and a half hours in length. The purpose of the second interview was to ask the participants to check the transcripts for accuracy, to clarify meanings, to add to the ideas that they had shared during the first interviews, and to validate my interpretations of the main ideas and themes emerging from the interviews. All the participants agreed with my interpretations, although some parents expanded on a few points. All changes and new ideas were recorded. At this time, I also shared with the participants some of the major themes and issues that were emerging from the first interviews, and invited them to talk to me about how they saw themselves the same or differently.

Before the final draft of this thesis was written, participants also had an opportunity to read and comment on the findings outlined in Chapter Four.

Analysis of Data: Thoughtful Reflection

The data consisted of the seven taped interviews, the written transcriptions of these interviews, field notes, and journal reflections. In some instances, the participants made some very meaningful statements before the tape recorder was turned on, or after it was turned off. In such cases, I entered these data into my journal, which I used as a secondary data source. Immediately after each interview, I also dictated my field notes, consisting mainly of reflections on the interview, or insights regarding the possible interpretations of the data. I transcribed all of these field notes shortly after they were recorded, and used these as another secondary data source.

Within a day or two after the first interviews, I personally transcribed each interview verbatim. Having completed each transcription, I listened to each interview again, checking with the typed transcription line-by-line for total accuracy. This process of conducting the first interviews and transcribing each one myself took about one month of constant work. During this time, I felt "driven" to ask the questions that would lead to the richest data, to listen closely to the responses of each of the participants, and to do the transcriptions as accurately and faithfully as possible. I felt very possessive about each of these steps, and I believed that it was essential that I not share any of these tasks with anyone. During these early stages, I was also aware that my "analysis" had already begun, as different ideas about possible themes naturally occurred. These early thoughts and ideas also became part of my field notes and memos, and this overlapping of data collection and analysis improved both the quality of the data being collected and the quality of the later analyses.

At this point, as I had outlined in my Research Proposal, I had planned to begin the process of content analysis, identifying, coding, and categorizing the primary patterns in the data. My intention at that time had been to follow closely the grounded theory analysis procedures outlined by Strauss and Corbin (1990); that is, breaking the transcript down into meaning units, paraphrasing, assigning labels or tags, grouping and re-grouping these tags into topics or themes, and following this procedure for each separate interview. However, as I listened over and over again to the taped interviews and re-read the transcripts, I became aware that the parents had told me "stories" of their children's experiences, and that it was in these stories that I would be able to learn about each parent's perspectives of his/her child's schooling experiences. These were stories that could not be "broken down"; they needed to be listened to and understood in their totality. So I decided to take some time to re-think my approach, and to consider other ways of analyzing my data.

Within the realm of qualitative research, there are various methodologies or perspectives from which to choose. The different perspectives vary according to basic assumptions, purpose, and method of data collection, but they probably vary most with respect to the methods of data analysis. As I looked at other research that appeared similar to the type of inquiry I was considering, it seemed that the data analysis most commonly used was some type of content analysis (Strauss & Corbin, 1990). Content analysis, with its use of terms and methods such as open coding (breaking down, examining, categorizing), and axial coding (putting data back together by connecting categories), seemed somehow contrary to my goal of understanding "parents' perspectives." It seemed to me that taking excerpts of people's expression of their experiences (and those of their child), and analyzing these individually, might risk decontextualizing the expression from the experience as a whole. Patton (1990) gives support to this viewpoint, and stresses the need for both context sensitivity and holistic inquiry. In a recent study on the experience of hope in children living with cancer, Danielsen (1995) described a similar perspective:

> To take people's expressions of their experience of a phenomenon, and label them with words apparently borrowed from a scientific paradigm, may allow us to better categorize or organize the data, but I question whether it brings us toward a better understanding of the experience. Perhaps

> individuals' expressions are not orderly and neat, but might that also tell us something of their experience? (p. 28)

In a discussion of qualitative analysis strategies, Miller and Crabtree (1994) suggest that the research question, the goals of the research, and the data itself must be closely examined before selecting the appropriate method of analysis:

> The goal of exploration, the absence of significant literature about the question, and the use of interviews argue for a style that is unstructured, fosters intimate contact with the text, and minimizes perceptual filtering in the initial analysis... An immersion/crystallization style or a very open editing style (such as hermeneutics) with no explicit perceptual screen is thus appropriate. (p. 347)

It seemed to me that these considerations all fit in well with this study. Moustakas (1990) and Van Manen (1990) both suggest that thematic analysis is most effective with such data sources as art and story. Moustakas' (1990) heuristics approach encourages a gentler, more holistic approach to analysis than the one I had initially envisaged. He suggests leaving individual cases intact, and exploring themes that emerge from the individuals' expressions. Only after individual depictions are formed does the researcher begin to combine the various case depictions in search of larger trends. Van Manen (1990) was also guiding me, when I read his admonition that "too often theme analysis is understood as an unambiguous and fairly mechanical application of some frequency count or coding of selected terms in transcripts or texts" (p. 78). Van Manen went on to say that:

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure--grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning. (p. 79)

Themes are simplifications, or attempts at organizing, capturing, and structuring experience. By identifying themes, the researcher is striving to better understand, or make sense of the experiences that have been described.

I went back to Miller and Crabtree (1994), who claim that all qualitative analysis must address three basic steps: (1) developing an organizing system, (2) segmenting the data, and (3) making connections. They also divide qualitative analysis into four styles: (1) immersion/crystallization, (2) editing, (3) template, and (4) quasi-statistical. In the first style, immersion/crystallization, the three core steps are "collapsed into an extended period of intuition-rich immersion within the text" (p. 345). This method, based largely on the work of Moustakas (1990), seemed to fit very well with my study and the data that had emerged.

In the company of a close friend and professional colleague, I retreated to a beautiful, remote location in the Rocky Mountains, where some friends had made their home available for our use. For six days, Colleen and I listened to the taped interviews, read the transcripts, talked about each of the participants, and totally involved ourselves in what I would call a process of immersion/crystallization in the data. After listening to each interview, we spent time discussing the main ideas and "themes" that emerged from each one, and prepared a summary statement for each interview (case analysis). As we continued this process, we found ourselves becoming aware of some "meta-themes," the themes that seemed to be significant for each participant in one way or another. Once these "meta-themes" became clearer, we found ourselves involved in yet another process, which I would call the "cross-case analysis." This was a variation of what Glaser (1992) refers to as the constant comparative method, and involved comparing each of the interviews, and checking to see if and how the "meta-themes" applied.

Once this immersion/crystallization stage seemed to be complete, I returned once again to each individual transcript. By this time, it seemed appropriate to do the type of analysis that I had planned to do in the first place: breaking the interviews into meaning units, paraphrasing, and coding each meaning unit. As I did this final step in the analysis of each interview, I became aware of how well I knew the data by now. It seemed to me that what I was doing now was yet another way of introducing "rigor" into the study.

I delivered or mailed the transcribed interviews to each of the participants, along with the summary statement of main ideas or themes which had emerged from the interview. In a covering letter, I invited each parent to read through the transcript, to make sure that I had accurately heard what he/she was saying. I also asked parents to read the summary of my analysis of the interview, to see if they agreed with these themes that I had identified as the most important, and to see if there was anything more they would like to add. During that same week, I made telephone contact with all of the participants, to tell them about the progress of the study, and to make arrangements for our second interview. I told them that at these interviews, I would also like to talk to them about some of the ideas set forth by others, and to ask them how they might see these ideas the same or differently.

After weeks of immersion, thinking, rethinking and returning to the data, a variety of themes were solidified, and these in turn became the basis for a creative synthesis of the data, which resulted in the writing of chapters four and five. Following this data analysis and the subsequent write-up of the results, the resulting themes and findings were provided to each of the participants. This added to the longitudinal aspect of the study, as the participants were encouraged to note any changes in their perspectives since our first interviews. Further, participants were asked to review the findings, and determine how well these "fit" with their own experiences.

Ethical Considerations

In accordance with University of Alberta policy, an application was made to the Department of Educational Psychology Ethics Review Committee, and the research procedures to be followed throughout the study received approval on April 19, 1995.

I then phoned the people who had volunteered or agreed to participate in the study, and set up a convenient meeting time at a location of their choice. When I first met with each participant or participants, I carefully explained the purpose of the study and its design, gave them a copy of the Project Description (see Appendix C), and offered to give them a copy of the longer research proposal if they wished. After they agreed to participate, they were asked to sign a consent form (see Appendix D). Participants were given a copy of the consent form, and were assured that the consent forms would be kept in a secure location, separate from the data so that names would not be associated with the tapes or manuscripts.

Participants were assured that their participation was totally voluntary throughout the study, and that they would not be identified individually in any of the reports written as a result of the study. In order to protect their privacy, I invited each of the parents to select a pseudonym for themselves and for their child. Participants were also assured that if they did not wish to answer some questions, they could indicate this, and we would proceed to other questions. Finally, they were told that they could withdraw from the study at any time, without any prejudice.

Rosenblatt and Fischer (1993) state that there are two recurrent ethical problems in conducting family interviews (p. 175). First of all, revealing a family member's account of events, feelings, and perspectives may breach confidentiality and create problems in family relations, yet qualitative research reports often include verbatim accounts from interviews. Even if reports omit or alter crucial details, knowledgeable family members and others may recognize who said what. This problem was mainly solved by my decision to interview couples together whenever possible. With the three participants where this wasn't possible, I was careful to discuss this issue with them, and to invite them to make decisions about what they wanted to share with their partner. The second ethical problem discussed by Rosenblatt and Fischer (1993) is that qualitative family research interviews may be like therapeutic interventions. Even when people have been warned, they may find themselves more upset, self-disclosing, or moved than they expect or want to be. I was aware of the possibility that during the course of the interviews, participants might divulge information of a personal or difficult nature. If this should occur, I was prepared to take responsibility for referring the individual(s) to an appropriate counselling source. It was also possible that discussing certain perspectives of their children's schooling experiences might cause the parents some personal discomfort. As a trained therapist, I would be very sensitive to such issues, and would once again ensure that they receive appropriate counselling support as needed. Participants were also made aware that in consenting to participate in a study such as this one, there exists the possibility that they could begin to think about the issues from a different perspective than they previously did, and that issues might be raised that the participants might not have thought about before this time.

Another ethical issue has already been discussed above under the section entitled "Research Participants." This relates to the question of whether to interview parents together and separately. In order to avoid this problem, I decided that I would interview parents together as a couple, unless for some reason only one parent (mother or father) was able to participate in the interview.

Trustworthiness and Rigor of the Study

In any qualitative study, the researcher must find ways of ensuring that the findings can be considered credible (Bogdan & Biklen, 1992; Patton, 1990; Sandelowski, 1986). "Rigor" is the term that applies to the process of planning and conducting the research and analysis, whereas "trustworthiness" is related to the data, the results, and the conclusions reached by the researcher. Thus, rigor of the research is a prerequisite to establishing trustworthiness of the findings.

Patton (1990) suggests that the credibility issue for qualitative inquiry depends on three distinct but related elements: (1) a fundamental, philosophical belief in a qualitative approach; (2) the credibility of the researcher, and (3) rigorous techniques and methods for gathering and analyzing data. I have outlined my adherence to each of these elements throughout this chapter. Furthermore, I have kept careful documentation of research activities and have compiled a Study Time Line (see Appendix E) which allows the reader to follow the study from genesis to completion.

A primary method of enhancing credibility in qualitative research is to continually return to the data, the texts or expressions generated by the participants (Sandelowski, 1986). The ultimate judge of truth value is the researcher (Moustakas, 1990; Van Manen, 1990), although verification is also gained by returning to research participants throughout the interpretive stages. Throughout this research, I remained in close contact with the transcribed interviews, returning over and over again to the data for confirmation of my interpretations and themes. I also sought verification and clarification from the parent-participants, sharing with them the data from the first interviews, and the draft of Chapter Four.

Sandelowski (1993) claims that the best test of rigor in qualitative work is whether or not the researcher has managed to create "the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience" (p. 1). This was my goal in presenting the findings of the study in Chapter Four. To enhance the credibility of the text to the readers, I took care to include direct quotes from the participants as a way of substantiating claims and interpretations.

Another point that Sandelowski (1993) makes is that the typically narrative nature of the interview data makes the problem of determining accuracy of meaning and intention a "deeply theoretical and moral one." According to Sandelowski (1993), stories that people tell in interviews are themselves constantly changing, since they represent their efforts to order, find meaning in, and even live with the events in their lives. This is indeed the case for the stories that my participants shared with me. As I conducted the research, I was very aware that parents of children with cancer live with "uncertainty" on a daily basis, and that one of the by-products of uncertainty is frequently a decision to live day by day. So the "perspectives" that they shared with me are those of today, of this week or this month; they are not necessarily the perspectives I would have heard had I interviewed them shortly after their child's diagnosis, or three years from now.

Study Considerations

I recognize that this study necessarily has its limits. The information that I am presenting about parents' perspectives of their child's schooling experiences after a diagnosis of cancer, comes from the 11 parents with whom I met. It should also be noted that since all of the parents had volunteered for the study, there is a possibility of bias with respect to their being more "assertive" or outgoing than the general population. However, as a qualitative researcher, I believe that this sample bias does not affect the themes that emerged. In fact, it is reasonable to assume that the issues that were of significance to these parents would assume even greater importance for parents with less education, fewer "connections," or less self-confidence or ability to assert themselves and advocate on behalf of their children.

The reader is also reminded that although the research is intended to allow the insiders to "speak for themselves," it is the researcher who selects, organizes, interprets, and summarizes the material.

CHAPTER FOUR

FINDINGS

Meeting the Children

In order to better understand the parents' perspectives, it is important for the reader to have a sense of their courageous children.

Chester

Chester is now 8 years old and in grade 2. He was diagnosed with acute lymphocytic T-cell leukemia in May, 1993, just three months after his 6th birthday. T-cell leukemia is far less common than other forms of leukemia, and Chester's parents were told that his chances of remission were lower than they were for other types. At the time of his diagnosis, Chester was just completing kindergarten. He missed the rest of that school year because he was hospitalized for the first three weeks of treatment. Since that time, most of Chester's treatments have been administered on a weekly outpatient basis, although there have been numerous three and four-day stretches where hospitalization has been required. His treatment has consisted of chemotherapy, as well as numerous lumbar punctures and bone marrow tests. In February of 1994, Chester was also in the hospital for a month with pneumonia. Altogether, he missed 64 days of school in grade one. Although he is now in remission, Chester is still receiving treatment every three weeks, and will probably continue on treatment until late fall of 1995. Over the past two years of treatment, Chester has lost all of his hair three times, although it has now completely grown back. He has had to deal with many side effects of cancer and treatment, including fatigue and having to avoid strenuous physical activities when his blood counts have been too low. However, it would be impossible to know by looking at him now that he has been dealing with cancer. Chester looks like a normal, active little boy, with an impish grin and an obvious enjoyment of teasing others.

Chester lives with his parents, Murray and Jeanie, and his two older sisters, aged 10 and 11, on an acreage outside a small town about two hours away from the cancer treatment center in Edmonton. They are a very active family, and enjoy many outdoor activities such as horse-back riding and downhill skiing. Chester has played hockey as much as his treatment schedule and health have allowed over the past two years. His father, Murray, works for an oil and gas company and is involved in rodeo and roping competitions; his mother, Jeanie, teaches gymnastics, and both of Chester's sisters are active in gymnastics as well. Jeanie grew up in the area where their family now lives; she attended the same local school as a child, and has been very active as a volunteer in the school and the community. Murray describes his son Chester as "just a normal, rough-and-tumble boy, who likes to go get things, and do things." Jeanie says she still marvels at how adaptable Chester has been throughout the last few years:

> He's taken everything in stride. He's played hockey throughout, since he was diagnosed, played soccer, ball, or whatever at school. The hardest things were not being able to, and the things he hated most were the times when his blood counts would come back, and his platelets were low, and they'd say, OK, no sports, and no phys. ed. at school... and that was the hardest thing on him...

Frank

Frank is six years old. He was first diagnosed with B-cell lymphoma on March 2, 1992, when he had just turned three. The day after he was hospitalized and diagnosed, Frank lost his sight entirely, and he has been blind ever since. Frank's parents, Laura and Fenton, were told that chemotherapy had to be started immediately, since death could come within 72 hours if the tumor was left untreated. Naturally, losing his sight in the hospital, being so ill and having to undergo numerous medical interventions, were all traumatic for a three-year-old boy, and Fenton and Laura said that he withdrew completely for the first several weeks. Frank's therapy included chemotherapy, radiation, and steroid treatments. He was hospitalized for the first seven weeks of treatment, and then was in and out of hospital until he completed his treatments in September 1992, approximately six months later. Frank has been totally "off treatment" since that time, and his prognosis continues to be very good. Although his blindness has presented Frank and his family with a significant challenge, his parents agree that it has been "easier to deal with the blindness than with cancer." Frank also suffers from acute sinusitis and frequent nose bleeds, which both Laura and Fenton believe are related to the radiation treatments he received. They are also concerned that there may some endocrine problems, due to the radiation of his pituitary gland during treatment.

After finishing treatment, Frank spent one year in playschool with a special aide; he has been attending a regular kindergarten program for the past two years, and has had the same aide assigned to work with him. Frank is now an outgoing, assertive, and very independent little boy. He is already reading in Braille at a grade one level, and his verbal skills surpass those of most of his classmates. His parents are very proud of Frank's independence, and they encourage him to stand up for himself. Despite his blindness, there is no question in their minds that Frank belongs in an integrated setting. Laura says:

> Socially, Frank does very well. He's certainly not shy, and he's very upfront about his disability. When the other kids say, "well, how did you get blind?" he'll say, "well, I had cancer and that caused me to go blind," and off he goes, he keeps on going.

Fenton describes Frank's verbal and leadership skills:

> In his kindergarten class, he's a real leader, a real popular kid. Like in their circle time, he leads, he's always got strong responses to questions.

Fenton and Laura are both special education teachers. Laura teaches for the same school division that Frank attends, while Fenton works in a high school for a neighboring school system. Both Laura and Fenton are highly involved in the local parents' group, Kids With Cancer. Frank also has one older sister, who is nine years old and in grade four. Their family lives in a suburban area, having recently built a house close to a junior high and a high school that they hope Frank will be able to attend as he gets older.

Robert

Robert, 13 years old and in grade seven, is the oldest child involved in this study. He was first diagnosed with acute mylogenous leukemia (AML) in September 1986, when he was only four years old and had not yet started school. At that time, he was treated with chemotherapy for about a year and a half. Since Robert's family lived in a small town over two hours away from the urban cancer treatment center, these treatments resulted in a great deal of disruption for the entire family. In September 1987, Robert's parents, Clark and Lois, enrolled him in a private kindergarten (ECS) program, even though he had to miss a lot of school because of his ongoing treatments. In June of 1988, finding the travel to and from the treatment center too disruptive, Clark and Lois decided to move their family to Edmonton. In remission, Robert attended grade one at the local public school in Edmonton from September 1988 to June 1989. On September 5, 1989, the day he was to begin grade two, Robert's cancer relapsed. It was decided that he should have a bone marrow transplant in Minneapolis, one of the few centers in North America where these procedures were being done at that time. The donor for Robert's transplant was his older sister, aged nine years old. At the time of his transplant, Robert once again received chemotherapy, as well as some fairly intense radiation treatments.

One week before Robert's transplant in November of 1989, Clark, his father, was himself diagnosed with chronic mylogenous leukemia (CML). So Robert had a bone marrow transplant in Minneapolis in November 1989, and just a few months later, Clark also underwent a similar procedure in Vancouver.

Robert was away from school for his entire grade two year. When he returned to Edmonton in February 1990, Lois said that she was determined that he would not fall behind his peers, so she decided to "home-school" Robert, and make sure that he completed grade two before grade three began in the fall. He attended the regular public school for grade three, and after that year, Lois and Clark made the decision to enroll him and his three sisters in a private Christian school, which they have all been attending since that time. Although Robert has kept up with his grade level, his parents have noticed that he suffers from some cognitive difficulties such as short-term memory loss. He also has had some vision problems which now appear to have been corrected through laser surgery. Lois and Clark believe that the major problem at this time is that Robert's growth has been dramatically affected by the treatments he received. He is the shortest boy in his class, and Lois says he is still wearing some of the clothes that fit him five years ago. Lois and Clark both feel that Robert is suffering emotionally because he is not growing normally. According to Lois, Robert is a very bright boy, who has

> ...always known his limits... Like even in physical activity, or school work, or whatever, he will quit when he's tired, he will not push himself. He's a kid who'll take his abilities, his strong points, and he does the most he can with them. Like he's an easy-going kid, he likes to laugh. But he finds it hard physically, 'cause he's littler than everyone else.

Robert has three sisters; one older sister is 14 years old, and his two younger sisters are 10 and 8. Lois is a homemaker, and Clark works in sales and charity. Both Robert and Clark have passed their five-year check-ups in the past year, indicating that they can both be considered "cured" from cancer at this time.

James

James is 7 years old, and is just finishing grade two. He was diagnosed with acute lymphocytic leukemia (ALL), the most common type of childhood cancer, in November, 1991. At that time, James had just celebrated his fourth birthday. His parents had noticed that he had been complaining of leg pains for about a month, and he had also been running a fever. His treatments, which were begun immediately after diagnosis, included at least six bone marrow tests, lumbar punctures, and chemotherapy. He also had a "broviac" installed, a partially implanted venous access device located in the centre of the chest. The presence of a broviac reduces the need for needles, but the part of the tubing that extends down the body requires regular dressing, and reduced James' ability to go swimming or be involved in any activities that might dislodge the line. For the first six months, he went for treatments every week, and was hospitalized for a few days every second week. He also received daily chemotherapy for two and a half years, and was on a maintenance program of weekly injections and check-ups for the next year. Since June of 1994, James has been totally off medication, and now receives only monthly check-ups.

At the time of James' cancer diagnosis, he had not started going to school yet, since he was only 4 years old. The following year, he began kindergarten at the local public school, where his older brother and sister also went, and where his mother, Doreen, had been an active volunteer for many years. Although James had to miss quite a few days of kindergarten because of his treatments, he was able to easily keep up with his classmates. His broviac had been removed by that time, and according to Doreen, he was "normal" in every way. In grade one and grade two, James has missed very little school due to treatments or illness, and he is succeeding very well for his grade level. James seems to have absolutely no academic, cognitive, or physical late effects of cancer or the treatments he received. However, Doreen says that he suffers from fears, especially at nights, that she feels may be related to his experience with having had cancer. Doreen also describes a situation that demonstrates clearly James' sensitivity and consideration for others:

> One day [during James treatment] he was really gnarly, he was groggy all day, and really frustrated, not happy with anything... And later, he felt so bad, he said, "Mommy, I can't stand to be like this. Will God forgive me for the way I'm acting?" Like at four years old, he says will God forgive me for the way I'm acting. I said, honey, of course, it's not your fault, the drugs are doing that to you... like, he's such a sweetie through all of this, right? He's been really special through all this, like, he'll say to me, "Mommy, that's OK, you tried your best and that's all that counts, right? You tried your best!"

James lives in the city, with his parents, an older brother (aged 14), an older sister (aged 11), and a younger sister (aged 5). His father is an engineering technologist, and his mother is a homemaker. James' parents are committed Christians; they have a strong faith in God, and believe strongly in the power of prayer. Doreen, James' mother, has also become convinced of the preventive and healing value of various health products, and has worked hard to promote James' health through various nutritional supplements.

Elizabeth

Elizabeth, the only girl involved in this study, is eight years old and in grade two. She was diagnosed with T-cell lymphoma at the end of August, 1991, when she was just four years old. This type of lymphoma is very uncommon in a child as young as Elizabeth, and it took some time to make the final diagnosis, and then to decide on the best course of treatment for her. The protocol that was selected consisted of a very aggressive course of chemotherapy, which began in September and was mostly finished by Christmas of that same year. Elizabeth lost all of her hair, developed some serious mouth sores and had to endure numerous needles and tests during these four months.

Elizabeth, her older brother (aged nine), and her parents Barb and Tim, live together on a farm about two and a half hours away from Edmonton, where she received most of her treatments. Her mother, Barb, works as an accounting clerk, and Tim, her father, is a professional chuckwagon racer. Around the time that Elizabeth's cancer was diagnosed, her family also experienced many other challenges and sorrows. Elizabeth's grandmother was diagnosed with breast cancer in May, 1991; Elizabeth's uncle died of lymphoma in August, 1991; Elizabeth's brother, who was only six years old, was critically injured by a horse in July, 1991; and Elizabeth's father also had surgery to remove some suspicious-looking lumps.

Like James, Elizabeth had not yet started school when her cancer first appeared. By September, 1992, when Elizabeth was ready to begin kindergarten, her hair was beginning to grow back. She had to miss some school days that year in order to drive to Edmonton for monthly check-ups and treatments, but she seemed to keep up quite well with her classmates. The following year in grade one, however, she began to have severe stomach aches. She missed a lot of school on account of these stomach aches, and had all kinds of tests to try and determine their cause. Tim and Barb were finally told that Elizabeth had an ulcer, and that it seemed that her stomach problems were mainly emotional in nature. She was referred to the child psychologist at the cancer treatment institute, and over the period of the last year, the stomach aches have almost all disappeared.

Elizabeth is a lively, talkative little girl, with a ready smile and a keen interest in talking about her experience. When I drove out to their farm to interview Barb and Tim, she seemed very curious about our conversation, and was the only child in the study who was actually present throughout the interview. It was evident to me that Elizabeth's presence did not affect the interview in terms of inhibiting Barb or Tim's comments; this is a family where everything seems to be discussed frankly and openly, and everybody's voice is heard. Barb and Tim seem to admire and respect Elizabeth's opinions. At one point during the interview, Barb mentioned that Elizabeth would need to do well in school, since she has plans of becoming a "cancer doctor." While Elizabeth nodded her head and smiled broadly, Barb added,

> But she wants to do lots of things... The other night, she said, "Can I just do one thing when I get big?" I said, "No, you can do as many as you want!"

At this point, Elizabeth said, "I'm going to do a whole bunch!"

Roger

The last child is Roger, who is 10 years old and in grade five. Roger was diagnosed with T-cell leukemia, (the same type of cancer as Chester), in September, 1991. At that time, Roger was almost seven years old, and was just beginning grade two. For the first year after his initial diagnosis, Roger was a very sick little boy. He was immediately hospitalized, started on chemotherapy treatments, and was not able to leave the hospital at all for the first seven months. During that time, Roger became very ill; he was unable to eat or swallow for many weeks, and was in bed or a wheelchair a lot of the time. He had numerous fungal infections, and suffered from recurring chicken pox. He lost all of his hair, and he remained bald for the next two and a half years. By March of 1992, he was allowed to come home for a few days at a time, but for the next few months, he spent more time in hospital than he did out of hospital. Roger was on chemotherapy for two and a half years, until January of 1994. In the spring of 1994, he underwent surgery on his esophagus, and also had his broviac removed.

Roger only attended school for 12 days in his entire grade two year. However, he managed to complete the requirements for grade two, with the assistance of his mother, Cindy, and the teacher at the hospital. The following year, he enrolled in grade three at the local public school, but he was away from school at least half the time that year as well. By the time Roger entered grade four, he was beginning to attend school more regularly, and this past year in grade five, he has missed only about half a dozen days. In grade four, Roger was placed on a "modified" program, but he is now coping successfully with the regular grade five program. He is an excellent reader, and is now reading at a grade 10 level. His spelling skills are also very advanced. However, Roger has a lot of problems that his parents, Cindy and Bart, believe are directly related to his cancer and treatment. He is quite a heavy boy; his gross-motor skills have also been affected and he has received services of an occupational therapist to help him develop these skills. He has problems with fine-motor skills, such as handwriting, and his short-term memory has also been affected. He has attention difficulties, and there are obvious delays in his social and emotional development. Recently, Roger has developed some very strong separation fears (relative to his mother), and he has begun seeing the child psychologist for help in this area. In spite of all these challenges, Cindy and Bart express a lot of admiration for Roger's accomplishments, particularly for the way he has kept up with his grade-level, and the plans he has for his own future. Bart says,

> It amazes me that he was able to do that [keep up with his grade level], and his reading level is just... well, he reads words that I can't even pronounce. Also, you know, you listen to him talk, and he's got some ideas that, probably when Walt Disney was his age, he was saying exactly the same things, like he's planning to open a place called "Awesome Waters." It's all thought-out, right down to the diagrams... it's very interesting, it's almost... you almost wonder about the possibility of parts of it coming off...

Roger lives in a suburban area with his father Bart, an engineer, his mother Cindy, a high school teacher aide, and his older brother, aged 13. Cindy, like Chester's and James' mothers, has also been highly involved as a volunteer at her children's school. Cindy and Bart are also quite involved in the Kids With Cancer parent group.

General Comments on Findings of Study

As I mentioned earlier, it was often difficult for parents to limit their comments to their thoughts about their child's schooling experiences. Most of them told me about a number of experiences that were not necessarily connected to schooling, but were more generally connected to the experiences they and their family had since their child's cancer diagnosis. They all spoke about how the child's cancer diagnosis had been a major crisis in their family's life, but many of them said that, over time, they had learned the importance of seeing cancer "in perspective." Many parents said things like, "You know, life goes on," or "You've got to keep a positive, healthy attitude." They all spoke of how they had to find a balance between being both realistic *and* hopeful.

Although I deliberately chose not to ask parents to comment directly on the question of whether or not they were satisfied with their child's schooling experiences, their responses to my questions, and the stories they told me about their child's schooling experiences, gave me a very good sense of their satisfaction or dissatisfaction. As I talked with the 11 parents in the study, I found that there was a whole range of parental satisfaction, from very satisfied to quite dissatisfied with what their child had experienced at school. However, it was significant that, regardless of the parents' level of satisfaction with the schools, the themes that emerged were strikingly similar for all participants. They all spoke about the importance of schooling; of the need for parents to be their child's advocates and the main "liaison" between the medical world and the school; of the importance of having "connections"; of being honest and open about cancer: and finally, about how important it is for teachers to become more knowledgeable about childhood cancer and its impact on an entire family.

It is important to note at the outset that each of these six children has so far managed to keep up with his/her expected grade level, in spite of what were very major school absences for some children. In some cases, the parents attributed this to the child's own "brightness" or motivation to keep up with peers; in other cases, to a "special" teacher (either in the hospital or at the child's school). They all believed, however, that their own efforts and determination not to let their child fall behind (even to the extent of home-schooling) had been very important in their child's success in school.

As I analyzed what made the difference in terms of the parents' relative satisfaction with their child's schooling experiences, a number of factors seemed to come into play. One factor, obviously, was related to the child's current health and the extent of his/her side effects as a result of the cancer and/or its treatment. The length and intensity of the treatments required also came into play. Some of the other factors, however, were related to things over which it seemed to me that we might have a lot more control, such as the school's response to dealing with the child and childhood cancer, and the connections, or power and perceived credibility that the parents themselves experienced in their relationship with the school.

Another overall theme that emerged is that schools on the whole are not prepared to deal with these children who are survivors of cancer. This is not surprising, considering that we are talking about a population of students that was virtually non-existent up to 15 or 20 years ago. Many of the parents have been quite satisfied with individual teachers and even the entire school in certain situations, but most of them have felt dissatisfied with the school's response as a whole. Cindy, Roger's mother, said:

> The individual teachers, we know well enough... [but] I think it's the administration. And it's not, it's not even necessarily our school administration... but I think it's all administration, on whole, I don't think anybody's got anything in place for this whole scenario...

Parents said that they often felt that educators, by and large, are mainly uninformed about childhood cancer and its effects, and that their responses are often based on outdated or wrong information (such as the idea that a diagnosis of cancer means inevitable death). There is also the whole issue of how educators view the school's role in the child and the family's life; many of them did not seem to understand how important it was for these children to be made to feel as "normal" as possible.

Another overall issue that emerged from the research was that these parents, reflecting a more general societal trend, are far more inclined to question the medical system and the education system than a similar group of parents might have been a generation or two ago. Parents are very clear that they know their child and their child's needs better than anyone else does; parents say that what is less clear is whether educators as a whole are prepared to grant parents the equality status that parents believe they should have as partners in their child's education.

Before beginning this research, I had thought that there might be some differences between mothers and fathers in terms of their perspectives of their child's schooling experiences. As I analyzed the interview data, what emerged was a high degree of consensus between both members of a couple. During the joint interviews, the two parents would frequently agree with one another, supporting what one or the other had just said, or providing me with yet another example to support what one parent had just said. Even with Chester's parents, whom I interviewed separately, there was an amazing similarity in their viewpoints with respect to Chester's schooling experiences. James' mother Doreen, whom I interviewed alone (and not her husband) was also very emphatic in her belief that I would have heard very similar perspectives if I had been able to talk with her husband as well. This finding supports Daly's (1992) statement that parenthood is generally contingent on a shared construction of reality. In some cases, one parent, most often the mother, was a lot more involved with the child's schooling; this might account for the lack of differences in perspectives, since the less involved parent would be more likely to accept the more involved parent's perspective. However, even when it seemed that both parents were equally involved in the child's schooling, the parents' perspectives were more similar than different.

One area where there were some differences was between the rural and the urban families. The parents from rural areas spoke about the support they received from the community, in terms of emotional, physical (child care, baking, etc.) and financial (local fund-raising activities) support. They felt that the people in their community were all aware of their child having cancer, and that many people expressed care and concern. Teachers and administrators at the school all knew about their child. In the urban areas, the parents generally turned to their friends, church or family for support; they also had to take more of the responsibility for making sure that people at the school knew about their child's condition.

Conquering Heroes

The title of "Conquering Heroes" was actually given to me by Cindy, one of the parents in this study. When I asked her what the school had done to help her son Roger's psychological and emotional adjustment, she replied:

> They didn't... so that's why I think... like, with a lot of these kids, they're kind of like a conquering hero that comes back... if the school would do it properly... And that definitely wasn't the case here. Instead, we're different. We're not somebody who's fought and won... which is what it should be. Instead, we're somebody who did something different.

I was struck instantly by Cindy's use of the term, "conquering hero," and I decided at that moment that I needed to highlight this term when I reported on the study. It seemed to me that the conquering heroes are not just the children; the parents are also "conquering heroes."

Each of the parents in this study was presented with the challenge of having a child diagnosed with cancer. As I learned from talking with these parents, very strong initiatives have been required of them as they dealt with this challenge. I also heard that these parents have learned that if they aren't prepared to be the conquering heroes that are called for in this situation, their children will not get the help and attention they need. However, even conquering heroes sometimes need support. The themes that emerged from the study give further elaboration of the type of support that these conquering heroes, parents and children, wish they could receive in our society.

Themes

There were six main themes that emerged from the analysis of the interviews, and each of these main themes has a number of sub-themes or related issues. It should be noted that the themes are not presented in any order of importance, because they were all important in understanding the parents' perspectives. The themes are:

1. The importance of schooling
2. Childhood cancer affects the whole family
3. Parents as advocates and initiators
4. The importance of "connections"
5. Honesty and openness about cancer
6. Parents' expectations for the schools

The Importance of Schooling

All of the parents in the study agreed that schooling was very important for their child. At the same time, no one was willing to say that it was any more or less important than it had been before their child had cancer; they generally said things like, "I've always thought schooling, getting a good education, was important," or "I think schooling is important for all children." Most of the parents said they didn't differentiate schooling for their child who had cancer from their other children's schooling in terms of importance. For example, Chester's mother Jeanie said:

> I don't differentiate his schooling from our daughters' schooling, as far as importance. I consider school to be very important, always have.

Some of the parents spoke of schooling as the child's "job" in our society. Speaking of how getting a good education has become a necessity in today's world, Chester's father Murray said:

> It doesn't make much difference [the cancer], I don't think, to me... Like I told him, everybody has to go to school. It's part of what you have to do. It's one of the things you have to do. I tell him, definitely a good education is the way to go, you know. Go and get a good one, because it will pay off in the long run. It might take a while to surface, but it'll pay off in the long run. I don't think there's any difference whether he's got cancer or not. School is, like I told him, a good thing to have. People need that education nowadays in order to get any work.

Tim, Elizabeth's father, said something very similar:

> You better go to school... it's the only thing that's going to carry anybody anymore. For me, I could have quit school at 15, and been a big farmer, but that's not profitable anymore. Kids nowadays have to have an education in order to survive.

Doreen, James' mother, explained that when he was first diagnosed with cancer, all that mattered to her was the health of her child, that he would get better and stay alive, but that:

> ... when that's all said and done, like, you have to go on with life, and schooling is very important. I mean, it's important to everybody in society, that's the way that you get to be knowledgeable. Schooling is important for every child, regardless of health or disease, it's very important.

While they all agreed that schooling was very important, many of the parents said that their perspective on schooling had changed since their child's cancer, or that they focused on different aspects of schooling as being more important now than before. For some, school was the best place where the child would develop social skills. Speaking about Chester, Jeanie explains in this way:

> I think, for him, school is as much a socialization thing as a place for learning, the learning is a secondary thing for him... That's where all his buddies are.

Frank's parents spoke about how they now view schooling for both of their children in a different light:

> School is important, but we certainly have a different perspective of it. There's a lot more to life than school. If we have an opportunity to do something on a particular day, we're certainly not going to say, "Oh, you have school today, so you can't do that." I think we just have a much different perspective on things now,... that it's not the end-all or be-all, it's important, without question, I mean, you have to go, you have to get your education, but... I think, too, the emphasis has to be on learning, not so much content... And I think we can learn in other ways, not just within the school setting (quote from Laura).
>
> We just don't get hung up on just school being the focus of our lives, that's for darn sure (quote from Fenton).

Roger's parents said that their way of thinking about what was really important about their children's schooling had also changed:

> It used to be we were really caught up in their marks... I mean, I think like all parents, you want to make sure your child does really well, and you get caught up in how well they do. But I don't think I'm so caught up in... I mean, education is very important, 'cause you're not going to get anywhere in life these days unless you've got a good education, but, on the other hand,... life's really short, and if you don't get a whole lot out of what's happening now, I mean... you don't know when you're going to be...

> Also, it really mattered to me before that my kids got perfect attendance every year. I would never do that anymore, I mean, school really matters, I'd never pull them out of school for just anything, but on the same token, if there's something special that's going to happen, and maybe it happens twice a year... I would rather make sure they were able to do that, or see that... (quote from Cindy).
>
> Well, the "effort" marks that we see on the report cards are way, way more important than the actual marks themselves... And that's something we've kind of changed in our personal reward system that we have for the kids. Yeah, that's totally changed (quote from Bart).

In one way or another, most parents also talked about how they believed that although education was important, it was even more important for a child to be a "well-rounded" person. For example, Cindy said:

> For me, I think school is still vitally important... but, I think it's even more vital to be a well-rounded person, I think you've got to have more than just a wonderful education, because you can have a wonderful education and be a real nerd... And if you're not socially accepted with people, you'll get less than if you have a really poor education. I don't want my children ever to have a poor education, but I'd rather have a poor education and be accepted by everybody, and have a zillion friends, than have no friends, and be an intellectual nerd. Because I think you're going to get a whole lot of places with being able to get along with people, I think that's the most important skill that they need to learn,... and you learn a lot of that at school.

Murray, Chester's father, stressed that, for him, being a well-rounded person meant having a balance between academic and practical skills:

> In my own personal views, the practical is important too. And with my children, what I try to do is get them involved in things like helping out, so

> they learn practical things. As far as I'm concerned, the practical and the educational side are both important... for everybody.

School as a Normalizing Factor

Most parents saw school as <u>the</u> normalizing factor in their child's life. The child's successful integration at school also seemed, in many ways, to provide a normalizing influence in the entire family's life. These children, who have experienced cancer, have had to deal with so many "abnormal" situations, and school is one place where parents see that they have a chance to be "just a normal kid" again. Jeanie, Chester's mother, explains:

> I mean, without school, where would he get a chance to be a kid again? ...Because they grow up so fast, and they have so much that's, you know... he can tell you the names of his drugs that are that long, and he knows his diagnosis, and... I'm sure all of the kids that go through this, age about 20 years in maturity, as far as knowledge. Because, I mean, they face, they basically face death... I mean, most kids go through their childhood thinking they're invincible, and, you know, death is something that happens to old people, and... not even so much the actual disease, having it themselves, and the diagnosis, as watching the other kids, seeing the other kids, when they get really sick and die... And that ages them.

Doreen, James' mother, said that for her, school was a place where every child can learn to feel good about himself, if the teachers handle things in the right way:

> Every child, every person in the world needs something that they can be good at, and concentrate on that... And for the teacher to be made aware of that, and stress that during the times that are difficult... 'cause everybody's good at some things, and lousy at other things. It's important for adults to be really aware, and to do what we can to make school a safe environment for all children.

Roger's mother, Cindy, also spoke about the normalizing impact of school for children with cancer:

> I think school, for these guys, is what makes them normal. School is the only constant that they can have with anything... If you have to do normal things, then obviously... I mean, if they live in a make-believe world, well, we'll take him to Disneyland every week, and everyone is going to always buy them toys... I think all that tells them is, they're definitely going to be different, and probably forever. Like if they don't get that kind of [message], that we know you're going to be OK, so that means you have to [go to school] and you have to learn this stuff... It's the only thing that I think shows them that there is definitely a future for them.

Importance of Being "Normal"

Being normal, and frequently looking normal, emerged as major issues that were connected to the parents' sense of the importance of schooling in their children's lives. Almost everyone spoke of wanting to have their children treated as normally as possible under the circumstances. When asked what advice he would like to give to the school, Chester's father's [illegible]nse was to say:

> Leave him in as normal of an atmosphere as possible. That way they don't feel they're any different, you know. Otherwise, if they're kind of put up on a pedestal, or you're watching them every minute of the day... they know that, they can sense that, when somebody's trying to pamper them, or somebody's trying to make an ordeal of it. Let them be a kid, that's what they're here for... Just let them be themselves, within their own limitations. Don't single them out. I guess, of course, everybody has to be aware of the child, and of his needs, but... pretty well try and treat him as normally as possible.

Jeanie, Chester's mother, supported this approach, and said that she made arrangements for Chester to be in a specific classroom, where she knew the teacher wouldn't "coddle him" too much. James' mother Doreen said she thinks that teachers need to find a balance between treating these children normally, and still watching out for them:

> Not baby them, or give them special privileges at all... because they shouldn't be spoiled that way... But just, just keep a watchful eye out, you know.

Many of the children, including Chester, Robert, Elizabeth, and Roger, all had to deal with losing their hair as a result of their treatments. Baldness in a young child is a very obvious treatment side-effect, and each of these children had to deal with some of the inevitable attention and teasing that came as a result. Robert's parents talked about how his kindergarten teacher helped him to "fit in" with the other kids, even though he was bald and couldn't always keep up physically with the other kids. Because Robert is so much smaller than all of his peers, his parents are now especially concerned about the impact that this is having on him emotionally and socially. They are trying very hard to convince the doctors to place Robert on a growth hormone, because, as Lois says:

> I just want a normal child here, I want normalcy for him... And if he's got to go through, like the next five years of schools, with his peers... His security is just going to go down, his self-esteem is just going to go down further and further... And I don't want that to happen to him. He's too nice of a kid to have that happen to him.

Roger's parents both talked about how important it had been for him to begin developing his own little group of friends over the past year. Since he was bald for almost three years, and missed so much school for two years, he has had a much more difficult time being a "normal" student than some of the other children in the study. Cindy tells the story of what happened when the school suggested that Roger might begin using a computer at school because of his difficulties with handwriting:

> They wanted him to start using a computer last year, they had a little lap-top for him, but his comment to me was, over and over again, "I'm so tired of being different, I just want to be like everybody else... I don't want to carry this around." So, it probably wasn't the right thing to do, but I was tired of him being different too... Like, if I can... just let him have a chance to be 10 years old, and do things everybody else does.

Planning for the Future

Although the parents all realized how serious their child's cancer was, they all seem to have had a great deal of hope that they would be among the fortunate ones whose children survive the disease. Not only are these parents all very hopeful about their children's survival, but many of them spoke about how they and their child had very definite plans for the future. Jeanie says that Chester, who loves hockey...

> talks years in the future, he talks about it, he wants to play in the NHL, he talks about having a family, you know, so... He doesn't let it hold him back, or think in short-term, or anything, because of it.

Robert's mother Lois says that he has many ambitious goals, and that schooling is related to at least some of these goals:

> Robert and Jason [his closest friend] have dreams of cruising in a car together when they get older... And they will, they will. He wants to succeed... You know, and he has dreams, like he has the wildest dreams. And I think he will succeed at something.

Elizabeth's parents believe that it's important for her to do well in school, because she has big hopes for herself. When she talked about how important schooling is, Barb said:

> Elizabeth says she wants to be a cancer doctor when she gets bigger... So she's going to have to have lots of school!

According to his parents, Roger also has big plans for himself in the future. He's planning to open a place called "Awesome Waters," which he already has all thought-out, including diagrams of the place. Roger's father says,

> You know, you listen to him talk, and he's got some ideas that, probably when Walt Disney was his age, he was saying exactly the same things... You almost kind of wonder about the possibility of parts of it coming off. He's definitely planning a future.

According to the parents, for each of these children, being academically and socially successful at school is a major part of supporting these hopes and dreams for the future.

Childhood Cancer Affects the Whole Family

All of the parents in the study stressed how much their entire family had been affected by their child's cancer. It was striking to me to hear them speak so strongly in terms that showed me how the entire family had "gotten" cancer. The parents' conversations were peppered with comments like, "when we were in treatment," or "we've missed a lot of school," indicating how they were all very closely identified with their child who had cancer. All of the parents also expressed concern with how their other healthy children had been affected by their brother or sister's cancer. First of all, these siblings all had to deal with extended times when one or both parents had to be at the hospital for the sick child's treatments. The siblings also dealt with their own fears and concerns for their brother or sister, and with having to face schoolmates and teachers who might not have a very good understanding of childhood cancer.

One of the most dramatic examples of this theme was the response that Elizabeth's parents gave me at the very start of our interview, when I asked them to tell me about her schooling experiences since she was first diagnosed with cancer. Rather than say anything about Elizabeth or her experiences, Barb immediately began to tell me what had happened to Elizabeth's older brother, who was six years old and in grade one at the time:

> Danny was just starting school, and I remember it was pretty hard on him... 'cause he ended up with a lot of problems at school, like behavior problems, and I think a lot of it was caused by the stress... of the illness, and the upheaval that was going on, his Mom wasn't home... He was steady in trouble. But things were never settled around here for a very long time.

Because they are part of a close extended family, Elizabeth's father said that her cancer also affected her cousins who attended the same school as well:

> It was her problem, but it's not only her problem. And I think even my nieces and nephews... we're pretty close. They're at the same school, the whole bunch of them. And you could see it in the kids, 'cause whenever we'd gather, they were all so close, the kids were like a little gang. I mean, that whole thing, like these kids, they stick together, and so they're all affected by it.

Jeanie, Chester's mother, talked about how she decided to "push" for more education about cancer at the school after she saw the impact that it was having on her two daughters:

> I didn't actually get in there [in the higher grades] until later on in the year, when the girls started having some troubles with some of the kids on the playground. I think they had as much or more as Chester did, because the films had been shown and the questions had been answered in the lower grades, and those kids had a better understanding... And I think the younger kids are more open sometimes than the older kids. And the girls were getting things like, "How can you stand to be near him? Aren't you afraid you're going to catch it? Don't come near me, I'm afraid that you'll give it to me..."

Robert's parents said that they had also found it important to inform their other children's teachers about his condition, and the things that his sisters might be going through. Lois recounted the following story, which illustrates how much Robert's older sister was affected by her brother's illness:

> Well, the first year he was sick, she was in grade two, and she went to school, and they were asked to draw a picture of, if they could have anything in the world, draw a picture of what they would want... And most of the kids put like, they wanted money, or they wanted toys, or they wanted to go to Disneyland. But she drew a picture of Robert in the hospital bed, hooked up to his IV poles, and she wrote on the bottom, "I just want my brother to get better."

Lois and Clark said they know how much their younger daughters were affected as well. One daughter was only a year and a half when Robert was first diagnosed, and although she was too young to understand, she was certainly old enough to miss her parents and her brother when they were away from home so much. In fact, this was the main reason that Clark and Lois decided to move to Edmonton from the small town where they lived, even though it meant losing a lot of their financial security. The following year, when Robert was in Minneapolis for his bone marrow transplant, the girls were separated from their parents for five weeks throughout the Christmas season. Looking back, Robert's parents wish they had done things differently. Lois says:

> If I had to do it over again, I would beg my family to bring the girls back down there. 'Cause that was too hard on them... The worst thing is to split up your family.

Clark adds, "Yeah, life's too short, we should have just taken them and lived there until we were done."

Some of the parents spoke about how the child's cancer had brought them much closer together as a family, and that it had given their family a "cause" to rally around. According to Lois:

> Like, cancer in one way was a blessing to our family. Before, we thought we had everything, a house, cars, we had playtoys, we had everything going for us. And then our world started to fall apart, so we banded together... We knew we had to pull together, to help our son. And that kept us together.

Even when the siblings didn't show any obvious effects of having a brother or sister with cancer, the parents said they knew that there was an impact. Roger's parents talk about Roger's older brother Sam, who is now 13, but was nine years old when Roger was first diagnosed:

> From an outside appearances point of view, you'd look at him and think, wow, that's amazing, you know. He's doing very well in school, did his thing, came home, did his homework... And on the surface, you'd look at it and say, from an educational point of view, it had no impact on him. But it was all the other stuff, the stuff that was underneath, you know... like not having a Mother around for a lot of time. (quote from Bart)
>
> Sam is the kind of kid that, he's there for you, he's such a helpful kid... And he'd never let anybody know, but one day we were driving one of his friends home in the car, and somebody said something about Roger being sick, and laughed about it. And Sam said, "It wasn't funny,"... And this kid said, "Well, I'm sure it wasn't that big a deal for you." And Sam, who doesn't lose it with his friends very easily, started yelling, and he said, "What do you mean it was easy, I didn't have my Mother or my brother for a whole year and a half! Don't tell me it was easy, you don't know." And that's the first time he's ever, ever said anything. (quote from Cindy)

Cindy went on to say that she knows that she is not as close to Sam now as she was before Roger got sick. She said that although some of the closeness they once shared is now starting to come back, it was almost like "we fought and made sure he'd [Roger] still be with us, but, you know, it's almost like I lost [Sam]... like, not lost, but..."

Parents' Perspectives Affect Children's Experiences

The parents in the study all had a strong sense that their own actions and reactions had a significant impact on their children's experiences, not only the sick child, but their other children as well. At some point during each of the interviews, I asked each of the parents to comment on how they thought their perspectives had affected their child's schooling experiences. Here are some of the responses I received:

> [What we did] had a huge effect... the whole schooling side of things, the way he got through grade two and grade three, required such a lot of dedication and kind of push, and constant monitoring and making sure things happened, and... And needed somebody like Cindy to be there, to be his advocate. Because, bits and pieces of what you need are actually there, but they don't come and find you, you have to find them. (from Bart, Roger's father)

> I don't think, if we hadn't been involved as we were, that Roger would have gotten a lot of the things he really needed to get. I think he would have been left behind, and at the very least a grade behind, and probably been quite demoralized, from an educational point of view... definitely been left behind. (from Cindy, Roger's mother)

> Probably a lot... I would say, a lot... I know at first, well, we didn't know what was going on either, and you just kind of numb yourself... It's the

only way you can get through it, is to just totally numb yourself, 'cause if you ever stopped to think about it, well... But, we just carry on, doing what we're doing. We've always been honest with her, and she's learned that's the way to deal with things. (from Barb, Elizabeth's mother)

I think my attitude really helped with his schooling experiences, because I'm not, like, a bundle of nerves, like, oh no, what's happened, you know, that kind of thing... I've learned not to be, and that's through just, time and time again, where scares have come to us, but there's nothing there. I always share [with James] that school is a really good place for him, and I remind him of some of the good things. (from Doreen, James' mother)

I think [our actions] have made school into a very positive experience for him... Like, one of the things that we have really pushed for is the whole independence thing. I get very irate when I see people doing things for him which I know darn well he can do for himself. And we're like that with him at home, and the fact that we have these expectations of him here, they know that at school... And I think that has made him be that much more successful at school. I think if we hadn't offered our input at critical points with regards to what was happening with his program, he wouldn't be where he's at today. (from Laura, Frank's mother)

I'm sure [how we've dealt with things has affected Chester] quite a lot... but how you deal with things tends to be how you've been dealt with. I mean, you have a way of dealing with things, and that doesn't really change, in some ways. You have a certain kind of way that you deal with things, and that's how your kids are raised to see you dealing with them that

> way. So he already had that perspective, going into the disease. Basically, in our family, it's always been, "Well, this happened, but life goes on." You have to assimilate this into your life, but you still have other things, I mean, that's a part of it, but it's not all of it, and you just go on. (from Jeanie, Chester's mother)

> Well, [our attitude] had to have a lot... I always say, the apple doesn't fall very far from the tree, and... I think it's just from, I guess, the way we've always handled things, that he... he took it pretty well, you know, compared to a lot of other kids we saw. Even a lot of the other parents we met would say, "How can you guys be so calm?" you know, and "I'm chewing my fingernails off." Well, does it help you to chew your fingernails off? It doesn't really help anybody or anything, because everybody senses it, if you're not relaxed about it... I'm not going to say we were real comfortable with it, but I mean, we put on a pretty good front. And as far as schooling and that, like we told him, it's all part of the system. You go in there and do your best, and that's all we can ask of you. We were lucky that he was that way, ... but I think a lot of it comes from Jeanie, she's very level-headed about stuff like that too... So she handled things well. (from Murray, Chester's father)

Finally, Robert's parents said that they thought their actions and behavior had probably affected "90%" of Robert's experiences. They said that they had been told by one of Robert's doctors that a large part of his recovery was going to depend on their attitude towards it, and they told me stories of some children who they said had died, because their parents had "given up" on them, or were not willing to keep fighting to support them.

Parents as Advocates and Initiators

All of the parents in the study felt very strongly that they had to assume a role as the major advocates for their child with cancer. They also reported that it had been largely left up to them to be the "liaison" between the hospital and the school. Some parents agreed that it was natural that these roles would be taken up by parents, but many of them expressed concern or even frustration with the lack of support they received in carrying out this role. Some also questioned whether that responsibility should be so totally left in the hands of parents. The main message that I heard with respect to this theme was that parents of children with cancer have to be strong and assertive, and that if they are not able or willing to "fight" for their child, the children will almost inevitably lose out. The term "fighting for their child" was one that I heard frequently from these parents. James' mother Doreen, one of the parents who was most satisfied with her child's schooling experiences, nevertheless talked about the need for parents to "really fight" for what their child needs. She said:

> If parents need extra help, like an extra aide, or something like that, they should really fight for that, to have that. You initially, as a parent, I think, would have to ask for it yourself. 'Cause the school's not going to go, just say... I mean, lots of times, schools just aren't prepared to deal with kids who have special needs. I would go and ask for help, wherever, I wouldn't depend on anyone else to make the connections.

Some participants said that they believe that parents will always have to be their child's advocates, because:

> ...nobody understands your child, or cares about your child, as much as you're going to... So, if you're not willing to advocate for them, then... I mean, it's all well and fine to say that I think the school should be doing a

> lot more, and I think they should, but if you're not willing to advocate for your child, it's like anything else... if you're not willing to put in the effort.

When I asked what advice she would want to give other parents who were in situations like hers, with a child diagnosed with cancer, Chester's mother Jeanie answered:

> You know your child best, so be your kid's advocate, and find out as much as you can about the disease. You know, parents have to learn to be forward... You have to, and if it's not a natural tendency, work at it, because it's in everybody's best interests.

Robert's parents, Clark and Lois had this advice::

> Pursue all the avenues... When push comes to shove, push... Because you have to push. You might not be popular, and you might have someone saying to you, "Oh, no, no, that's not the way it is..." But if you feel that's the way it is, then you strive and you start checking out every little avenue. And you see what's out there... Parents have to be aware of their child, and what they're about. You have to be assertive, you can't just sit back, and take everything...

James' mother had some even more specific advice in terms of parents being their child's advocate vis-a-vis the school:

> Parents should first of all make the school aware, of course. But not just the teacher, even approach the Principal, in case the child might get picked on in any way, because of the way they look, or anything... It's that kind of thing, that the Principal should be made aware of, and the parents should keep real close contact with the school... And make sure that there are sessions for other kids, to teach them about [cancer], to make them more aware, more appreciative. Also I think we need to make sure that the teachers are all aware, and are keeping close track of these kids -- academically, their work habits, if there is anything they are afraid of...

> Well, and if the teacher is not sympathetic, to remove him from that class, and have him placed in another class. It's worth it, right? The child already has enough struggles, with the chemotherapy, and some days, not feeling so good, you know...

Parents as Initiators

Some of the parents talked about how their own personal qualities had given them some definite advantages in terms of dealing with the schools. For example, Chester's mother Jeanie said that she felt that she was a "fairly forward" person, and that she was comfortable initiating contact with the school, and asking them to do certain things such as showing the students a film explaining childhood cancer or requesting a specific teacher for Chester. Jeanie believes that she has been able to educate a lot of the teachers and students at the school about cancer, because she isn't reluctant to initiate discussions or respond directly to the questions. Similarly, Doreen said that she "naturally" thought of how to initiate contact with the school about James' condition, largely because she had already had a lot of contact with the school over some of her older son's learning difficulties. However, Doreen recognized that for other parents, it might be a lot more difficult to initiate things in this way. Other parents supported this concern. For example, Cindy said that she herself would find it very difficult to take the initiative to go and talk to a whole assembly of students at Roger's school about childhood cancer:

> I'm not the kind of person... like, we made sure that they [the school] were well aware that all the stuff [like films about childhood cancer] was there, but I don't like making waves for stuff that, sounds like you're just trying to push your child... Some people can, if they have the right personality, if they're not intimidated, but some of us are intimidated too easily... to be, I mean, I'll advocate for [Roger], on a one-to-one basis, but I'm certainly not... and I guess I would, if push came to shove, but I'm not going to

> stand up in front of all the school and say, listen, this is what you need to know...

Lois, in talking about what happened when Robert returned from Minneapolis after his bone marrow transplant, tells this story:

> When we came back here at the end of January, and I started to look into school, that was the disappointing part... that no one came to us and said, "What about grade two?" And our thing was, there's no way he's going to repeat grade two... Like if it takes us till the fall of grade three, he's going to make grade two. So I got a hold of the school system, and I said, "Look, I want some correspondence." And so they agreed to a tutor, twice a week for an hour... And Robert was tired, I mean you had to get him right in the morning or forget it, 'cause he had no energy. And I ... pretty well taught him, like the tutoring was a bonus, it was sort of to relieve me and get more of the practical in there... So, he went right through until the end of July, he passed grade two, and was keen for grade three.
>
> If we hadn't gone to bat and fought for all these things, where would he be? It was, you know, it was totally left on our hands... And it was hard...

Parents talked about how they had all become very knowledgeable about childhood cancer, the treatment their children were receiving, and the possible side effects. Most of the parents also saw themselves as people who had been "forced" to face the seriousness of cancer head-on, because now it was affecting them and their families so directly. Lois describes how she and Clark became the initiators in much of Robert's treatment:

> We've always been parents that have taken things head-on... We've always read up on everything we can read up on, we've always gone the extra mile. I even went to the point where I kept a day-to-day diary of Robert. And the doctors used to come in and say, well, how did he act last time on this

> chemo? And I could tell them, I could tell them everything about the whole day, every day.

Bart, Roger's father, describes how his wife Cindy was "thrust" into the role of advocate for their son:

> She became totally absorbed in this..., she was the one that was thrust in there, that became the advocate for everything... not just schooling, I mean, all the stuff... Making sure he got the right meds, everything.

At the same time that these parents felt it was important for them to become as knowledgeable as possible about their child's disease, they also wish that the schools would be more open to doing some of this learning as well.

Lack of Liaison Between Hospital and School

Most parents said that there had been little or no liaison between the hospital and the school concerning their child. Consequently, much of the responsibility for this liaison role fell to the parents. Robert's mother said, "When you're done treatment, it's scary, because all of a sudden, you feel like you're left out to dry."

> There was never any follow-up... Like, we were told even at the hospital that, if there was ever a problem with him in school, let them know, they'll have someone come out and speak at the school... Nothing, like nothing... They've never followed up. Their follow-up is zero. There's no connection. Robert's doctor could not tell you today how Robert is doing in school. He hasn't even asked us how he's doing. They've never asked anything, like they never say, does he have trouble in school? ... They never sent anyone out from the [cancer institute], nobody, to talk to these kids at the school.

Elizabeth's parents said that to their knowledge, no one from the hospital had ever called the school to pass on information about Elizabeth's diagnosis or treatment. Tim, Elizabeth's father, said that the information was shared with them as parents, but "there wasn't really anything else."

Jeanie presented an exception to this finding. She said that she was aware that the nurse from the cancer institute had called the school initially to inform them of Chester's diagnosis and treatment, and of the implications for him when he returned to school. Jeanie also said that she thought that if she herself had not felt as comfortable taking over from there, there might have been even more liaison between the cancer institute and the school. However, as she said:

> I thought it was probably easier for me to go do it, than for them to have to try to explain it over the phone. And I was also comfortable going into the classrooms and talking about the disease and what could happen... But I know lots of people aren't comfortable doing that. And in that way, I think it would be easier if there was a person that was sort of a liaison between the hospital and the school... Somebody who would go into the school, and talk to kids, and let them know, you know what [cancer] is, and answer their questions... 'Cause the teachers aren't equipped, or comfortable, answering them.

Doreen, James' mother, said that she was given some information about childhood cancer, which she found helpful, but that no one at the hospital ever really talked to her about possible side-effects of treatment. One day, she went into the nurses' washroom by mistake, and read a paper on the wall that talked about all the learning disabilities that some children have, especially when they've received radiation treatments. She said that she feels very grateful that James has none of these side-effects, but that "her heart goes out to those kids who do have learning disabilities."

Lois said that Robert's school Principal suggested that she come in to the school and talk with Robert's class about cancer, which she did. However, she says that she felt this would have been far more effective if it had been carried out by someone other than Robert's mother:

> What happens is, [the other kids] look at it, oh, it's Mommy looking after her little boy, you know... It would need to be somebody, a medical person, or a teacher that has dealt with kids in the hospital, who says, look... Have you guys ever experienced death? Do you know what it's like? Do you know what it's like to be away from your family?... And that's what I really think is lacking. I don't know what other parents go through, but I really think there's a lack between the hospital and the school.
>
> I also think that parents already have too much on their plate, doing what they're doing, just watching out for their child's medical needs, and their psychosocial needs... without having to make sure that the rest of the school understands.

Cindy, Roger's mother, summed up this whole idea of the need for better liaison between the medical world and the school, when she said:

> We didn't have any intervention at all between [the cancer hospital] and the school, which would have been wonderful. The school didn't really do anything to prepare all the students for Roger coming back... the fact that he'd be bald... The grade two teacher did, though, she took a picture of him and put it up on the wall, but... I mean, I don't think they understood the significance of any of this. They didn't like, I've heard of some schools that would have a rally in the gym so that the kids understand what was going on... others show the Charlie Brown film... They didn't do any of that stuff. It would have been wonderful if we could have come back knowing that they'd [the other students] already been sat down and told,

> this the scenario, this is what's going to happen, this is what you should expect...
> There has been one psychologist from [the cancer hospital] who has assessed Roger a few times, and she contacted our guidance counsellor, and our occupational therapist, to discuss his program. But there's nothing else in place, to make sure that they have good connections between school and hospital... there just isn't anything... And, it's a definite need that everybody expresses. Some parents are lucky, because their school just happens to be that way. Not because they've ever had to deal with it [cancer] before, but they just... whoever happens to be their administrator is a person who's really clued in to what people need... But I think that's definitely not the norm... I mean, anything we've heard, from any of our friends, has been how desperately they felt they needed this support... that isn't anywhere to be found.

The Importance of Connections

In one way or another, all of the parents in the study spoke about the importance of having connections. For some of them, the connections that made a difference in terms of their child's schooling experiences were related to the relationships that the parents had already established with the school. For example, Chester's mother, James' mother, and Roger's mother had all been actively involved as parent volunteers at their children's school, long before each of these children was diagnosed with cancer. They had become known at the school, and felt that the teachers and administrators already respected them and viewed them as credible, reasonable, cooperative parents. Here, Chester's mother Jeanie describes her relationship with the school:

> I think I have a very good relationship with the school, because I have always, from day one, been comfortable... Well, I went to school in that school, how could I not... Well, it's that way in a small town. I know all the teachers, I've always gone in as helper in the classroom, and gone on fieldtrips, and... But that's a luxury, we've been fortunate for me to be able to have, because I don't have to work outside the home.

James' mother Doreen describes a very similar experience in terms of her connection with the school:

> When James started kindergarten, I already knew James' teacher, because my other two kids had her. And she might even have known [about James' cancer] before, because I was in there, like I always work at the school. They respect me there... And I think a lot of it has to do with my work there, too. I've been volunteering at the school for many years. So of course they're going to respect me, because I know them, they're like my friends, right? And I'm not the type of person that as soon as something goes wrong, I'm going to go make a stink about things, either... So they're really open to when I do have to say something, they're really open to that.

For Frank's parents, Fenton and Laura, their sense of connection was more related to their professions as teachers, who knew the school system and how to "work" within it to have their requests heard and responded to. They also feel that they have developed a very strong relationship with Frank's teacher, who has been with him for the past two years. Because of their own positions as teachers, Laura and Fenton often find themselves called upon to consult with other parents of children with cancer:

> A lot of other parents come to us about school issues, and you know, it comes back again to being in the system, and being informed, and being able to, you know, take the time to sit down and write letters, to know who those letters should be addressed to... 99% of the parents who have

> children [with cancer] don't have that type of school knowledge, to do it. We know the processes to demand these services... And most of the parents out there, even just to come to grips with the long-term issues of survival, let alone any of the educational issues... it's a big struggle for families.

Elizabeth's parents, Barb and Tim, did not seem to have the same level of connection with the school, even though Tim had attended the same school himself as a child. In fact, although they know some of the teachers personally, Tim and Barb don't have a great deal of respect for many of the teachers in the school system. Their sense of connection seemed to come largely from their relationship with Barb's mother, who was a retired teacher with many years of experience. They frequently consulted with her for advice as to how to proceed when they ran into problems or difficulties. Barb explains:

> We got a lot of coaching from my Mom, too. She's been a teacher for like, 34 years. And so, she'd ask me questions, and I'd ask her questions, and then she would tell me what I should do. Or I'd be afraid to phone [the school], 'cause I didn't want to bother them, and she'd say, "Well, no, you just phone them." So then I would, and things would be better.

Parents felt a sense of power and control when they had connections, and having these connections helped get things accomplished or made their tasks easier. In some cases, parents were forced to find or create their own connections. Lois and Clark, Robert's parents, felt a lot of frustration in terms of both his medical and schooling experiences. They wished that someone had been there to support them, to talk to the other students at the school. Lois says:

> This kid has survived death. He sees death around him all the time. And yet, no one has come forward, other than [the psychologist at the cancer institute], but we had to go forward for that too... to comfort him, to nurture him through it. No one has taken him aside and said, "OK, we're

> going to talk to the school." Even the Principal's support has come only when we called the meeting.

For Clark and Lois, their sense of "connection" seem to be more closely allied to the relationships they had developed with some of the medical personnel in Minneapolis when Robert had his bone marrow transplant. Now, when a problem comes up, they say that they don't hesitate to call their contact in Minneapolis (an oncology nurse):

> If we don't like what we hear, we phone Minneapolis. And see, most parents wouldn't do that, but we have an "in" down there.

Although most of the parents spoke very highly of individual doctors or nurses in terms of feeling a good sense of "connection" with them, there were also a lot of frustrations expressed towards the medical specialists. Some parents felt that the medical people were generally reluctant to acknowledge the side effects of cancer treatment:

> The majority of us are just parents, and we don't have, I mean, we know what our child was capable of, but trying to get somebody else to believe that they used to be able to do this, and now they can't, is really, really difficult... because you've never documented your children before, because they were average, or normal. So it's kind of, you know in your gut, what your child was able to do, but trying to get anybody else to believe you is next to impossible.

Speaking on this same issue, Fenton, Frank's father said:

> We've met with some of the oncologists, and had parents of children with cancer who have gone back to their oncologists, and said, you know, she's having all sorts of problems in school, you know... And the oncologists' reply back to them might be, "Well, she was hyperactive before, it's unlikely that this is, that you can draw any conclusions from that." Well, if the medical community takes that kind of an approach to dealing with the

> parents, if a classroom teacher takes the initiative to phone the physician, what's the physician likely going to say? Well, probably the same thing.

Both Fenton and Laura believe that there should be a lot more direction available to help parents of children who are long-term cancer survivors, and that some of this direction has to come from the medical community:

> Rather than saying, now that your cancer is cured, you're no longer our responsibility. Parents are telling us that these other components are in fact a result [of cancer and treatment], and they need to be dealt with.

Honesty and Openness about Cancer

All of the parents stressed how important they believed it was for them to be honest and open with their children about cancer. They had all received support from the medical people in sharing information directly with their children, and most of the parents felt that they had themselves been treated with a great deal of honesty and directness on the part of doctors and nurses. Many of the parents spoke about how they had learned to trust their child to know his or her own limits, and they also talked about how they had learned to be honest about cancer with their other healthy children.

When Chester's cancer was first diagnosed, and he was in the hospital, Murray said his son asked him:

> "Dad, a lot of people are worried about me dying, aren't they? People have come from all over, and they've sent stuff from all over." And I said, "Well, there is that possibility. We can't lie to you, but you're doing great and your tumor is shrinking, it's looking good for you. We're not going to say it's not going to happen, but it sure looks the other way right now."

Robert's mother, Lois, gives an example of the honest way they dealt with Robert's questions when he had a relapse at the age of 7:

> [Robert] just openly asked his father, "Am I going to live or am I going to die?" And that's when Clark said to him, "You're going to die if we don't get something done, and you're going to stand a chance if we go for this transplant."

Elizabeth's parents said that they also believed in the importance of being honest with their daughter, even though she was only 4 years old at the time she was first diagnosed with lymphoma. Lois says:

> With her treatment and all, everything that was going on, we just told her everything... What was going to happen, and why,... and if she had any questions, they were answered. She had to know what was happening to her.

Chester's mother, Jeanie, explains how they dealt with this issue with their son:

> You have to be honest... we've told him everything! I figure, there have been a couple of times when I've sort of, not been sure about telling him things with other kids, especially kids that have relapsed, or kids that are not doing very well... And you sort of hold back. But I've found from those situations that they usually found out, and even then what they assume is worse than what you'd tell them anyway, so it's better to just be really straightforward, and tell them. He knows that his disease is serious, that if he doesn't come for treatment, and he doesn't go through all the procedures and the tests, and whatever, you know... it would more than likely come back. So, in that way, it is serious, but... he also knows that at this point, if he finishes everything out, follows his doctor's orders, the chances are very good that he's going to survive this.

When she went to talk to the other students about Chester's cancer, Jeanie found that the same honest approach was the best way to handle questions:

> I went into a grade five classroom last year, and I mean... Kids are straightforward, and they said, "Could he die from this?" I said, "Yes, he could,"... And the teacher was just horrified, that the child would ask that, but it's a legitimate question. I said, yes, he could die from it, but I said chances are pretty good that he's going to survive it now, he's got through the worst of it. Like I say, they're thinking those questions anyway, they might as well ask them.

Some of the children's own openness and honesty about their own cancer can also help other people to feel more comfortable talking about the disease. Doreen says that James

> ... even tells people himself, he says, "I had leukemia, I had cancer." He just told somebody the other day, and he just says this on his own, and in that way he's very mature, and he knows what's happening. And I think he's had to, because of what he's gone through...

Lois talks about the importance of being willing to trust Robert to be honest, and to know his own limits:

> He's always known his limits... Like even in physical activity, or school work, or whatever, he will quit when he's tired, he will not push himself. If he wants to lay down, he'll lay down, if he wants to sit quietly, he'll sit quietly. We've always tried to give him the freedom to do that too, never tried to force him to do something that he didn't want to do.

Murray, Chester's father, says something very similar about his experience with his own son:

> They figure out their own system, like they know what their limitations are, you know... Once they push them a few times, they know where they can go and where they can't with that... That's what it looks like is happening with Chester.

Most parents expressed a wish that the school would deal with cancer with the same type of honesty and openness that they have in their families. In this respect, communication between parents and teachers was felt to be very important. The last theme, which deals with parents' expectations or hopes for the schools, will elaborate on this issue.

Parents Expectations for the Schools

This last theme emerged largely from the question that I asked of everyone, "What advice would you like to give to the schools about how to help children with cancer and their families?" It also came out of the totality of the interviews, because as parents shared with me their perspectives on what had happened with their child's schooling experiences, they often told me what they wish had happened.

As a former school teacher and administrator, I was most impressed by how reasonable these parents' wishes for the school were. None of the parents had expectations that I considered to be unreasonable or "out of line." In fact, most parents talked about how aware they were of the increasing demands being placed on classroom teachers, and were careful about not asking for things that would place additional stress on the schools.

Some of the basic recurring themes among the parents' wishes were: the importance of all teachers being informed and knowledgeable about childhood cancer, the need for information and education at the whole school level (and not just the child's classroom), and the value of having someone at the school level who would take overall responsibility for the child with cancer. This responsibility might involve ensuring that any teachers who dealt with the child were fully informed, monitoring the child's progress, being alerted to any problems that might arise, and making sure that any fears or misinformation among other students were addressed. Parents said that a lot of misinformation among other students were addressed. Parents said that a lot of misinformation still exists about cancer in general, and even more so about childhood cancer. Jeanie, Chester's mother, talked about how important education about cancer is:

> Education is a big thing, for everybody at the school...All the teachers, like the entire staff, not just the child's teacher, because she's not always the one on the playground, she's not always the one in the hallway... And she's not even always the one in the classroom. So the entire staff of the school... And the kids in the whole school, too, especially if there are siblings, because... just the grade, that one grade that the child is in, to me, doesn't cut it. It's not enough, because there's other kids that they encounter. And I think the more people that are educated about cancer, the easier it goes for everyone.

Jeanie would even go so far as to say that there should be education about cancer in all elementary schools:

> Even if nobody in that school gets cancer, somebody, somewhere that they know, every one of those kids, every one of those teachers, are going to encounter cancer somewhere in their lifetime... So, why is it that it's not talked about? I mean, they have drug education, sex education, AIDS education, you know... everything else, they come in and talk about, and yet... cancer is still that c-word, you know.

Elizabeth's parents felt that when their older son was having behavior problems at school, when Elizabeth's cancer was first diagnosed, the school was generally quite "ignorant" about the possible effect that his sister's disease and the family's disruption might be having on his behavior.

Fenton, Frank's father, talked about how important it was that schools recognize that these children are somehow different from the rest of the student population, and that having had cancer affects a child and his or her family in very significant ways. One of the problems, Fenton pointed out, is that many of these children don't have an obvious disability, like being in a wheelchair. In fact, both Fenton and Laura feel that in a sense, they have been "fortunate" in that Frank's side-effect of cancer is his blindness:

> Because it's a very obvious disability, he gets an aide, he gets [access to] consulting services. So potentially all of the other side-effects that he may have, might be addressed, as a result of all this other programming that's taken place. So in that respect, we're very lucky, I think.

Parents also spoke about how helpful it was for their child to have a teacher who knew the child well, and understood both the academic and psychosocial implications related to the child's disease. Frank, James, and Roger, had all had the same teacher for the past two years in a row. Since the interviews for this study were conducted in late April and May, there had been a lot of time for these teachers to work closely with each of these children.

Some of the parents were well aware of various school re-entry programs that have been established in other areas. None of the children in this study had benefited from any such programs, but all the parents felt that these would have been helpful if they had been in place. However, many parents stressed the fact that it's more than the "school re-entry" point that is important. Lois, Robert's mother says:

> I think somebody should come and talk to the whole school... Not only about what the child went through, and is going through,... But also to let them know how to help the rest of the family. This is not just a short-term thing, it's a long-term thing. And I think there has to be a support, and I think not only <u>once</u>, but it needs to be an ongoing thing.

For all of these children, being a cancer survivor did not mean being unscathed by the disease, even when the long-term effects "only" consisted of lingering fears or recurring stomach-aches. For the majority, the effects were a lot more significant; blindness, stunted growth, attention difficulties, fine and gross motor impairments, and emotional problems were some of the challenges faced by the children in this small study sample.

Tim, Elizabeth's father, said he wished the teachers and the other students would have had a better understanding of what she had gone through. For Tim, the "psychological" part was the most important. It seemed to him that when the educators have had some previous experience with cancer, they become more sensitive to the needs of the child with cancer, and of the entire family.

> I think there's a better understanding at the school now, because the Principal who is there now, well, her husband has cancer. And, I mean, it would be something that really hit home with her, and really be passed on now.

Doreen said that when James went to grade one, his teacher was already familiar with childhood cancer, because she had another child with leukemia in her class a few years ago. This experience also helped her to feel more comfortable with having James in her classroom. Chester's mother, Jeanie, said Chester had a teacher whose niece had leukemia, helping her to understand some of the things that were involved.

The advice that each these parents wanted to give to the schools was strikingly consistent. Chester's father Murray probably explains it best; everyone's main concern with the school begins with wanting the children to be treated "as normally as possible":

> Don't single them out. Of course, everybody has to be aware of the child, and of his needs, but... pretty well try and treat him as normal as possible, taking into consideration his stage of treatment or whatever. I think they should be left in as normal an atmosphere as possible. That way they don't feel they're any different. Otherwise,... they can sense that, when somebody's trying to pamper them, or somebody's trying to make an ordeal of it. Let them be a kid, that's what they're here for. Just let them be themselves, within their own limitations.

Laura, Frank's mother, describes what all parents in this study believe to be important for the schools to know and do:

> First off, I think they need to understand. Many teachers have so many of their own fears about cancer. They think of cancer as being, well, it's the "Big C" of course, and if you have cancer, you're going to die... And [they think] I cannot allow myself to become so emotionally involved... You know, so they've got all of their own fears and emotions to work through, too. I think just providing them with the information about the different types of [childhood cancers], and sure, provide them with the information that this child may relapse and die, but in the meantime, it's very, very important that he be treated like the others. Teachers need to know specifically what the potential long-term effects of this are going to be. There also needs to be somebody there within the school that is going to follow these children through. Just to provide the information to the classroom teacher when the child is first diagnosed is not sufficient. Because nothing may emerge that year, and the file may get lost somewhere, and suddenly in grade four, this kid can't do math. There has to be somebody responsible for following the child through, and passing the information on.

Laura thought that this person should probably be the school counsellor, although it might also be an administrator or a special education coordinator. This person could also assume responsibility for educating the teachers about cancer, and some of the possible long-term effects.

Concluding Comments

The six themes that I have presented in this chapter represent a summary of these 11 parents' perspectives on their children's schooling experiences. All of these parents want people to know about childhood cancer, because they want to do what they can to make sure that misinformation is corrected, and that we can all begin to understand how to support "childhood cancer survivors" and their families. As Chester's mother said, "Cancer is the scariest word in the world, when you know nothing about it... the scariest word in the world."

I have tried to present these parents' perspectives in as honest a way as I could. At the same time, I wanted the parents themselves to feel that they have been well listened to, and that I have at least begun to truly understand their perspectives. The courage and determination of each of these parents is an inspiration to me, and I continue to think of them as the "Conquering Heroes" that this study attempts to highlight. Robert's mother, Lois, summed up what I believe each of these parents could have said:

> I want Robert to grow up saying, "My Mom and Dad did everything they could for me, even if I have to be this way... My Mom and Dad did everything possible to fight for me." And that's what we've always told Robert, no matter what, we will go to the ends of the earth fighting for you. And he knows that.

CHAPTER FIVE

DISCUSSION

Introduction

After the main themes have emerged from the study, the qualitative researcher returns to the literature to compare and integrate these findings with the work of others in the field. Time is also taken to reflect on the findings of the study, to integrate these findings with current literature, to suggest how existing literature might be understood in light of the findings, and to propose new ideas that could better account for these findings. This chapter also presents my personal reflections on the data that emerged from the study I conducted.

A Theoretical Perspective

In Chapter Two, I presented Birenbaum's (1990) suggestion that families construct an "illness representation," and develop an illness perspective as they learn to live with the effects of cancer and its treatment. Birenbaum's review of the childhood cancer research resulted in identifying two levels of illness representation in the family, encapsulation and at risk. Encapsulation activities include "normalizing" activities as much as possible and controlling the meaning of the experience. At-risk activities involve those strategies that are aimed at overcoming the illness and blocking its recurrence. Both of these levels are evidenced in family coping strategies.

For parents of children with cancer, it was my assumption at the outset of this study that both encapsulation and at-risk activities would be occurring, and that these would in turn impact on the parents' perspectives on their child's schooling experiences. The research data seem to support this assumption. Parents spoke about how they wanted the school to treat their child "as normally as possible, while keeping a watchful eye" on the child. The parents who were most satisfied with their child's schooling experiences were the ones who felt that this had been done by the school. Parents wanted the child's schoolmates to be informed about cancer, so they could better understand what the child with cancer had experienced and "normalize" that experience as much as possible. At the same time, they also wanted educators to be aware that a child who was a cancer survivor might have some very specific needs, and to be sensitive to other needs or difficulties that might still not have emerged or become obvious.

How people deal with stressful situations has frequently been referred to as "coping." Some researchers consider coping to be a personality trait, while others prefer to describe coping behavior as a style. Others go further and consider coping to be a transactional process between the person and the environment, and thus to be constantly changing (Van Veldhuizen & Last, 1991). This last approach is the one most consistent with the present study, and I heard the parents describe a process that was on-going, and changed with the school, the child, and the family's circumstances. Although in this view of coping as a process, a certain consistency in the individual's reaction pattern is not ruled out, the emphasis lies on the ongoing interaction between the person (or persons) and the environment.

On the Importance of Openness and Honesty

The parents I spoke to all felt strongly that open communication about childhood cancer was of utmost importance, and that any true "understanding" could only come about once people (both adults and children) were honestly informed and educated about the disease. In searching for and developing control of childhood cancer, it has been suggested that communication about the disease is an important device for the child and the parents (Rothbaum et al., 1982). Once again, this assumption is one that has been strongly supported by the present study. According to Rothbaum et al. (1982), a life-threatening disease is a situation in which primary control is limited and, partly due to this, the individual has to rely on secondary types of control. Neither the child with cancer nor the parents are capable of averting the threat created by the disease by way of direct action. For this reason, control of the situation will be sought, among other things, in processes which enable them to understand, accept, and deal with the situation.

All of the parents in this study talked about how honest they felt they had been with their own children, and how much they wish that schools, and society in general, would adopt a similar attitude in talking about childhood cancer. In a foreword to Bearison and Mulhern's (1994) book Pediatric Psychooncology: Psychological Perspectives on Children with Cancer, Koocher discusses how dramatically pediatric oncologists have changed their views, over the last 25 years, about sharing information with children about cancer. Until the late 1960s, medical specialists were generally inclined to shield children from fears of death. Since then, there have been significant transformations in the field of pediatric oncology, including an awareness of the importance of openness and honesty with the child, and of the various psychological aspects of cancer treatment. The opinions on what a child with cancer can be told about his or her disease can be classified into two approaches: an open approach and a protective approach. The protective approach consists of protecting the child, as much as possible, from the real meaning of the disease. The environment pretends there is nothing seriously wrong. The open approach consists of informing the child about the diagnosis and prognosis. The life-threatening character of the disease is acknowledged in communication with the child.

Van Veldhuizen and Last (1991) believe that attempts at secrecy are "doomed to fail, and actually feed the child's unrealistic fearful fantasies" (p. 60). Their study confirms a previous assumption that open information has a favorable effect on the child's emotional experience. Jeanie, Chester's mother, summed this up by saying, "what they assume is worse than what you'd tell them anyway." The parents in this study believed strongly that their children did better as a result of being treated with total honesty concerning their cancer and its treatment.

On the Importance of Families and Schools Working Together

Before undertaking this study, I speculated that for the parents of a child with cancer, it could be that schooling takes on added significance, either as a "normalizing" factor or as a symbol of the possibility of a future (Ross, 1984). On the other hand, I thought that schooling might have become far less important to parents of children with cancer, assuming a lower priority in their lives given the life-threatening nature of the disease that their children had faced. To my surprise, I found that, in this study, neither of these assumptions was confirmed. In fact, all of the parents insisted that their child's schooling was very important to them, but that it was no more or less important than it had been before their child had cancer. Some of them spoke about how their perspectives on schooling had changed, however, and that they now found themselves emphasizing very different aspects than they once had. For some, the aspects that had become most important were the child's social and emotional growth, particularly with respect to getting along with others and developing good social skills. The child's sense of self-worth, of independence, and of "not being different" became a high priority for some parents. Several parents stressed that "marks" had become less important than knowing that their children were trying their best, and that the process of learning was at least as important as the content itself.

It has been well established that students succeed in school best when families and schools cooperate to achieve common educational and behavioral goals for the students (Epstein, 1992). A typical approach to the breakdown of relationships between parents and schools has been to try to assume that the "cause" is rooted in the emotional dysfunction of a parent, or in various other family difficulties (Minuchin, 1974). However, systems theory tells us that breakdowns among people working together are rarely caused by one party only, but are a result of the interaction or "dance" that develops among the individuals concerned. Small initial misunderstandings can escalate into increasingly polarized situations, where neither party feels he or she can trust the other. In such cases, an adversarial relationship can easily develop. Since it is usually difficult to tell where or how the "dance" has started, what is more helpful is for the entire system to change in some way. One party changes his or her reactions, a new element is introduced, or new information becomes available. Awareness and understanding can allow people to change their reactions as early as possible, so that the situation can change or be managed more productively for the student. For example, if parents seem anxious or over-demanding, school personnel may react by giving parents a message to "back off", and in turn the parents perceive the school's withdrawal as evidence that they have to work even harder to advocate for their child. Instead, educators need to find ways to make the parents feel affirmed for caring and advocating for their child.

Gibbons (1988) reports on research showing that children and families who are particularly vulnerable with respect to schooling experiences include: (1) those of low socioeconomic status, implying less accommodating schools for children with disabilities; (2) those with a passive attitude; (3) those with a tendency to withdraw; (4) those demonstrating cultural differences with school personnel, which often results in poorer communication; and (5) those families with closed communication patterns, limiting their ability to resolve conflictual feelings. These findings are consistent with comments made by parents in the present study, such as how they found it important to be assertive, to initiate contacts with the school, to keep the lines of communication open, and to keep "fighting" for what they felt their child needed. It also supports one of the other themes that emerged from this research, on the importance of parents having "connections."

Reflections of an Oncologist

Halfway through this study, I met with one of the chief oncologists who works most closely with children with cancer and their families. I wanted to share with him some of the preliminary findings of the study, but I was also curious to hear the perspectives of someone from the "medical" world on this issue of children's schooling experiences after a cancer diagnosis. I also wanted to hear this doctor's comments on the role of parents, and how he thought the parents' perspectives might affect the children's schooling experiences.

One of "Dr. Smith's" first comments was that he couldn't agree more with one of the "basic assumptions" of this study, that parents' perspectives have a significant impact on the child's experiences. In fact, he said that this was something he had personally observed over and over again; that how parents cope and deal with their child's cancer, the necessary and painful treatment, and other experiences that the child faces, has a tremendous impact on the child's reactions and how the child in turn deals with these experiences. He also said that the study of the late effects of cancer and its treatment was gaining increasing interest and importance in his field, and he believed that a better understanding of parents' perspectives was an essential component in this area.

With respect to the children's schooling experiences, Dr. Smith said that he thought there were two quite different issues involved. One had to do with "re-entry" issues, and these involved mainly the educational and psycho-social components. The other issue had to do with the "late" side effects that seem to be emerging; some of these are cognitive in nature (learning disabilities, short-term memory loss, etc.), while others are more physical and emotional in nature. In terms of re-entry, Dr. Smith said that his observation was that the response of the school depended to a great extent on the principal. This supports a view that was expressed by several parents in this study, that the school administrator's response and direction had a great deal of impact on the child's schooling experience. However, it seems that the parents in this study would prefer not to differentiate between the "re-entry" issues and the possibility of the emergence of late side effects. These parents' perspectives with respect to their children's schooling experiences are more "wholistic." They believe that when the educators are well-informed about childhood cancer and its effects, they also will tend to be sensitive to the possible late effects associated with the disease or its treatment.

Dr. Smith also stressed that cancer can be a very positive experience, for parents and families, as well as for the child with cancer. At the same time, he speculated that the school as a whole can also benefit from this experience. Staff and students in a school have an opportunity to learn about childhood cancer, to become more sensitive to the individual needs and challenges of children (and their families), and to experience some of the benefits that can come from "pulling together" around a specific issue or cause.

Finally, Dr. Smith cautioned me not to lose sight of the fact that what I have been learning about are only the parents' perceptions of a situation, and that the medical people, the school personnel, and the children themselves, all have their own perceptions as well. As I reflected on the significance that this meeting with "Dr. Smith" had for me, I realized that it had provided me with the kind of "connection" that parents in this study spoke about. I felt that my research had been validated, and that my interests and concerns were being shared by another person who had an important position in this area.

The Unpredictability and Uncertainty of Childhood Cancer

It is often pointed out that the most salient characteristic of childhood cancer is the unpredictability of its course and final outcome (Van Veldhuizen & Last, 1991).

> Childhood cancer creates a situation which is dominated by uncontrollability. Technical progress attained in medical science in the past decades makes the limited knowledge of the etiology and the relatively limited possibilities for controlling this disease glaringly obvious. The disease process does not have clearly defined stages in which a complete control or cure of the disease can be guaranteed. Furthermore, the potential control of the disease process is mainly in the hands of the doctor. Children and parents cannot influence the disease process very much. Moreover, parents must entrust most of the care of their child to others in the hospital. (p. 16)

Cancer is frequently referred to as a "chronic" illness if the child survives beyond the first or second year after diagnosis, in the sense that the presence of latent cancer cells cannot ever be completely ruled out. However, Van Veldhuizen and Last (1991) point out that it may not be realistic to label a child, who has not exhibited any physical complaints or disease symptoms for many years, as a chronically ill child. Permanent damage as a result of the disease or treatment which hinders normal functioning would sooner lead to the child being labelled as handicapped than as chronically ill. What can be called chronic is the permanent threat and the long-term period of uncertainty. Due to the unpredictability of the course of the illness and the long-term uncertainty about the final outcome, the child and parents find themselves in a situation between hope and fear. The anticipated threat of a fatal outcome hangs above their head like a "sword of Damocles" (Koocher & O'Malley, 1981). From the moment that the first symptoms of a serious illness manifest themselves in the child, numerous uncertainties arise. Prior to the diagnosis, there is the uncertainty whether the terrible suspicion will be confirmed. After the diagnosis there is uncertainty about the prognosis, the length and severity of the treatment, the length and number of hospital admissions, the side effects of therapy on the well-being and development of the child, the complications which could arise, and the test results which could indicate a remission or a relapse.

In my study, Frank's parents said that they had found dealing with his blindness far easier than dealing with cancer itself. When I reflected on this statement, it made sense to me that blindness was something "certain," and that Laura and Fenton knew exactly what they were going to have to deal with in this respect. With childhood cancer and the ever-present possibility of recurrence or relapse, however, the situation is quite different. In other studies, parents have expressed the feeling of uncertainty through remarks such as, "the real hell of this is that you just don't know" (Van Dongen-Melman et al., 1986).

Cohen (1995) reports on a very recent study of the "triggers" of heightened parental uncertainty in chronic, life-threatening childhood illness. In these families, even if the disease is under control or in remission, parents know that it can reoccur with little or no warning. It is this knowledge that keeps the threat of loss always in conscious or subconscious awareness. However, although the threat posed by the disease remains constant, the perception of the threat does not remain at the same level of intensity at all times.

Cohen's study identified some of the triggers that caused a heightened level of awareness of the uncertainty. These triggers include routine medical appointments, body variability, keywords and provocative questions, changes in the therapeutic regime, evidence of negative outcomes, new developmental demands, and night-time. The trigger of "keywords and provocative questions" seems to be the one that educators most need to be aware of, and sensitive to. Parents reported how a thoughtless or unfortunate choice of words can seriously impair their ability to manage their awareness of the uncertainty (Cohen, 1995). This finding was also supported in my study, and highlights the importance of the school's response in supporting both parents and the child with cancer. Developmental changes in the child can also trigger new concerns and heighten uncertainty about what is in the child's best interests (Cohen, 1995). Robert's parents demonstrated this "trigger" as well, when they shared their concerns about the impact that his small stature is having on his emotional adjustment as he enters adolescence.

Cohen (1995) also reports that a common strategy that parents consciously employ, especially during times of heightened uncertainty, is to try to live one day at a time. All of the parents in the present study were acutely aware of the seriousness of childhood cancer, and were doing their best to help their family to live *with* the cancer, rather than *in spite* of it. It seems to me that many parents who are exquisitely aware of the seriousness of their child's illness and are trying to attain (or retain) some degree of family normality by consciously controlling that awareness may be thwarted by "professionals" who mistakenly assess their behavior as denial. Once again, it seems to me that both medical specialists and educators need to be very sensitive to these parents, and avoid unnecessarily increasing their anxiety.

Childhood Cancer can also have Positive Results

Maguire (1983) claims that most parents try "desperately" to search for an explanation as to why their child has contracted cancer. This was not something that any of the parents talked with me about, although they almost all spoke about how they felt that cancer had had some positive benefits for themselves and for their family. In a study conducted by Van Veldhuizen and Last (1991), parents of children with cancer were not found to have more psychological and psychosomatic stress reactions, or to experience any more anxiety than persons representing an average of the population. These findings contrast with data in other literature, which show more anxiety and depression in parents of children with cancer (Maguire, 1983). In fact, the results of Van Veldhuizen and Last's (1991) study showed that most parents of children with cancer display an adequate adjustment to the illness, and do not experience a prolonged disruption of their emotional balance. In my conversations with parents throughout this study, I also observed that most parents are optimistic about the chances of survival for their child; although they do not completely deny the thought of possibly losing their child, they have found ways of pushing these thoughts to the background.

Besides negative feelings, many parents associate positive feelings as well with the situation created by the illness (Koocher & O'Malley, 1981; Van Veldhuizen & Last, 1991). These positive feelings clearly express a shift in values which occurs during the course of the illness. Just as in the study by Koocher and O'Malley (1981), all of the parents in this study expressed a feeling that their family has grown closer together as a result of this experience, that they had made some very close friends, and that they had a much clearer sense of their priorities.

I have found this discrepancy in results of studies to be interesting. My sense, after talking with the parents in this study and reflecting on the literature I have read, is that although having a child with cancer cannot help but be a distressing and difficult experience for a family, perhaps the positive effects have a "counter-balancing" effect. One of the end results of this effect might be that these families do not demonstrate any more dysfunction than the general population. Kazak (1994) suggests that positive adaptation after a serious illness like childhood cancer supports the notion of resiliency, with most individuals using successful coping strategies. She believes that it also raises the question of the role of family systems and other systems (e.g., schools, medical facilities) in supporting children as they end treatment and resume a more nearly normal childhood.

It seems to me that just as there are positive aspects of cancer for the child and his or her family, the schools can also reap tremendous benefits from the experience of having a student with cancer. It provides an opportunity for the entire school to pull together, to have a common focus, cause, or concern. Staff and students are offered a gift of becoming more sensitive to the needs of others, to the preciousness of health, and to the importance of supporting one another. Childhood cancer, although rare, is certainly a "democratic" disease. It affects children from every socio-economic level, and cultural or ethnic background. Cancer is something that "just happens," and unlike many of the other dangers in our children's lives, it cannot be prevented by parents being more vigilant or doing anything of a preventative nature. It could happen to any one of our families. Now that increasing numbers of children are surviving cancer, schools are, in a sense, being offered an important learning opportunity.

How do Schools View these Children: As Victims or Conquering Heroes?

These children may be physically and emotionally frail on their return to the school, but they are nevertheless "conquering heroes." After having done this study, I have become convinced that seeing the children (and their parents) in this light would also have an impact on teachers.

It has often been assumed by teachers that "sick children really don't belong at school." After all, their ability to learn is certainly impaired by their physical or emotional difficulties. However, the results of this study, and a review of the literature on children who are survivors of cancer, suggest that in the lives of these children (and their families), the role of school extends far beyond a merely academic one. The parents told me how important school was as a "normalizing" factor, not just in their child's life, but in their own as well. Given the circumstances, all of the parents want the child's schooling experience to be "as normal as possible." As one of the parents said, the child's return (or entry) into school also is a symbol that there is "definitely a future for this child."

Throughout this study, I found myself wondering about how aware teachers generally are of the importance of a child's return to school after a cancer diagnosis. It also seems to me that the educators' awareness and sensitivity to the issues that these families are facing would be a very important component in facilitating the child's school experiences. For example, a recent study by Van Veldhuizen and Last (1991) found that parents of children with cancer seemed to "project more situation-specific emotions of anxiety and insecurity, and feelings of helplessness" (p. 236). Van Veldhuizen and Last speculate that this could indicate that parents deny their own negative emotions, but do project these onto others. If these findings and speculations are true, it seems to me that the school would be a "natural" target for these negative emotions. Educators who are aware and sensitive to these predictable parental reactions might be more willing to understand, and to provide parents with the type of support that they need at that time, rather than reacting in a defensive or disparaging manner.

Van Eys (1991) presents the concept of the "truly cured" child, proposing that cure has at least three components: a biological cure, a psychological cure, and a social cure. He says that biological and psychological cures have already been realized, but that social cure is yet to be achieved. In order for this to happen, Van Eys suggests that both educators and medical care personnel must begin to consider the chronically ill child a "normally sick" child, in the sense that is it also normal for a child to be sick, and that a sick child is thus "normal." Since children are basically geared to developing normally, we must find ways of adapting our environments to allow full development of each child's potential, and the best quality of life possible. Van Eys believes that this will be done when, together, we "teach children to realize their potential by motivating them, teaching them self-acceptance, and making self-reliance possible" (p. 169). According to Van Eys, the barriers to this happening lie not in mechanical problems, but rather in our <u>perceptions</u> of cancer, of children, and of "differentness."

The parents in this study all had a sense of the importance of their child being considered "normal" at school. In Van Eys' language, these parents are asking that the educational community find ways of beginning to see cancer as "something normal" that has happened to their child. Life, the business of the child, must be ongoing, not in spite of the cancer, but with the cancer. All of these parents want to avoid having a "biologically cured" child who is a psycho-social cripple. Parents are very clear that they do not want support structures that isolate the child from normal development in any way. Normalization is a difficult task, and demands a structure of care in which the child and his or her family are trusted participants.

Conclusion

Frank (1991) tells us that:

> Stories we tell ourselves about what is happening to us are dangerous because they are powerful. Stories come to us from many sources; some we seek, many happen without our notice, others impose themselves on our

> lives. We have to choose carefully which stories to live with, which to use to answer the question of what is happening to us. (p. 81)

The parents in this study have all very carefully chosen the stories they tell themselves about their family's experience with childhood cancer. However, it would be a mistake to assume that they have not also been influenced in their choice of story by the responses they have received from the medical system and the school. Because of the power of these stories in the lives of the children and their entire families, it is most important that all of the professionals involved with the child carefully consider their roles in the authoring of these stories.

CHAPTER SIX

IMPLICATIONS

> "Until very recently, medicine dealt primarily with acute diseases. The miracle of modern medicine was wrought with the understanding of the etiology of acute epidemic diseases. Prevention controlled epidemics and treatment avoided serious sequelae. During that time, schools taught well children. A child was either well, or too sick to go to school. There was little in between." (Van Eys, 1982, p. 161)

Our current medical era is the era of the chronic disease. As a consequence, schools face a new challenge. Van Eys (1982) states that for the child whose life has been affected by cancer, the major elements in shaping his/her future are family, education, and medical care:

> If there were an equal partnership between parents and child with medical care and education, the charge of total care for the chronically ill child would be met to a very large degree through cooperation between medical personnel and educators. (p. 163)

Yet, Van Eys (1982) states, there is "precious little" in the educational literature describing this interaction in a constructive way. Van Eys' review of the literature failed to reveal any descriptive or investigative articles on existing collaborative efforts between medical specialists and educators; instead, we have a phenomenon whereby "side-by-side teamwork without true cooperation is rampant in our world of complex care delivery" (p. 163).

Children who survive a diagnosis of cancer, and their parents as well, are "victors" or "conquering heroes" by the very fact that they are alive. However, when I spoke to the parents in this study about their perspectives on their child's schooling experiences, I learned that, for most of them, "the fight" goes on. As their children's main advocates vis-a-vis the school, parents view themselves as needing to be particularly vigilant and strong. In a very real sense, these parents believe that unless they continue to be the "conquering heroes" called for by the situation, there is a good likelihood that their children's needs may not be met by the educational systems currently in place. These parents want and deserve to be listened to very carefully by both the medical establishment and the schools.

My sense is that we have "lost" people in our institutions, and that what is needed at this time is a truly quantum leap to integrate our medical, social, and educational worlds. This phenomenon is certainly not limited to children with cancer; it extends to children with all types of special needs, including various chronic physical and emotional diseases. I believe that care of children ought to be a collaborative undertaking, requiring joint planning by parents, educators, and medical personnel. There is a need for continuing education of all involved, so that each party is aware of the problems inherent in the setting of the other groups. Deasy-Spinetta (1993) states that parents, schools, and the medical system must begin to view one another as partners, each with a unique responsibility in the child's total care:

> For students with cancer to survive as fully-functioning productive members of society, there must be a partnership between schools, medical teams, and parents to promote sound academic and social development as part of total care and cure. (p. 4)

Furthermore, because children who are survivors of cancer come to school with a range of developmental, academic, and medical needs, educational programs for these children need to be individualized to meet the specific characteristics of the child, the family, the treatment centre and the school district.

Implications for Parents

The parents in this study said that they have found it very important to become knowledgeable about cancer, to be honest about it within their family, and to share this information with the schools. For some parents, taking on this advocacy role has been a daunting task, especially for those who don't view themselves as "naturally" outgoing or assertive. Not all people are comfortable with assuming the leadership function that seems to be necessary in this situation, but as Chester's mother said, "You have to learn to be forward; if it's not a natural tendency, work at it, because it's in everyone's best interests."

Many of the participants in this study also felt strongly about the importance of parents supporting other families of children with cancer, by sharing their knowledge and experiences with the schools. Finding and receiving support was viewed as critical by all of the parents in this study. Every family had some type of support system in place; this support gave them the strength to carry on during the difficult times. For several of these parents, the parents' support group, Kids With Cancer, was an important connection with other families who also were dealing with childhood cancer. Other support systems that parents mentioned included extended family, church groups, friends in the community, specific teachers and various medical personnel.

Adams and Deveau (1988) suggest to parents that how they deal with their child's school has a major impact on the child's schooling experiences. They suggest that parents, teachers, and principals need to work closely together, and find ways of supporting one another. Parents of children with cancer will continue to be the primary ongoing advocates for their child, both in the hospital and at school. As such, Adams and Deveau (1988) believe that one of the parents' goals must be to establish a long-term relationship of trust with the school. Such a relationship is more likely to develop if parents become knowledgeable about their child's disease, treatment plan, and various side-effects; if they can remain strong and clear in their communication with school personnel; and if they can find ways to continue receiving support themselves.

Implications for Schools

Most programs that have been developed to assist children with "school re-entry" after a diagnosis of cancer have been developed by nurses and pediatricians, who have seen the need for such programs. As Van Eys (1982) has noted, there has been very little proactive direction from the educational community in this area. This finding is perhaps not surprising, given the relative recency of treatment advances in childhood cancer. These medical advances have resulted in a "lag" in terms of the schools' general preparation to meet the needs of these students.

However, the time has now come when schools must begin to pay greater attention to a new student population, that of the cancer survivor. I also believe that it is appropriate that schools assume equal responsibility for initiating contact, and maintaining ongoing communication with both the medical community and the parents.

One of the most important issues for the parents in this study was that schools need to be better informed about childhood cancer and its treatment. Parents felt that it was crucial that all staff in a school become well-informed and current about the disease, not just the child's teacher, and that schoolmates need to be educated about the disease as well. Based on their experiences, these parents also felt that the schools need to identify someone who can assume overall responsibility for the following tasks: developing an appropriate educational plan for the child, initiating peer group awareness and support, making sure that all staff who deal with the child are knowledgeable, and monitoring the child's progress on an ongoing basis.

Communication between the home, school, and treatment center is necessary during the child's entire course of treatment. For children who suffer cognitive, physical, or emotional late effects of disease or treatment, this communication may have to continue for many years thereafter. The school's part of the total treatment program should ideally be managed by a person who can serve as an ongoing advocate for the student, and provide a bridge between the home, hospital, and educational community. Long-term intervention also means attention to siblings, who may be responding to the changing dynamics at home.

Educators also need to be aware that words reflect attitudes, and must be chosen with care in discussing the child with cancer. As Chester's mother said, "Cancer is the scariest word in the world, when you know nothing about it... the scariest word in the world." All the parents in this study wanted people at their children's schools to know about cancer, and they believe that information is the best way to begin changing some of our societal attitudes towards, and misinformation about, cancer.

One of the videotapes that I reviewed as I conducted this study is entitled "School: Obstacle or Opportunity? Coping with Chronic Illness in the Elementary Classroom" (Cincinnati Children's Hospital Medical Center, 1983). The film focuses on the experiences of three children of elementary school age, one with a brain tumor and the two others with leukemia, as they return to school after their cancer diagnosis and treatment. The emphasis in this film is on the important role that the educators play in the child's schooling experiences. Parents' perspectives are referred to indirectly, but the main message of the video is that the school can provide these children with unique opportunities to feel a sense of normalcy, of accomplishment, and to build important relationships with peers. The film states that there is no universal road map to direct educators; instead, each school must formulate its own plan to facilitate the programs for individual students. At the same time, the video does provide four general suggestions that could help the schools be more effective in supporting these children and their families. Each of these suggestions echoes directly comments that have been made by parent-participants in this study.

First, teachers need to be honest about their feelings, and be willing to examine their fears and concerns about cancer, and then to admit their limitations in dealing with this on their own. Secondly, the schools must communicate with the child's family, the hospital, and other community resources, so that information can flow freely among all concerned. Thirdly, schools need to set realistic goals, and *together with the parents*, decide what is most important for the children. Finally, they must share information about childhood cancer with other students; this involves dealing openly with questions, providing clear and simple explanations, and encouraging discussion. The film makes the point that this approach teaches healthy children about dealing with crisis and change, as well as helping the ill students regain a sense of normalcy about their lives. I would add, based on my discussions with the parents in this study, that such an approach would also relieve parents of the feeling that they are alone as advocates for their children, and would provide support to the entire family as they meet the challenges that they face after a diagnosis of childhood cancer.

Another point made in the film and strongly supported by the present study, is that there is a big difference between sympathy and a truly empathic response. Sympathy is related to expressing care and concern, but empathy involves understanding, sensitivity to the needs of others, and positive actions that can make a difference for the child and his or her family.

Implications for the Medical System

Hospital personnel need to transmit medical information to the schools, and ensure that such information is both child-specific and education-related (Deasy-Spinetta, 1993). It is also very important for physicians to evaluate how treatments might affect school attendance, school performance, and socialization of the children. Most of the parents in this study wished that their child's doctor showed more interest in knowing how the child was functioning at school. They felt that it was important for doctors to know about how the illness was affecting the child in other areas of his or her life. Having this information would assist medical personnel in seeing the child as more than "just a patient with cancer," and understanding the child's functioning in a more wholistic manner.

As mentioned previously, most school "re-entry" programs have been developed at the initiative of medical personnel. At present, in north-central Alberta, two nurse-practitioners who are based at the cancer treatment institute have assumed responsibility for establishing initial contact with a child's school after the child is diagnosed with cancer. However, this program has only been in place for the last year or two, and none of the parents in this study reported that this service had been available when their child was either returning to or entering school. Parents also expressed a concern that school "re-entry" programs may not be targeting young children who are first diagnosed with cancer during their preschool years. All of the parents in this study indicated that it would have been helpful for them and their child if there had been a stronger liaison between the medical system and the school. Even in situations when children are diagnosed before they have entered the school system, for most of them the long-term implications of having cancer are significant enough that these should be discussed thoroughly with the school personnel.

Implications for Future Research

The findings of this study enhance our understanding of the parents' perspectives. In order to learn about the implications of other perspectives, there is a need to also hear from the children, the teachers' (or school) perspectives, and the medical personnel.

Adolescents who are cancer survivors are faced with developmental issues that pertain to their specific stage of development. A further study of parents' perspectives of adolescents' schooling experiences would be useful, in order to establish whether there are issues specific to this particular age group that have not emerged from this present study.

A study of teachers' views on working with children who have been diagnosed with cancer could provide us with further information on the needs experienced by educators as they deal with this emerging student population.

Finally, a longitudinal study of children diagnosed with cancer would allow a researcher to study parent, teacher and child perspectives over an extended period of time, and could lead to more specific identification of both helpful and less helpful strategies employed by each of these individuals.

REFERENCES

Adams, D. W. (1992). Parents of children with cancer speak out: Problems, needs and sources of help. Toronto: Candlelighters Childhood Cancer Foundation Canada.

Adams, D. W., & Deveau, E. J. (1988). Coping with childhood cancer: Where do we go from here? Hamilton, Ontario: Kinbridge Publications.

Allen, K. R., & Walker, A. J. (1992). A feminist analysis of interviews with elderly mothers and their daughters. In Gilgun, J. F., Daly, K. & Handel, G. (Eds.) Qualitative methods in family research. (p. 198-214). Newbury Park, Calif.: Sage.

American Federation of Teachers. (1992). The medically fragile child in the school setting: A resource guide for the educational team.

Bearison, D. J., & Mulhern, R. K. (Eds.) (1994). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Becker, C. S. (1986). Interviewing in human science research. Methods, 1, 101-124.

Bibby, M. A. W. (1993). Teachers' perspectives of giftedness among students who are deaf or hard of hearing. Unpublished Doctoral Dissertation, University of British Columbia, Vancouver, B.C.

Birenbaum, L. K. (1990). Family coping with childhood cancer. The Hospice Journal, 6(3), 17-32.

Bogdan, R. C. & Biklen, S. K. (1992). Qualitative research for education. Boston: Allyn & Bacon.

Boss, P. (1988). Family stress management. Newbury Park, Calif.: Sage Publications.

Bracken, J. M. (1986). Children with cancer: A comprehensive reference guide for parents. New York: Oxford University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. Developmental Psychology, 22(6), 723-742.

Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, Mass.: Harvard University Press.

Cairns, N. U., Klopovich, P., Hearne, E., & Lansky, S. B. (1982). School attendance of children with cancer. The Journal of School Health, 52(3), 152-155.

Canadian cancer statistics 1994. Published by the National Cancer Institute of Canada, Toronto.

Carpenter, P. J., & Sahler, O. J. Z. (1991). Sibling perception and adaptation to childhood cancer: Conceptual and methodological considerations. In Johnson, J. H. & Johnson, S. B. (Eds.). Advances in child health psychology. Gainesville: University of Florida Press.

Carpenter, P. J., & Levant, C. S. (1994). Sibling adaptation to the family crisis of childhood cancer. In Bearison, D. J. & Mulhern, R. K. (Eds.). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Carter, E. A., & McGoldrick, M. (Eds.). (1980). The family life cycle: A framework for family therapy. New York: Gardner Press.

Chang, P., Nesbit, M., Youngren, N., & Robison, L. (1987). Personality characteristics and psychosocial adjustment of long-term survivors of childhood cancer. Journal of Psychosocial Oncology, 43-58.

Charlton, A., Pearson, D., & Morris-Jones, P.H. (1986). Children's return to school after treatment for solid tumors. Social Science and Medicine, 22(12), 1337-1346.

Chekryn, J., Deegan, M., & Reid, J. (1987). Impact on teachers when a child with cancer returns to school. Children's Health Care, 15(3), 161-165.

Cohen, M. H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. Qualitative Health Research, 5(1), 63-77.

Daly, K. (1992) The fit between qualitative research and characteristics of families. In Gilgun, J. F., Daly, K. & Handel, G. (Eds.). Qualitative methods in family research. Newbury Park, Calif.: Sage.

Danielsen, S. M. (1995). Exploring hope with children living with cancer. Unpublished Doctoral Dissertation. Edmonton, Alberta: University of Alberta.

Deasy-Spinetta, P. & Irvin, E. (Eds.) (1993). Educating the child with cancer. Washington, D. C.: The Candlelighters Childhood Cancer Foundation.

Deasy-Spinetta, P. (1981). The school and the child with cancer. In Spinetta, J. J. & Deasy-Spinetta, P. (Eds.). Living with childhood cancer. Toronto: C. V. Mosby.

Deasy-Spinetta, P. (1993). Educational issues for the child with cancer. In Deasy-Spinetta, P. & Irvin, E. (Eds.). Educating the child with cancer. The Candlelighters Childhood Cancer Foundation, Washington, D. C.

Deasy-Spinetta, P. M. & Spinetta, J. J. (1980). The child with cancer in school: Teachers' appraisal. American Journal of Pediatric Hematology/Oncology, 2, 89-94.

Doherty, W. J. & McCubbin, H. I. (1985). Families and health care: An emerging arena of theory, research, and clinical intervention. Family Relations, 34, 5-11.

Drotar, D., Crawford, P. & Bush, M. (1984). The family context of childhood chronic illness: Implications for psychosocial intervention. In Eisenberg, M. G., Sutkin, L. Chronic illness and disability through the life span: Effects on self and family. New York: Springer.

Epstein, J. L. (1992). School and family partnerships: Leadership roles for school psychologists. In Christenson, S. L. & Conoley, J. C. (Eds.). Home-school collaboration: Enhancing children's academic and social competence. Maryland: National Association of School Psychologists.

Feldman, F. L. (1980). Work and cancer health histories: Work expectations and experiences of youth with cancer histories (ages 13-23). Oakland: American Cancer Society, California Division.

Figley, C. (1989). Helping traumatized families. San Francisco: Jossey-Bass.

Frank, A. W. (1991). At the will of the body: Reflections on illness. Boston: Houghton Mifflin.

Gibbons, M. B. (1988). Coping with childhood cancer: A family perspective. In Power, P. W., Dell Orto, A. E., & Gibbons, M. B. (Eds.) Family interventions throughout chronic illness and disability. New York: Springer.

Gilgun, J. F. (1992). Definitions, methodologies, and methods in qualitative family research. In Gilgun, J. F., Daly, K. & Handel, G. (Eds.). Qualitative methods in family research. Newbury Park, Calif.: Sage.

Giorgi, A. (1970). Psychology as a human science. New York: Harper & Rowe.

Glaser, B. G. (1992). Emergence vs forcing: Basics of grounded theory analysis. Mill Valley, CA: The Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. Chicago: Aldine.

Granowetter, L. (1994). Pediatric oncology: A medical overview. In Bearison, D. J. & Mulhern, R. K. (Eds.). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Greenberg, H. S., & Meadows, A. T. (1991). Psychosocial impact of cancer survival on school-age children and their parents. Journal of Psychosocial Oncology, 9(4), 43-56.

Greenberg, H., Kazak, A., & Meadows, A. (1989). Psychological adjustment in 8-16 year old cancer survivors and their parents. Journal of Pediatrics, 114, 488-493.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. Educational Communication and Technology Journal, 29, 79-92.

Guba, E. G., & Lincoln, Y. S. (1981). Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches. San Francisco: Jossey-Bass.

Henderson, A. (1989). The evidence continues to grow: Parent involvement improves school achievement. Columbia, MD: National Committee for Citizens in Education.

Hughes, P. M., & Lieberman, S. (1990). Troubled parents: Vulnerability and stress in childhood cancer. British Journal of Medical Psychology. 63, 53-64.

Kaplan, D. M., Smith, A., & Grobstein, R. (1974). School management of the seriously ill child. Journal of School Health, 44(5), 250-254.

Katz, E. R., Kellerman, J., Rigler, D., Williams, D., & Siegel, S. E. (1977). School intervention with pediatric cancer patients. Journal of Pediatric Psychology, 2, 72-76.

Katz, E. R., Rubinstein, C. L., Hubert, N. C., & Blew, A. (1988). School and social reintegration of children with cancer. Journal of Psychosocial Oncology, 6(3/4), 123-140.

Katz, E. R., Varni, J. W., Rubenstein, C. L., Blew, A., & Hubert, N. (1992). Teacher, parent, and child evaluative ratings of a school reintegration intervention for children with newly diagnosed cancer. Children's Heath Care, 21(2), 69-75.

Kazak, A. E. (1994). Implications of survival: Pediatric oncology patients and their families. In Bearison, D. J. & Mulhern, R. K. (Eds.). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Kazak, A. E., & Meadows, A. T. (1989). Families of young adolescents who have survived cancer: Social-emotional adjustment, adaptability, and social support. Journal of Pediatric Psychology, 14, 175-192.

Kirten, C., & Liverman, M. (1977). Special educational needs of the child with cancer. Journal of School Health (March), 170-173.

Koocher, G. P., & O'Malley, J. E. (1981). Damocles syndrome: Psychosocial consequences of surviving childhood cancer. New York: McGraw-Hill.

Kupst, M. J. (1994). Coping with pediatric cancer: Theoretical and research perspectives. In Bearison, D. J. & Mulhern, R. K. (Eds.). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Kupst, M J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six year follow-up study. Journal of Pediatric Psychology, 13, 7-22.

Lansky, S. B., Cairns, N. U., & Zwartjes, W. (1983). School attendance among children with cancer: A report from two centers. Journal of Psychosocial Oncology, 1(2), 75-82.

Lansky, S. B., List, M. A., & Ritter-Sterr, C. (1986). Psychosocial consequences of cure. Cancer, 58(2), 529-533.

Lavee, Y., McCubbin, H. I., & Olson, D. H. (1987). The effect of stressful life events and transitions on family functioning and well-being. Journal of Marriage and the Family, 49, 857-873.

Lazarus, R. S. (1991). Emotion and adaptation. New York: Oxford University Press.

Libow, J. A. (1989). Chronic illness and family coping. In Combrinck-Graham, L. (Ed.) Children in family contexts: Perspectives on treatment. New York: The Guilford Press.

Lightfoot, S. L. (1978). Worlds apart: Relationships between families and schools. New York: Basic Books, Inc.

Maguire, G. P. (1983). The psychological sequelae of childhood leukaemia. In Duncan, W. (Ed.). Pediatric oncology: Recent results in cancer research, 88, 47-56.

Marton, F. (1981a). Phenomenography: Describing conceptions of the world around us. Instructional Science, 10, 177-200.

Marton, F. (1981b). Studying conceptions of reality: A metatheoretical note. Scandinavian Journal of Education Research, 25(4), 159-169.

Marton, F. (1988). Phenomenography: Exploring different conceptions of reality. In D. M. Fetterman (Ed.). Qualitative approaches to evaluation in education: The silent scientific revolution (pp. 176-205). New York: Praeger.

McCormick, D. (1986). School re-entry program for oncology patients. Journal of Pediatric Oncology Nurses, 3(3), 13-17.

McCubbin, H., McCubbin, M., Nevin, R., & Cauble, A. (1981). CHIP - Coping health inventory for parents. In McCubbin, H. I. & Patterson, J. M. (Eds.). Systematic assessment of family stress, resources, and coping. St. Paul: University of Minnesota.

Meadows, A. T., & Hobbie, W. L. (1986). The medical consequences of cure. Cancer, 58(2), 524-528.

Miller, W. L., & Crabtree, B. F. (1994). Clinical research. In Denzin, N. K. & Lincoln, Y. S. (Eds.). Handbook of qualitative research. London: Sage.

Minuchin, S. (1974). Families and family therapy. Cambridge, MA: Harvard University Press.

Morse, J. M. (1994). Designing funded qualitative research. In Denzin, N. K. & Lincoln, Y. S. (Eds.). Handbook of qualitative research. Thousand Oaks: Sage.

Moustakas, C. (1990). Heuristic research: Design, methodology, and applications. Newbury Park, CA: Sage.

Mulhern, R. K. (1994). Neuropsychological late effects. In Bearison, D. J. & Mulhern, R. K. (Eds.). Pediatric psychooncology: Psychological perspectives on children with cancer. New York: Oxford University Press.

Nielsen, J. M. (1990). Introduction. In J. M. Nielsen (Ed.). Feminist research methods. Boulder, CO: Westview.

Niles, D. (1992). Children with cancer: Educational needs from a parental perspective. Unpublished Master's Thesis, University of Alberta, Edmonton, Alberta.

Northouse, L. (1984). The impact of cancer on the family: An overview. International Journal of Psychiatry in Medicine, 14, 215-242.

Osborne, J. W. (1990). Some basic existential-phenomenological research methodology for counsellors. Canadian Journal of Counselling, 24, 79-91.

Overholser, J. C., & Fritz, G. K. (1991). The impact of childhood cancer on the family. Journal of Psychosocial Oncology, 8(4), 71-85.

Patton, M. Q. (1990). Qualitative evaluation and research methods (Second edition). Newbury Park, CA: Sage.

Peckham, V. C. (1993). Cognitive late effects: Introduction to the research. In Deasy-Spinetta, P. & Irvin, E. (Eds.). Educating the child with cancer. The Candlelighters Childhood Cancer Foundation, Washington, D. C.

Peckham, V. C. (1989). Learning disabilities in long-term survivors of childhood cancer: Concerns for parents and teachers. Journal of Reading, Writing, and Learning Disabilities International, 5(4) 313-325.

Peckham, V., Meadows, A., Bartel, N., & Marrero, O. (1988). Educational late effects in long-term survivors of acute lymphocytic leukemia. Pediatrics, 81, 127-133.

Rolland, J. S. (1987). Chronic illness and the family: An overview. In Wright, L. M. & Leahey, M. (Eds.) Families and chronic illness. Springhouse, Pennsylvania: Springhouse Corporation.

Rosenblatt, P. C., & Fischer, L. R. (1993). Qualitative family research. In Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R. & Steinmetz, S. K. (Eds.). Sourcebook of family theories and methods: A conceptual approach. New York: Plenum Press.

Ross, J. W. (1984). The child with cancer in school. In Fithian, J. (Ed.). Understanding the child with a chronic illness in the classroom. Phoenix: Oryx Press.

Rotheram, M. J. (1989). The family and the school in childhood illness. In Combrinck-Graham, L. (Ed.). Children in family contexts: Perspectives on treatment. New York: The Guilford Press.

Rubenstein, C. L., Varni, J. W., & Katz, E. R. (1990). Cognitive functioning in longterm survivors of childhood leukemia: A prospective analysis. Developmental and Behavioral Pediatrics, 11, 301-305.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.

Sanger, M. S., Copeland, D. R., & Davidson, E. R. (1991) Psychosocial adjustment among pediatric cancer patients: A multidimensional assessment. Journal of Pediatric Psychology, 16(4), 463-474.

Sawyer, M. G., Toogood, I., Rice, M., Haskell, C., & Baghurst, P. (1989). School performance and psychological adjustment of children treated for leukemia. American Journal of Pediatric Hematology/Oncology, 11, 146-152.

Speechley, K. N., & Noh, S. (1992). Surviving childhood cancer, social support, and parents' psychological adjustment. Journal of Pediatric Psychology, 17(1), 15-31.

Spinetta, J. J., & Deasy-Spinetta, P. (Eds.) (1981). Living with childhood cancer. Toronto: C. V. Mosby.

Strauss, A. L., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage.

Van Dongen-Melman, J. E., Pruyn, J. F., Van Zanen, G. E., & Sanders-Woudstra, J.A. (1986). Coping with childhood cancer: A conceptual view. Journal of Psychosocial Oncology, 4(1/2), 147-161.

Van Eys, J. (Ed.) (1982). Children with cancer: Mainstreaming and reintegration. New York: Spectrum.

Van Eys, J. (1991). The truly cured child? Pediatrician, 18, 90-95.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. London, Ontario: Althouse.

Van Veldhuizen, A. M. & Last, B. F. (1991). Children with cancer: Communications and emotions. Amsterdam: Swets & Zeitlinger, Inc.

Williams, K., Ochs, J., Williams, M., & Mulhern, R. (1991). Parental report of everyday cognitive abilities among children treated for acute lymphoblastic leukemia. Journal of Pediatric Psychology, 16, 13-26.

Wright, L. M., & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention. Philadelphia: F. A. Davis Company.

APPENDIX A

INTERVIEW GUIDE

The general question guiding this study is simply, "What is your perspective on your child's schooling experience since he/she has been diagnosed with cancer?"

My initial opening statement was, **"Tell me about your child's schooling experiences since he/she has been diagnosed with cancer."**

I also prompted parents to talk about what happened (1) at the time surrounding the child's cancer diagnosis, (2) at the time of school entry or re-entry, and (3) what is presently happening.

Related general questions might include the following:

1. How is your child's schooling going since he/she was diagnosed with cancer?
2. What do you think would help the schools to do a better job with kids like yours?
3. What are some things that you think schools should know or do?
4. Describe your relationship with the school...
5. What are some of the helpful things that the school did?
6. What were the problems?
7. How could these problems or obstacles be overcome?
8. What have been your strategies for coping with your child's schooling?
9. How do you think your reactions (and actions) might have affected your child's schooling experiences?
10. When you have approached the school regarding various aspects of your child's schooling, what reaction did you receive? (Did you feel that you were understood?)
11. Can you tell me about the "connections" between the medical world and the school? (How? Who? When? What impact did it have?)

12. How important is this issue (i.e., schooling) to you now? What relevance does schooling have for children who have cancer?

****Remember to keep asking about emotions as well as thoughts!!**

A very useful prompt to get further elaboration on a point is **"Can you tell me more about that - why you thought that/said that/felt that?"**

APPENDIX B

DEMOGRAPHIC DATA

Pseudonyms ____

Gender, Age, and Grade of Child ______________________________

Child's Diagnosis (and age at diagnosis) _________________________

Date of Diagnosis __________________________________

Treatment History and Dates

____

____

____

Prognosis (if known)

____

____

Family Description (parents, siblings, parents' occupations, school achievement of parents, etc.)

____

____

APPENDIX C - DESCRIPTION OF THE RESEARCH PROJECT

Parents' Perspectives of their Child's School Experiences after the Child's Diagnosis with Cancer

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Introduction

Over the last fifteen to twenty years, childhood cancer has gradually evolved from an inevitably fatal illness to a life-threatening chronic disease. At the same time as more children are surviving a diagnosis of cancer, there has been a recent educational trend towards integration of students with special needs into regular schools and classrooms, and towards at-home care rather than long-term hospitalizations. The population of "survivors of childhood cancer" has not usually been included in any "special education" category, and has not received as much research attention as other student populations. However, a current estimate is that one out of 1,000 children is now a survivor of childhood cancer.

The implications of childhood cancer for the child and his or her family are many, and affect every area of their lives, physically, socially, emotionally, and academically. It is generally considered important for the child with cancer to be made to feel as "normal" as possible. The quality of a child's school life is vital to the child's mental and emotional health, which in turn significantly affects the child's physical health.

Furthermore, a diagnosis of childhood cancer is not individual; in a very real sense, the whole family "gets it." Quality of life for children and their families is to some extent dependent upon the characteristics and sensitivity of the schools that the children attend. The function of the school in the child's response to the disease has been described as the setting for the most frequent encounters with the community, school in our society being the "work of children."

According to many experts in the field, a child's ability to cope with a serious illness is largely dependent on the behavior of the adults in his/her immediate environment, with the child's parents being the most significant. Like all human behavior, the behavior of parents is largely shaped by their perspectives of a given situation. Thus, studying parents' perspectives with respect to their child's schooling experiences is important, since these perspectives inevitably affect the parents' and the child's behavior.

The research project described below is based on the following assumptions:

(1) that parents of children with cancer will have "thoughts and perspectives" regarding their child's schooling experiences, and that they are likely to have encountered some challenges and difficulties in this area,
(2) that parent perspectives are an important factor in the child's overall school experiences and achievement, and
(3) that "schooling" can be defined broadly as all of the formal educational experiences that the child receives.

Purpose and Description of the Study

The purpose of this study is to describe parents' perspectives of their child's schooling experiences after the child has been diagnosed with cancer. Since there has been limited research in this area until now, a "discovery-oriented" approach will be used. Approximately ten parents will be selected to be interviewed by the researcher, and an open-ended questionnaire will be used as the basis of the interviews. Follow-up interviews will be done with the participants to verify that the researcher's interpretation of the interview is consistent with the parent's understanding of what they wanted to say, and also to identify any additional thoughts that may have occurred between the interviews.

Participants in the study will be selected to reflect the perspectives of both mothers and fathers, and will consist of parents whose children are not considered terminally ill. The study will also focus on elementary-aged children (ages 5 to 11), and will include parents who live in both urban and rural areas. Furthermore, the researcher will ensure that the participants include parents of children with different types of cancer, as well as children who have survived the diagnosis for up to five years.

The grounded theory approach will be used to analyze the transcripts of the semi-structured interviews. Depending on the results of the analysis, it may be possible to generate theory concerning parent's perspectives of their children's schooling experiences.

Practical Importance of the Study

In addition to the advancement of theoretical knowledge, one of the objectives of this research is to assist schools in meeting the needs of children who have been diagnosed with cancer. The study will also have practical implications for psychologists and counsellors who work with the families of children with cancer.

APPENDIX D - Consent Form for Participants

Parents' Perspectives of their Child's Schooling Experiences after the Child's Diagnosis with Cancer

Researcher: Marianne Gareau, Ph.D. Student in Counselling Psychology
University of Alberta, Edmonton, Alberta
Phone: 469-9975 (home)
Supervisor: Dr. Don Sawatzky

I understand that I am volunteering to participate in a study in which I will be asked to describe my thoughts and opinions regarding my child's schooling experiences since he/she has been diagnosed with cancer. I am willing to share my thoughts and opinions with the researcher, but I understand that I can withdraw from the study at any time without prejudice, and that I do not have to answer any questions that I do not want to answer.

I understand that the interview will take approximately one hour and will be audiotaped; the researcher will later transcribe and analyze the interview. I also understand that I will be asked to review the transcription and analysis of my interview at a later date, and that I will have at least one other meeting with the researcher to expand or clarify my thoughts with her. Information obtained from the interview will be used for Marianne Gareau's doctoral dissertation and possible future publications.

The study has been explained to me, and I have had the chance to ask questions about the study. I understand that my name and identity (as well as that of my child) will be kept confidential in any reports written about the study, by changing names and other identifying factors. The audiotapes will be kept secure, and will be destroyed when the study is completed.

I am satisfied that I have been given sufficient information about the study, and I am willing to participate in the study by sharing my thoughts and experiences with Marianne.

____________________	____________________
Date	Participant
____________________	____________________
Date	Researcher

APPENDIX E

Study Time Line

Project Title: Parents' perspectives of their child's schooling experiences after the child's diagnosis with cancer

Investigator: Marianne Gareau, M.Ed., Provisional C. Psych., Ph.D. Candidate

I. Proposal Development

Sept. 1994 - March 1995	Course work in counselling research, family research methodology, and readings in qualitative research. Reading in the area of childhood cancer, pediatric psycho-oncology, working with families, and relationships between families and schools. Development of research question and proposal.
March 1995	Met with Pediatrics team at the U. of A. Hospital to present the objectives of the study, and receive feedback on proposal.
April 1995	Candidacy exam completed.
April 1995	Educational Psychology Research and Ethics Committee approval.

II. Selecting Participants

Oct. 1994 - Dec. 1994	Contact with representatives of the parents' group, Kids With Cancer, to discuss the proposed study.
Jan. 1995	Notice placed in Kids With Cancer newsletter, asking for parent volunteers for study.
April 1995	Direct contact made with all participants to establish meeting times, expectations for the study, and consent forms.

III. Data Collection

April - June 1995

Interviews with parent participants

Parent A	#1. April 25, 1995 #2. June 6, 1995
Parents B & C	#1. April 26, 1995 #2. June 6, 1995
Parents D & E	#1. May 3, 1995 #2. June 12, 1995
Parent F	#1. May 11, 1995 #2. June 7, 1995
Parent G	#1. May 15, 1995 #2. June 6, 1995
Parents H & I	#1. May 15, 1995 #2. June 23, 1995
Parents J & K	#1. May 18, 1995 #2. June 8, 1995

Researcher observations, notes, and memos continued throughout this phase.

Personal transcriptions of audio-tapes into text within 24 hours of each interview.

Identification of preliminary themes from first interviews and discussion with participants.

IV. Data Analysis

May - July 1995

Comparison of audio-tapes to transcripts.

Reading and re-reading of texts, listening to transcripts (alone and with a colleague); immersion into the data.

Analysis and interpretation of all the interviews.
Themes identified from each interview.

Comparison of themes among all participants (cross-case analysis).

Discussion and verification of individual and shared perspectives with participants (second interviews), and refinement of themes.

	Second review of literature, and comparison with findings of the study. Discussion of findings with professionals in the fields of qualitative research, education, family counselling, and pediatric psycho-oncology.

V. Presenting the Results

July - Oct. 1995	Verifying themes and reflections with original data. Searching for discrepancies. Writing (and re-writing) of final dissertation.