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Children Living in the Shadow of Parental Cancer

by

Michelle B. Goodman

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

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"Living in the Shadow of Mom's Death"

A Drawing by Eleven-year old Steven

Shadow: "A figure projected in silhouette on the ground or other surface by means of interception of light; a space from which light has been intercepted; semidarkness; semiobscurity, shelter, protection, or security afforded by someone; the merest hint, trace, or implication, as, a shadow of doubt; a dark part of a picture; any actuality that seems unreal; a spirit or ghost; an imperfect and faint representation; an inseparable companion or follower, a remnant, as, a shadow of a former self; a period of unpleasantness; a dire promise or threat; an evil that impends." (New Webster's Dictionary, 1984, p. 884)

THE 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 Children Living in the Shadow of Parental Cancer submitted by Michelle B. Goodman in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

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To the parents who allowed me to step into their shadows; and to their children who shared the light beyond.

Abstract

This study explores the phenomenon of "living with parental cancer," with a group of twenty-three children of fifteen cancer patients who were in varying stages of the disease process. Ten girls and thirteen boys, ranging in age from three to fourteen years, completed semi-structured tasks involving puppet play, drawings, and stories about cancer. The researcher designed a drawing task, "the temporal continuum drawing technique," as a means of encouraging the children to focus attention on various times during their parent's illness. The tasks provided the foundation and direction for interviews held in the participants' homes.

A phenomenological analysis of the data (transcribed interviews, drawings, and stories), based on a compilation of suggestions from various phenomenological researchers, revealed eighteen themes which characterize the experience of "living with parental cancer." Despite the rich differences across participants (different ages, personalities, family backgrounds, stages of parent's disease, duration since diagnosis, death, or relapse, etc.), they experienced many themes in common. The themes include: an increased sensitivity to parents, death, and loss; misunderstandings and confusions about disease etiology and treatment; adapting to changes in peer, school, and family living; feeling sadness, anger, fear, and anxiety but suppressing it in the presence of others; coping in self reliant ways but wanting to talk to experienced age peers. The unique ways in which different children expressed the same themes are highlighted by including quotations from the interviews, reproductions of their drawings, and three case studies.

"Shadow" is one of the many metaphors and symbols chosen by the children to describe the state of semiobscurity, semidarkness, and general uncertainty as to whether or not their parent would die and when. There was a space in their lives from which light was intercepted. Nevertheless, the children were able to see beyond the shadow and appreciate some of the lighter and brighter sides of life.

The discussion emphasizes a move away from a developmental-structuralist approach in conceptualizing children's overall experience of cancer and death towards an existential-phenomenological approach. The researcher emphasizes that children's concerns are often the same as adult concerns and are real human issues. Further research is recommended which focuses on a variety of issues, including the interrelatedness

between parents, child, and sibling when a parent has cancer. Practical work with individual children should consider the value of attending to symbols and images in their words and drawings as a means of better understanding the experience of living with parental cancer.

PROLOGUE

> I was terribly bewildered and confused and angry at thirteen, because I did not know how to act or behave with my mother. Did not know if she knew she was dying, was cut off from her physically, and had no one with whom I could talk to about it. The immensity of my mother's dying and her pain were things I needed to deal with then, but could not do so alone. Because we children were protected from the knowledge of what was happening until all hope was gone and because our father was very busy dealing with his own pain, all my attendant feelings had to be dealt with many years later. (Arlene Dollard, personal communication, 1983)

Arlene, now 37, related the above words to me twenty-four years after the death of her mother from lung cancer. She is still undergoing psychiatric treatment for depression which she attributes to the days in which she helplessly, without assistance, watched her mother deteriorate and then die. Her adverse childhood experiences have continued to affect her. Their influence is felt in how she is mother to her children and how she was wife to the man from whom she is now separated.

My discussion with Arlene peaked my curiosity, my interest, and became the basis for the following research endeavor. My background in child psychotherapy along with my research experience in the area of childhood bereavement led me to question the nature of the child's experience while a parent <u>may</u> be dying. My practical training in a cancer hospital helped me to rephrase this inquiry and my question became "What is it like to be a child while a parent has a life-threatening, and possibly terminal, disease?" More specifically, "What is it like to be a child of a cancer patient," to be "Living in the Shadow of Parental Cancer?"

"Shadow" is a metaphor for "living with parental cancer" generated by eleven-year old Steven whose mother had recently died from lung cancer (see Frontispiece). Shadows infiltrate his drawing, a drawing in which he portrays himself as being wrought with fear. He is haunted by the "shadow of mom's death." The shadow of cancer appears in the bottom left hand corner. His one drawing says more than any story could, as does his chosen metaphor. His metaphor reflects the period of his life from the time of his mother's diagnosis until now, two months after her death. He felt threatened as evil loomed around him. He developed fears of being alone and of the dark. He lived, like other children in my study, in a state of semidarkness, and semiobscurity, not knowing if his mom was going to "live or die or what?"

The capriciousness of the disease process with its series of relapses and remissions, the general aura of silence which word of cancer generates within the home and without, and the mutual desire among parent and child to protect each other from disturbing possibilities, emerge as reasons why the child's question remains unanswered. The child of a cancer patient lives in a state of fear, uncertainty, in a "shadow of doubt." Whether a parent is dying or not, the child who learns of a parent's cancer diagnosis, lives with a fear most children may never know--the fear that mom/dad <u>may</u> be dying. This is so, even once a parent is "cured." They know only part of the picture and the rest, through their vivid imagination, becomes worse than the reality. There is a space in their lives from which light has been intercepted. The children can no longer do many activities with their parents <u>together</u> as a family.

The children in this study whose parents have died live with the shadow of their parent, with an inseparable companion or follower who watches over them. For many, the experience seems unreal. Beyond the shadow, however, there is light. Although thoughts and concerns about their parents always loom in the backs of these children's minds, they are able to appreciate, sometimes more acutely than before, the lighter and brighter sides of life.

These children use many metaphors and symbols for cancer and their experience of it. In the following study, we will see that cancer becomes a symbol for what is dangerous and unknown to these children. The children communicate their experience through their words, their drawings, and through their behaviour.

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I. INTRODUCTION

A. Need for the Study

Cancer has become widespread in recent years with almost 90,000 new cases being diagnosed each year in Canada (Fine, 1984). For people between twenty-four and fifty-five years one person in seventeen will develop cancer before they reach fifty-five years (Fine, 1984). These people have young children. Cancer is a scourge which takes a heavy toll on patients, families, and the entire community. It remains a continuing challenge. Already, some progress is being made, many patients are being cured, and many have had troublesome symptoms relieved. An early diagnosis brings a better prognosis. Knowledge of causes indicates that some cancers can be prevented. Once an acutely fatal condition, cancer remains serious but may or may not be fatal.

In the last decade, there has been a research explosion focused on the role of psychology in cancer etiology, the disease process, and treatment. It has been recognized that the health of a patient's spirit is equally as important as the health of the individual's body. Because the spouse is seen as pivotal in the adjustment of the cancer patient, recent research has investigated the partner's experience. Whereas, attention in the social science literature has focused on the difficulties children face following the death of a parent (e.g., Furman, 1974; Tessman, 1978), clinicians and researchers are now beginning to recognize the importance of looking at the experiences of children who live with a parent whose illness remits, recurs, and may or may not recur again.

Children of cancer patients are potentially at high psychological risk for at least three reasons. First, the emotional stress of bereavement--grief--has been well documented and one can only speculate on the amount of stress which accompanies the uncertainty of an anticipated death. Prolonged grief has been associated with academic failure, somatic complaints, fear of being alone, death fantasies, and unwillingness to initiate or maintain friendships (Bendiksen & Fulton, 1976; Bernstein, 1977; Greenberg, 1975). Childhood bereavement has been associated with higher rates of depression in adulthood (Beck, Sethi, & Tuthill, 1963; Bendiksen & Fulton, 1976; Birtchnell, 1973; Brown, 1961; Templer, 1976). While there has been no literature on the effects of impending death on young children, the effects may, in fact, be even more stressful than bereavement.

Secondly, cancer, unlike other catastrophic illnesses, carries with it an unrelenting legend which sometimes impacts the family more than the substance of the disease itself (Murphy, 1983). Instilled in our society is the myth that cancer means death. Cancer has assumed this ominous position because, while many medical improvements have been made, there has not been a commensurate improvement in cancer treatment or prevention (Dunlop, 1985). Cance [illegible] umed the position in the public mind that tuberculosis once had, that cholera had b [illegible] at, or that the black death had centuries ago. Cancer has become the modern day leprosy; cancer patients and their families, more often than not, are treated like lepers. Children in families where a parent has cancer, run the risk of being isolated and abandoned because of societal myths and fears about this disease.

Thirdly, children of cancer patients are often a neglected group since the healthy mate must devote so much time and energy to the severely-ill spouse (Kubler-Ross, 1981). Children of sick parents are forced to assume more responsibility for themselves and they often become a pseudo-parent to younger siblings and confidante to the well but distressed parent (Wellisch, 1979).

Paralleling the lack of attention that children of cancer patients receive from their parents during the illness experience, is the relative neglect given the topic by researchers. Studies which deal with families and severe illness tend to focus on the family as a system and on interactional patterns, family routines, and role changes, but not on the experience of individual members (Anthony, 1976; Burnham-Jones, 1979; Clarke, 1980; Kaplovitch, 1982; Koos, 1946; Parsons & Fox, 1952; Welch, 1981). Some studies claim to be looking at the psychological impact of cancer on families but focus only on the spousal dyad (Cooper, 1984; Naysmith, Hinton, Meredith, Marks, & Berry, 1983; Parkes, 1975). Most pertinent to this study, research has focused on the needs and concerns of patients and their spouses, but not on those of their children (Kogan, 1979; Shlain, 1979; Vettes, 1977; Wenderlein, 1978).

There are many studies which research families of pediatric cancer patients and several researchers have focused on the perceptions of children while they themselves have cancer, or on the perceptions of healthy siblings following their brother's or sister's illness (Iles, 1979; Carandang, Folkins, Hines, & Steward, 1979; Lavigne & Ryan, 1979;

Cairns, Clark, Smith, & Lansky, 1979; Sourkes, 1980). Having a parent with a life-threatening illness may have some of the same implications for a child that having an ill sibling does. The literature, however, does not attempt to make such comparisons.

An exhaustive search of the medical and social science literature revealed only six articles which investigate the experiences of children of cancer patients (Adams-Greenly & Moynihan, 1983; Cancer Care Inc., 1977; Grandstaff, 1976; Rosenfeld et al., 1983; Rosenheim & Ichilov, 1979; Wellisch, 1979). None of these studies examines the child's view of his/her world. There is not one study to date which attempts an in-depth exploration of the child's world while a parent has cancer. Nor are there materials available to children who want to prepare themselves emotionally for what they and their families might experience during the disease process. Cancer reverberates within the entire family system, not only within the ill individual. Understanding children's needs and concerns throughout their parent's disease is prerequisite to developing therapeutic and pedagogic materials specifically for such children's use.

A child's view of cancer and his or her experiences of living with a cancer patient, to a large extent, will be a reflection of sociocultural attitudes towards cancer. What are some of the current events, social trends, and sociocultural attitudes which may, in fact, influence a child's experience of cancer in a parent?

Contemporary Issues

Long before hearing word of a parent's cancer diagnosis, the child has already had much experience with cancer. Cancer receives daily national and international attention from the media. Children are inevitably affected by what they read and hear.

Terry Fox and his successor, Steve Fonyo, have brought national attention to cancer and have become national heroes. But even heroes die. Terry, in spite of his struggle, despite his attainment of star (and subsequent immortal) status, died. Hearing of his death reinforced for many of us, children and adults alike, how horrific and indiscriminate cancer can be. We are reminded of this annually as the Terry Fox campaign continues with marathons in his honour.

The Canadian Cancer Society's campaign reinforces for us the potential perils of cancer. "Cancer can be beaten" but can't be beaten yet! This slogan, an attempt to promote an attitude of hope for the cure of cancer, has paradoxically become another reminder of how many cancers still "can't be beaten."

Almost daily we are made aware of the latest carcinogens. We are cautioned against eating certain foods and living in certain industrial areas or in homes with certain kinds of insulation. The role of psychological stress is a popular topic for consideration in terms of cancer initiation, promotion, and progression. Thus, we are reminded to watch what we eat, what we do and how or where we do it, for fear of getting cancer.

Two contemporary changes in hospital policy--the hospice movement and allowing young children to visit parents in cancer hospitals--are inevitably influencing the cancer experience for children. The hospice movement has enabled people to die at home. With thirty percent of all patients choosing (and able) to die at home (Bentley, 1984), and with children spending time in cancer hospitals, children are more and more able to participate in their parent's last days of living and can help to provide a natural environment for their parent's death.

All of these contemporary issues--the Terry Fox-Steve Fonyo and Canadian Cancer Society campaigns, frequent warnings about cancer-causing agents, the hospice movement--are constant reminders that cancer exists and that it can be fatal. By the time a child hears of a parent's cancer diagnosis, s/he[1] has already had much experience with cancer and with the cancer legend.

The Cancer Legend

> Modern attitudes to cancer have developed as a garden which has been either cultivated or neglected by man through the ages. For many years the garden has been unattended and false ideas and concepts have grown like weeds [illegible] choked the facts and realities. What remains is a confused state composed [illegible] fear, disbelief and fantasy--the present-day attitudes to cancer--and these [illegible] now completely wrong. This attitude must be changed, weeds are to be [illegible]moved and correct attitudes cultivated. (Deeley, 1979, p. 2)

Cancer, unlike other illnesses, carries with it an unrelenting legend which [illegible] impacts the patient and family more than the substance of the disease itself (Murphy, 1983). Collectively, the notions that cancer is incurable, that its victims suffer unbearable pain, that a cancer diagnosis is a stark sentence of death, constitute what Murphy (1983) refers to as the "cancer legend." Despite the fact that 42% of all cancer patients fully

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[1] Throughout the dissertation "s/he" will be used to represent she/he pronoun.

recover from their illnesses, and many return to lead normal lives, popular mythology still equates cancer with death (Gurien, 1984). While the assumption may have been valid several years ago, most experts agree that newer methods of detection leading to early treatment invalidate this widely held belief. Five-year survival rates are improving for most cancers. For example, the five-year survival rate for patients with uterine cancer has risen to 81%; breast, 63%; cervical, 64%; prostate, 63%; bladder, 61%; colon, 49%; and rectum, 45% (U.S. Department of Health and Human Services, 1982).

Many factors contribute to the fear and dread cancer provokes in our minds. We use the Latin term "cancer" or its older spelling "canker," to describe anything which erodes, sloughs, rots, corrupts, and so on (Deeley, 1979, p. 3). The word thus implies destruction, eating away, a spreading of evil or corruption. Secondly, whenever we hear about cancer directly or through the media it is often terminal cancer; cures are rarely considered "newsworthy." Thirdly, the ambiguity surrounding a cancer diagnosis (that patients who survive five years after diagnosis and treatment have an excellent chance of living normal lifespans, but that they must live with five years of uncertainty; that doctors cannot predict with certainty when a terminal patient will die), coupled with the course of the disease (an unpredictable series of remissions and relapses), contributes to the anxiety experienced by the patient, family members, and society, in general. Fourthly, cancer seems to strike indiscriminately since malignant cells can be active while the victim appears healthy; this also contributes to public fears about cancer. This fear is compounded as the disease discretely transmits from the original site to other organs and even to the brain (a process referred to as metastases). Finally, despite there being absolutely no support for such a contention, many people believe that cancer is contagious; many more people act as if this were so. Each year millions of dollars are invested in cancer research, yet many questions about cancer still abound. With so many pieces missing from the cancer puzzle, there is opportunity for people to fit in their pieces coloured with anxiety, fear, and mythology.

The psychological impact of cancer upon the patient and family depends to a great extent on each member's own set of beliefs as to the nature of cancer and what it can do (Nathan, cited in Gurien, 1984). Cancer is perhaps the most widely misunderstood of all diseases and yet the way one perceives cancer is instrumental in determining how one will react to it. Following is a brief definition of cancer.

B. Cancer: A Definition

> It's a disease which we don't know quite alot about. It attacks cells in the body and it diminishes the number, that means takes away, you might say destroys, white blood cells in your body. In your blood there's white blood cells and red blood cells and the red blood cells keep the oxygen going in your body and the cancer, they don't know how, but it gets in your body and starts destroying red blood cells. Finally, there's no cure for most cancer. . . .And well it's surprising how many people have cancer, when you think about it. And how little we know about it. Oh yes, without red blood cells you can't get oxygen to your heart and lungs and so forth and so that's how cancer kills.
>
> (Steven, eleven years old)

As Steven asserts, our knowledge of malignant disease is at present elementary and superficial. Often we are dealing with the unknown or that which is only partially understood. What we do know is that cancer, a general term for more than one hundred different diseases, is a disturbance in cell physiology. Some types of cancer include: sarcomas, which originate in the connective tissues; carcinomas, which grow in the skin or organ linings; leukemias, which affect the blood; and lymphomas, which invade the body's lymphatic system (Gurien, 1984).

All types of cancers share certain common characteristics. For example, all cancers originate when healthy body cells begin to mutate in some region of the body. Cancer cells, unlike normal cells, do not perform the normal functions such as repairing injuries. In an adult, normal cells are born only to replace ones that have died, but cancer cells live longer than normal cells and reproduce with no regard for the cellular death rate. There is a process of exponential growth. Over time, if left untreated, cancer cells begin to compete for nutrients with the healthy cells. Ultimately, they can crowd out the physical space of healthy cells either through starvation or by actually assuming the physical space of normal cells. Unlike their healthy counterparts, cancer cells can spread to far areas of the body, to repeat the process of cellular destruction in previously unaffected tissue (a process referred to as metastases). There are resulting devastating physical changes that the patient may undergo as the abnormal cells invade the body.

C. Nature of the Study

Statement of Purpose

The purpose of the following research is to *explore* and *present*, from the child's point of view, the experience of living with cancer in a parent. Phenomenological research methods of data collection and analysis were deemed most appropriate to actualize this purpose. Phenomenological research is the study of "lived experience," of the world as it is immediately experienced rather than as it is conceptualized, categorized, or theorized about. This study aims to come to a deeper understanding of the nature and meaning of the everyday experiences of children of cancer patients. Phenomenology offers the possibility of plausible insight which brings individuals in more direct contact with the world. The purpose of phenomenological research is twofold. First, the aim is to clearly *understand* the experiences of the participants (children of cancer patients), whose intentions and perceptions are the phenomenon's meanings. Secondly, once the phenomenon and its meanings are understood, the aim is to *make them clear to others* (Keene, 1982). The "phenomenon" being investigated in this study is living with parental cancer while one is still a child.

Phenomenological research can be seen as a dynamic interplay between the following:

(a) addressing a phenomenon which "seriously interests us" and "commits us to the world." It is important for the researcher to "experience" the phenomenon at some level;

(b) investigating experience as it is *lived* rather than as it is *conceptualized*. This involves what Husserl has called returning "to the things themselves," studying the experience firsthand (outside of the laboratory) with those who have had actual experience with the phenomenon;

(c) reflecting on the essential themes which characterize the phenomenon. In studying the phenomenon the researcher looks for motifs (while interviewing people or while reflecting on the dialogue afterwards) which combined give a "feeling for" what the phenomenon is all about;

(d) describing the phenomenon through writing. It is through written description that the phenomenological writer disseminates his/her "findings."

The procedures for carrying out phenomenological research will be elaborated upon in Chapter Three, the methodology section.

The "Writing" of Phenomenological Research

At this point it is important to mention something about "how" this dissertation will be written. Because the purpose of phenomenological research is <u>description</u> (and not the discovery of facts as is true for other forms of scientific research) different techniques or strategies are employed in the actual writing or reporting of the research. These strategies are intended to bring the reader as closely as possible to the experience being described. To meet this aim, the researcher "borrows" from the experiences and reflections of others (Van Manen, 1984, p. 55). In my study this is done first by including actual statements made by the participating children during the research interviews; and second, by including, in a few instances, the written correspondence (excerpts from doctor's progress notes and letters) of doctors and nurses who work directly with the parents of these children.

In order to further engage the reader in a dialogue with the research phenomenon and with the researcher, the writing will frequently deviate from the traditional objective style of research reporting:

> If it seems appropriate to you to use the pronoun "I" then use it; there's no reason to refer to <u>yourself</u> through some contortion like "the present researcher" in service of a crazy notion of objectivity. Similarly if you believe something to be true or false, then say so, you don't need to write about your research as if you were reporting results of a statistical test. . . .The demands of good language usage are difficult enough without erecting artificial barriers to clear prose out of a misguided belief that "scientific method" calls upon authors to be unclear. (Baritt <u>et al</u>., 1984, p. 16)

The writing will deviate in that it will take the form of a narrative when the phenomenon is being described (particularly in Chapter IV). "By evocatively, incantatively 'telling' about a phenomenon the reader is challenged to contemplate it. . . .Language that authentically speaks the world rather than abstractly speaking of it involves the reader in the phenomenon so that in the words, or maybe better, <u>in spite of</u> the words, we find 'memories' which paradoxically we never thought or felt before" (Van Manen, 1984, p. 39). The writing will also deviate in that the pronoun "I" (and other personal pronouns) will be utilized wherever it is deemed appropriate. By using the first person along with personal explanations and opinion, the researcher takes responsibility for the writing and by so doing emphasizes that the description is only one person's (his/her) interpretation of the phenomenon.

Research Questions

The following questions were considered during the course of the study:

1. What do children of cancer patients perceive their experiences to be during various phases of the illness process?
2. What are the common and individual concerns of these children?
3. What is the impact on children of living with the knowledge and experience of their parent's life-threatening illness?
4. How do children adapt to and cope with their parent's illness?

The research was conducted with an "eye to the consequences for action" (Baritt et al., 1984, p. 15). While reviewing the transcripts of the interviews with the participating children, recommendations will be formulated that are aimed at making their situation better for them.

II. LITERATURE REVIEW

At the time this review was written, there was not a body of literature which addressed the child's experience of having a parent with cancer, or even of a parent with a life-threatening illness. Correspondence with clinicians and researchers who work in cancer hospital settings in Israel, Canada, and the United States, has indicated that professionals in the field of psychosocial oncology (oncology being the scientific term for the study of tumours) are beginning to recognize these children's needs. They believe that preventive psychiatric work can be done by attending to children while their parents are ill and especially while the parents are dying.

> Cancer has profound emotional and experiential meanings for the ill person's family during the course of the illness and potentially for the remainder of their lives. Resolution of the illness as well as how the family deals with each other can have important influence ranging from psychological enhancement to serious disruption of developmental processes for some or all family members. (Wellisch, 1979, p. 231)

As professionals and non-professionals alike, we know how great the impact of having a parent with cancer can be on a child. Why have so few researchers explored the nature of these effects? The following excerpt from a letter received from Barbara Warren, Clinical Nurse Specialist of the Cancer Control Agency of British Columbia, provides some insight into the issue: "Unfortunately, although I have drafted a proposal for a study specifically on the reaction of patients' children in 1977, it has been in limbo since that time as my clinical responsibilities always seem to take priority" (1985, personal communication). As a result of my own initiation into a psychosocial oncology department, I understand that the urgency of the clinical work and the limited time for research, are indeed a reality.

There has always been a reluctance to enter into a child's world while s/he or a loved one is in crisis. We as adults are afraid of causing children unnecessary harm which we assume will happen if we discuss with them, study or write about, their experiences of having a seriously ill or dying parent. Gerda Lerner, in A Death of One's Own,[2] exemplifies this view in explaining why she did not include her children's reactions in her poignant and reflective narrative about how her life changed, as did her husband's, when he developed a malignant brain tumour:

> There is one deliberate omission: I have left out of this narrative everything essential pertaining to my children and their relationship to the event of their father dying. I have done this because I do not feel I know what their

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[2] Gerda Lerner, A Death of One's Own (New York: Harper & Row, 1978) p. 8.

> experience really was like nor do I feel that I could describe my perceptions of it without invading their privacy and causing them pain. This I have chosen not to do. (1978, p. 8)

Because professionals and parents alike are reluctant to intervene in the lives of children by discussing serious life and death issues with them, and because clinicians are too busy meeting the practical needs of cancer patients and their families to conduct research, research in the area pertinent to this study is scant.

In this chapter, seven studies, which are preliminary investigations into the lives of children of cancer patients, are reviewed. These studies include one unpublished manuscript received from Gerald Caplan of the Hadassah Hospital in Jerusalem. The review is followed by a content summary of the studies. Since death concerns will indubitably play a role in some of the participating children's thoughts, a brief review of how children are believed to conceptualize death is presented. Also included is a section on how these conceptualizations are transformed when a child is having direct experience with death or illness. For a more thorough review of the "children's conceptions of and reactions to death" literature, the reader is referred to Berlinsky and Biller (1982) and Lonetto (1980).

In Chapter Five, other literature deemed relevant for substantiating, elaborating, and clarifying the findings of this study, will be presented. This research will include studies done with cancer patients, both adult and pediatric, as well as research done with the healthy members of their families.

A. Children of Cancer Patients

Only seven studies focus explicitly on the influence of parental cancer on children. The four studies which limit their samples to adolescents will be discussed first. Wellisch's (1979) retrospective clinical study highlights the experiences of six adolescent children whose mothers were cancer patients. He saw these children and their families in psychotherapy and estimates that their need for psychosocial intervention predated their parent's cancer diagnosis. Wellisch interprets the behavioural disturbances in these adolescents (drug and alcohol abuse, rebellious behaviour, promiscuity) as manifestations of family disequilibrium precipitated or aggravated by cancer in the mother. He reports that most of the children became "pseudo-parent or confidante" to the well parent (p. 240). Wellisch also suggests that the parent's illness served as a regressive force which interfered with the adolescent's age-appropriate desire to individuate from his/her parents.

Rosenheim and Ichilov (1979) studied the effects of a short-term preventive psychotherapy program on twelve children of terminally ill cancer patients. The children, eight boys and four girls aged ten through fourteen, were compared to an equal number of children of terminally ill cancer patients who did not receive psychotherapy. Children who received up to twelve supportive sessions showed a decrease in their level of anxiety and an improvement in their school functioning (as measured by teacher and parental reports, and a structured anxiety measure all given pre and post-intervention) when compared to the control group. During the sessions, the therapist and researchers found the children to be preoccupied with the seriousness of the parent's illness and the possible consequences for their family's future. The children's fearful preoccupations interfered with learning and social adjustment. The children converted their anguish into psychosomatic symptoms when left unattended by their parents. Parents often avoided the children and could not discuss the illness with them. The children coped by "conducting business as usual," or by counteracting the feelings by "excessive out-of-home involvement" (p. 69). Most of the children were ambivalent about acquiring information for fear that talking about death might accelerate its occurrence. Rosenheim and Ichilov (1979) also report that the children experienced "irritability," "dysphoric mood," and "cognitive difficulties" (Ibid).

Rosenfeld, Caplan, Yaroslavsky, Jacobowitz, Yuval, and LeBow (1983) pursued a retrospective pilot investigation of eight adolescent daughters aged twelve through twenty of seven mothers who had a mastectomy two or three years previously. A two hour standardized interview was analyzed and common themes were generated. The researchers found that the older girls were more likely to see the illness realistically (without exaggerating or underestimating its seriousness). All of the girls were uncertain about the etiology and heritability of the illness. Six of the girls saw the disease as a serious threat to themselves in that they feared for their own health and/or for the demise of their parent. Only three girls experienced a transient decline in school performance in the month following their mother's mastectomy while all the others continued to function as per usual. Half of the girls suffered from psychological or psychosomatic symptoms during the acute phase of their mother's illness or afterwards. Most of the girls reported dysphoric mood disturbances (sadness, sleeping problems) during their parent's chemotherapy. None of the girls reported evidence of severe psychopathology or acting out behaviours during or following the illness.

Arnowitz, Berlowitz, Dietcher, Jacobowitz, Ronen, Stern, Winar, and Caplan (unpublished manuscript, 1984) used a combination of objective and projective measures to study the psychological reactions of fifteen adolescent children, seven male and eight female, aged eleven-and-a-half to twenty-one years. The mother was the patient in most of the cases with the most frequent diagnosis being breast cancer. In two cases, the father suffered from testicular seminoma. In four cases, the parent was in remission, while for others the cancer was diagnosed recently or reoccurred after a period of remission. A comparison group of twelve children of healthy parents was used. Six of the children in the experimental group did not participate in a second testing session. Structured tests were used to measure cognitive performance, mental status, conscious perception of self and family, and projective tests were used to measure coping style and covert perceptions. The index group (the nine children who completed the entire battery of tests) reported more symptoms of a depressed, anxious mood than did the control group. Psychosomatic symptoms were rare. On structured measures the adolescents presented as self-confident, and viewed their families positively while on the projective measures their responses were predominantly uncertain and pessimistic. These researchers imply that while children of cancer patients may appear to be adapting to their parent's situation, and even deriving more personal strength from it, inside they are depressed, anxious, and insecure about their future.

Grandstaff (1976) conducted a qualitative analysis of information gained from seventy breast cancer patients and their children over a two-year period (no reference is made to the ages, sex, or number of children). She found that the children initially feared that their mother would die, that the adolescent girls in the study identified strongly with their mother, supported their mother during the illness, and were fearful that they, too, would develop breast cancer.

A study by Cancer Care Incorporated and the National Cancer Foundation Incorporated (1977) is the only one which addresses children of varying ages (again, no reference is made to the distribution of ages and sex of the children). These two agencies sponsored a study of eighty-eight children from forty families in which a parent had some type of advanced cancer. Interviews were conducted with the spouses of the patient and not with the children. Of forty-one children who were reported to have had behaviour problems (poor school functioning, tearfulness, eating and sleeping disturbances, instances of acting out and aggressive behaviour) prior to their parent's cancer diagnosis, seventeen had additional or more severe problems during the illness. The remaining twenty-four were rated as having little or no change in symptoms. Of the forty-seven children who had no behavioural symptoms before the patient's illness, seventeen developed symptoms during their parent's illness.

The final article to be considered is one by Adams-Greenly and Moynihan (1983) in which they discuss a sequence of psychosocial interventions they have developed for working with children during the course of their parent's cancer. These interventions were designed to facilitate coping and long-term adaptation. Their findings are derived from their clinical work with children. They have found (as did Wellisch) that adolescents, in the process of separating from parents, are profoundly affected by the potential or real loss of a parent. Some adolescents ward off intensely sad emotions by trying to recapture good moods (Rosenheim and Ichilov, 1979). Adams-Greenly and Moynihan (1983) also found that children "from school age on utilize the age appropriate defense of intellectualization" to cope with their parent's illness (p. 57). In a finding parallel to Wellisch's, the stress of a parent's illness precipitates regression in the children which affects their ability to comprehend and integrate information. Additional findings by these authors include children becoming upset in reaction to their parent's changed physical, emotional and/or mental functioning and children fearing that they are to blame for either their parent's illness and/or angry outbursts.

Summary

The studies on children's reactions to parental cancer all concur that there are adverse changes in children's behaviours and experiences following the diagnosis of cancer in a parent. None of these studies focus on beneficial changes, or changes of a positive nature. Children who manifest behavioural symptoms at the time of diagnosis deteriorate during their parent's illness. Most children who have been functioning "normally" begin to develop behaviour and subjective disturbances. Only one study did not find acting out behaviours amongst the children (Rosenfeld et al., 1983). This finding might be attributed to the fact that the children, themselves, were questioned while in the other studies parental reports were used. Maladaptive behaviours which either developed or worsened during the illness experience included: alcohol abuse, promiscuity, rebelliousness, dysphoric and/or anxious mood, irritability, psychosomatic symptoms, and cognitive difficulties. Children were preoccupied with thoughts of parental disfigurement and/or impending death of themselves or their parents from cancer. These fears interfered with social adjustment and/or learning for many of the children. Adolescents who had a parent with cancer viewed their families and themselves more positively (than did their peers) on the surface, but latently they were uncertain and pessimistic. Finally, children were ambivalent about acquiring information about the disease, adolescents saw the disease most realistically, and adolescents became pseudo-parents or confidantes to both well and sick parents.

B. Children's Conceptions of Death: "Inexperienced" Children

There has been an immense amount of support in the literature for a cognitive-developmental view of children's conceptions of death. Although Piaget himself did not specifically research the question of how the understanding of death develops, his theory of cognitive development has been applied to the development of the concept of death. Nagy (1948) conducted the initial study in this area with 348 Hungarian children. Subsequently, other researchers have supported her findings (Kane, 1978; Koocher, 1973; Lonetto, 1980; Stillion & Wass, 1980).

Nagy used interviews, children's written stories, and drawings to explore the conceptualizations of death in Hungarian children aged three to ten years. She concluded that there are three age-related stages in children's understandings of death which correspond with Piaget's stages of cognitive development.

The first stage (ages three through five years) reflects the egocentric minds and magical thinking of preschool children. At this stage, children know that they must eat, sleep, and breathe, so they attribute life processes and consciousness to the dead person.

The dead continue on living. Nagy (1948) cites one preschooler as saying "The dead close their eyes because sand gets into them" (p. 7) and Lonetto (1980) refers to a child saying that the dead person "shakes the sand off and lives again" (personal communication). Death to these children is understood as separation and the deceased person is only temporarily immobile (Kane, 1978). Temporal orientation is "now"--death is thought of in terms of the present and the immediate and does not carry on into the future. To these children, death is reversible and the dead person will wake up in the near future.

In Rochlin's (1961) study, one researcher asked a five-year old "But surely you don't think the dead person still sees?" The child answered "No, they can't see poor things. It's dark in those coffins. But then at night when they come outside, they can see then. But not so well." Thus, while preschoolers know that the dead persons are buried underground, they view death as a kind of sleep or temporary state. The magical thinking which characterizes their development is reinforced by the way death is portrayed for them in fairy tales (Snow White and Sleeping Beauty, for example), in cartoons (the coyote in the Road Runner who always seems to return from death), and also by their own sleep which is temporary.

Anthony (1940) postulated an early developmental stage (ages three and four) during which time the child, restricted by limited speech, has no idea of death. She found that it was not until five years of age that they developed a limited or erroneous concept of death. Steiner (1965) reported that four and five-year olds denied thoughts of death but did admit to playing and dreaming about it. In a more recent research endeavor, Swain (1979) conducted interviews with 120 children under five years, and found that they tended to view death as reversible and escapable and not as inevitable and personally applicable. Prior to the age of five it appears as though children are systematically unaware of the reality and irreversibility of death (Safier, 1964).

During the second stage, children (five through eight years) learn about biological and human reality as they become more enmeshed in their academic and social worlds. They rely less on magical thinking and now recognize death as final, for others but not for themselves. Although they understand that death ends life, they feel it ends the life of the old and only through sickness or accident and not through natural processes. There is a tendency among children of this age group to personify death as a skeleton, monster, or ghost. This seems to be a way of bringing the phenomenon into an understandable cause-and-effect relationship (Stillion & Wass, 1980). It also offers the children the opportunity to believe that they can defeat or escape death. Lonetto (1980) and Mai (1985) have found the tendency to personify death in groups of Canadian children, though Swain (1979) did not find this tendency to any significant degree, in her group of American children over the age of five. During this period children are concerned with mutilation and dysfunctionality of the body after death (Kane, 1978; Koocher, 1973). Kane (1978) supports this notion of concern with dysfunctionality and reports that children have ideas such as: "Dead people can't move, blink their eyes, or work their mouths, they get hungry but can't eat because they can't move their hands, don't eat but do drink, and hear voices but don't answer" (p. 70).

The third stage of death understanding can begin as early as nine years. Children at this stage recognize death as inescapable and universal. They view it as personally applicable: a natural, internal destruction process that will happen to everyone, including themselves. Death is seen as being determined by internal forces such as bodily aging and not only as being taken away by powerful outside forces (skeletons, monsters, or ghosts). In a study by Childers and Wimmer (1971), eleven percent of the four-year olds recognized death as universal but by the age of nine, one hundred percent of the children did. Sixty-three percent of the ten-year olds, as compared to thirty-three percent of the four-year olds, recognized death as irrevocable. Alexander and Adlerstein (1958), Portz (1965), Steiner (1965), and others all report consistent findings which support a developmental view of death conceptions, even though they use diverse, contrasting methodological procedures and analyses.

Summary

There is considerable support for the notion that the child's conception of death moves from a state of non-awareness, through an intermediate stage where there is an awareness of death as external and, appearing in many monstrous forms, to one of an understanding of death as natural and universal.

C. Children's Conceptions of Death and Illness: Experienced Children

Proponents of the age-graded developmental model, Nagy and those who have duplicated her findings, do not consider children who have had direct experience with death, or at least they do not make any differentiation on the variable of death experience. Three researchers--Bluebond-Langner (1978), Kane (1978), and Carandang et al. (1979)--study populations of children who have had some type of experience with death, to find out their conceptions of death and/or illness.

Bluebond-Langner (1978) formulated a multi-faceted model of children's death conceptions while working with terminally ill children. She found that these children came to know that they were dying in terms that were thought only to be possible in children over nine years. Their views of death and dying, as indicated by their comments and behaviour, were a reflection of their experiences, concerns, and circumstances at the time of their illness. To these children (regardless of their cognitive-developmental stage) death and dying were viewed as mutilating experiences which incur separation. To them it was a final, irreversible fact of life.

Bluebond-Langner (1978) inquires:

> Do children's concepts of death develop with age, with newer, more 'scientific' explanations replacing 'fantasy' explanations? Or, are all views of death present at all times in one's development and does the particular account of death one gives at any one time reflect not so much age as social and intellectual experiences and psychological concerns and circumstances at the time the question is asked; and does the forum of such expression even belie the conception? (p. 51)

She proposes that the particular view of death or illness that a child presents at any one time reflects his or her social, cultural, psychological, and intellectual concerns. She argues, for example, that five-year olds speak of death as separation because most of their years are spent in first separations (e.g., parents leaving for work; children leaving home for school).

Kane (1978) has found experiences with death (though she does not specify what type of experiences) to be important in terms of concept development for children six years of age and younger. When children of this age experience death, Kane (1978) reports that they have a conceptual edge on their age peers which disappears as the other children naturally mature. Children up to six years of age who have had a death experience view death as final and irreversible but as escapable and personally remote. Instead of viewing death as being reversible and temporary which is typical of three to six-year olds, they view death more like the average seven to ten-year old. She found that children aged seven through twelve manifest the same maturity of concept whether or not they experienced death.

Carandang, Carlyle, Folkings, Hines, and Steward (1979) conducted an investigation to evaluate illness conceptualization (whether a child viewed illness as happening due to external or internal forces,for example) of children at different stages of cognitive development. Their study focused on how sibling illness influenced conceptualizations about illness. Seventy-two children, aged six-and-a-half years to fifteen years who had siblings chronically ill with diabetes were matched with thirty-six control children with healthy siblings. They found that illness conceptualization level often fell below pretested cognitive levels for these children and this was especially true for adolescents. Carandang and his colleagues conclude that a child's family experience with illness may contribute to the decalage phenomenon (a term coined by Piaget to describe the lag or slippage in cognitive functioning when a child in under extreme duress for extended periods of time)[3] among children with ill siblings.

Summary

Bluebond-Langner and Kane both report that experience with death gives children a conceptual edge on their peers. Kane, however, limits her findings to children six years of age and younger and found no such advantage for older children. Carandang et al. found experience with chronic illness to be an actual disadvantage for children, and this was especially true for adolescents. More research attention needs to be devoted towards children's conceptualizations of death and illness, for children who are actually experiencing these crises in their families.

Since it is my intention to approach each interview free of theoretical presuppositions and assumptions, I will not use the literature review as a framework but rather as a comparative base against which to interpret and discuss the children's experiences.

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[3] Jean Piaget, The Child and Reality. New York: Viking Press, 1973.

III. METHODOLOGY

> In graduate courses on research we have made much an ado about the nature of scientific evidence and the use of statistical inference that we have blinded our students to the essential issue: without fresh viable observation all the machinations of research methodology become an empty and self-deceiving ritual. There is no virtue in demonstrating that one can count or that one can compute Pearsonian correlation coefficients on the items he has counted; the trick is to know what things are worth counting in the first place. And no course in research methodology can teach us this. The skill can be acquired only through direct experience with the phenomenon we are seeking to understand, and can be matured only by developing within ourselves--as human instruments--the capacity to view with unfettered perception the world around us. (Halpin, 1966, pp. 287-288)

Only through "fresh viable observation" of children of cancer patients can I hope to understand their worlds, since I myself am not a child of a cancer patient. Recognizing this, methods of data collection and analysis have been chosen which promote qualitative research. Viewing the "world of children" through the eyes of children is the frame of reference which I have adapted from the phenomenological approach to research. This chapter elaborates on the phenomenological methods selected. The chapter starts with an overview of some issues relevant to the phenomenological study of the child, and as it unfolds, the value of the chosen methods becomes clear. A section on my personal background and research biases follows. As researcher, I am the most important "instrument" in this study and it is through me and my writing that these children's worlds will find expression. I have also developed a few instruments to facilitate and direct my research on the phenomenon under study; these are discussed. The chapter concludes with an outline of the methods of data collection and analysis utilized to meet the purposes of this study.

A. Phenomenology and the Study of Children

Phenomenology is the study of the world as we immediately experience it rather than as we conceptualize, categorize, or theorize about it. Traditional phenomenology has aspired to be a direct study of the phenomenon as given to the phenomenologist without any intermediaries (Spiegelberg, 1975). In its strictest sense a phenomenologist can only describe experiences s/he directly experiences. Spiegelberg and others (Baritt et al., 1984; Colaizzi, 1979; Giorgi, 1970; Merleau Ponty, 1962; Van Manen, 1984), however, address the issue of a broader phenomenology in which the researcher can study and understand a phenomenon s/he has not experienced. Phenomenology has become an umbrella term for any method which approaches a phenomenon in a subjective manner. According to Spiegelberg (1975), "there is no good reason for barring the road to a genuine phenomenology with a wider and richer scope" (p. 53). The approach to phenomenology that I have adopted is based on the work of phenomenologists who obtain their interpretation of the phenomenon by combining their own personal experience of the phenomenon with how it is experienced by others. Unless we rely solely on our childhood memories, recollections, and on remnants of our past when describing a childhood phenomenon, a phenomenology of childhood must become an indirect, vicarious one, a "phenomenology through vicarious experience" (Spiegelberg, 1975, p. 53).

Attempting to understand the phenomenon of being a child of a cancer patient is a different kind of task for the researcher who is not a child of a cancer patient. But each of us has lived with illness in the family. As children we have, at some time or another, known or feared the loss of a parent, and we are all familiar with "loss." When I think of cancer, I think of the pain and suffering of relatives, friends, and patients whose lives I shared. My own losses are stirred as are thoughts of my own mortality as I empathize--in the full emotional sense of the word--with children of cancer patients. It is through this empathy that I am able to gain access to, and begin to understand, the nature of their experiences. Furman (1974) insightfully describes the plight of those who choose to help and understand the children of seriously ill or deceased parents:

> . . .in our direct contacts with our patients and their families, in our private thinking and in our research discussions, we lived with the intense distress, pain, and anguish engendered by bereavement. We have come to understand that this emotional stress is an inevitable burden for all who work with bereaved children. It is essential in facilitating appropriate empathy and insight, and helpful in integrating an intellectual grasp of the psychic processes within the patient's personalities. Only those willing and able to bear the impact with feeling can hope to work with bereaved children [or with children of cancer patients] fruitfully and to understand them scientifically. (p. 9)

Experiencing the pain, anguish, and distress engendered by children of cancer patients, makes the phenomenological study more directly phenomenological. But essentially a phenomenology of any childhood experience introduces some difficult challenges for the adult phenomenologist.

Allen (1976) suggests that there are two seemingly antithetical demands for any phenomenologist who undertakes to investigate the phenomenology of the child. The first and most difficult claim, he asserts, is that the phenomenological investigation must preserve and describe the world of the child as the child does, without the observer imposing an adult viewpoint. Traditionally, psychologists (Piaget, Kohlberg, Chomsky, for example) view childhood consciousness as a function of adult consciousness. According to Merleau Ponty (1962), the task of developmental psychology is to describe childhood consciousness in a positive manner by seeing it as different in both content and organization from adult consciousness. Typically, however, developmental psychologists characterize it as incomplete, undeveloped, or as imperfect adult consciousness--a negative view of child development. For example, Piaget's classifications originate in adult language and adult categories. The initial content of children's statements are always transformed, in the process of interpretation, to a more formal language ("preoperational thought," "artificialism," "animism," "materialistic," for example). With all his sensitivities to children, it may be nevertheless said that Piaget's theoretical presuppositions lend him to disparage the child's own self-understanding of events. Silvers (1975) addresses the issue of how Piaget conceptualizes children's thought as progressing through transformational stages with the final stage being the stage of "true" maturity:

> When the child's accounts of why things happen in the way they do--for example, how a shadow is cast--departs from Piaget's common sense or scientific explanations, he does not try to pursue how the world could be understood their way. When the child informs him that the shadow emanates from the object, he does not inquire how it could be so, he does not pursue the poetic and practical understanding, but instead he uses the account to note its difference to a later stage which he titles "The Correct Explanation is Found." (p. 48)

The language that he and other developmental psychologists choose is not neutral but is biased in the direction of adult structures (Sardello, 1974).

The phenomenological approach attempts to articulate the formal structures of childhood experience and to clarify these with specific situated descriptions (Sardello, 1974). In this manner, Sardello (1974) explains, a phenomenological approach to human development avoids the accusation often directed at child psychology, that of being abstract.

The second demand for the phenomenological psychologist who chooses to study children is entwined with the first. Allen (1976) cautions the phenomenologist against radically severing the child from the human world, including the adult world, in whose structures the child also participates. Thus, while it is important to view childhood consciousness and development as having unique structures and qualities of their own and not merely as incomplete adult development, it is important not to exclude the child from the adult, human world, of which s/he is a part. "The difficulty for the phenomenologist is, thus, grounded in the very phenomenon of the child himself." (Allen, 1976, p. 76)

B. The Phenomenological Perspective

The result of phenomenological research, the phenomenological description, is based on a fusion of the perspectives of the participant[4] and the researcher (Colaizzi, 1979). Although the aim of the research is to elucidate the phenomenon as it is viewed by the experienced individuals being studied, the researcher (who is relatively inexperienced with the phenomenon) inevitably influences the elucidation for it is s/he who must understand it and then describe it for others.

The Participant's Point of View

There are a number of explanatory perspectives that could have been adopted to view these children's worlds--cognitive-developmental, behavioural, psychoanalytical. The chosen perspective, however, is phenomenological. This study is based on the premise that "children are the best informants of their own life experiences; that they are capable of being insightful observers and describers of their own life-worlds" (Wood, 1982, p. 4).

While there are various types of phenomenological research, all share the same goal of trying to understand the "subjects" from their own viewpoint. Bogdan and Biklen (1982) emphasize that "point of view," in itself, is a research construct and it is the way that phenomenological researchers approach their work. Bogdan and Biklen (1982) explain:

> Looking at subjects in terms of this idea (their point of view) may, consequently, force the subject's experience of the world into a mode that is foreign to them. This kind of intrusion of the researcher on the subject's world, however, is inevitable in research. (p. 83)

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[4] "Participant" is a term used to emphasize the dynamic involvement of the individual in the study. The term is an attempt to avoid the use of the label "subject" which implies one who is submitted to an experiment or study.

To do research and make interpretations, the researcher must have some kind of conceptual scheme. For the phenomenological researcher, "the participant's point of view" is the conceptual framework of choice whereby s/he gains access to the world of the participants in order to understand how and what meaning they attribute to events in their lives. Those who adopt this perspective in their research "believe that approaching people with a goal of trying to understand their point of view, while not perfect, distorts the subject's experience the least" (Bogdan & Biklen, 1982, p. 83).

The Researcher's Point of View

> While we have traditionally recognized that the characteristics of an experimenter may indeed influence behaviour, it is important to observe that we have not seriously attempted to study him as an independent variable. Rather, we have typically regarded the experimenter as necessary, but undesirable for the conducting of an experiment. Accordingly, in experimental psychology we provide prescriptions for controlling the extraneous variable; but seldom do we consider the experimenter variable further, and the extent to which we actually control it in our experimentation can be seriously questioned. (McGuigan, 1963, p. 421)

The objective attitude, characteristic of experimental psychology, is "a special kind of presence" rather than the removal of the presence of the researcher (Giorgi, 1970, p. 189). "If attempts to keep man, as researcher, out of the situation fail, then perhaps the solution is to put him completely in it"[5] (Ibid, p. 189). The fully engaged presence of the researcher is the solution of phenomenology.

The question then becomes "How does the researcher suspend his/her judgement to ensure the validity of results?" The major protection against bias is for the viewpoint itself to be made explicit, so that its validity may be circumscribed (Giorgi, 1970). Husserl (1982) called for "a suspension of judgement," an elimination of all presuppositions from the research approach (a process which he termed "bracketing"). By exploring beliefs and theoretical preconceptions and biases, Husserl believed that the researcher could arrive at the phenomenon reduced to its pure form (called the phenomenological reduction). More realistically, however, Merleau Ponty (1973), recognized that "the most important lesson that the reduction teaches us is the impossibility of a complete reduction" (p. xiv). There are inevitably theoretical preconceptions and personal biases which influence the study

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[5] Giorgi (1970), in Psychology As A Human Science, explains how three ways of controlling experimenter bias--minimal contact between experimenter and subject, double blind procedures, and replication of the experiment by different experimenters--do not truly solve the problem of experimenter bias.

and description of any phenomenon. "Consequently, despite many ways of handling the situation, the presence of the scientist in the making of his science is a way of life in psychology." (Giorgi, 1970, p. 221).

In many ways, the present study will inevitably be an example of "my way of being," and my world-view has indubitably influenced the choice of phenomenon, and the way I have chosen to study, analyze, and explore it. To increase my awareness of the personal bias I bring to the study of children of cancer patients, I asked myself the following questions, as recommended by Colaizzi (1979):

1. Why am I involved with this phenomenon? How might my personal history have influenced my selection of this particular phenomenon?
   How might my uniquely formed personality have influenced my choice?
2. What are my personal views on child and personality development?
3. Why have I chosen a phenomenological approach to research?
4. How will I suspend my judgements?

1. Why Am I Involved With This Phenomenon?

In responding to the first group of questions, I found myself reflecting on my childhood.

I remember how sensitive I was to separations from my parents and how often I struggled with concerns about their dying. Though separation anxiety characterizes early childhood development, my reactions, I believe, were sometimes exaggerated because of my experience as a child of a Holocaust survivor. At a very young age I learned about, and became sensitive to, the phenomenon of loss through death as I privately mourned the loss of my father's family. My selection of the phenomenon under study--the experience of cancer in a parent--comes from a deep sense of empathy I share with children who are at risk by losing a parent through death.

2. What Are My Personal Views On Personality and Child Development?

My views on personality and child development are influenced by my basic existential thinking and by the interest I have in questioning the concepts of life, death, and their meaning. I concur with Bettelheim (1977) that at each stage of our development--from childhood through to the later years of adulthood--we search for meaning in life and wrestle with death. I believe that children carry on an existential search--even very young children: ". . .the question of life and death is an existential question and is an expression of the child's basic curiosity and search for meaning. Children, like other people, seek to understand themselves, their relationship with others, and the world in which they find themselves" (Schneidman, 1980, p. 253). Oaklander (1978), a child psychotherapist, recounts her existential search as a child:

> I remember very clearly what it was like being a child. It's not so much remembering incidents and happenings, but remembering the knowings that I had never told anyone. I knew things. I wondered about life. I philosophized. And no one really knew this side of me. I thought about death and was in awe of the fact that life existed before I was born. I wondered at my parents for having lived as long as they had, and questioned whether I would live a long time. (p. 320)

I believe, too, in the potential self-enhancement value of crisis, and in the value of pondering our own finiteness as human beings. From a developmental viewpoint, the loss or threatened loss of a key relationship creates a crisis with heavy impact on a person's sense of identity, capacity to cope with change, and on feelings about others. Children are particularly vulnerable because their identities and coping mechanisms are only beginning to develop. In fact, losses of significant relationships in childhood can hinder the normal developmental processes and can lead to fixated behaviour at, or regression to, a level that interferes with the completion of social, psychological, and cognitive development. However, if the child is given guidance and support, s/he can face and emerge psychologically strengthened from crises. I see human development from the point of view of conflicts, inner and outer, which the healthy personality weathers, emerging and re-emerging with an increased sense of personal and social unity. The implications are that children who are experiencing the impending loss of a parent through cancer, are in a position to develop more sophisticated understandings and coping devices, that do not follow traditional developmental patterns.

3. Why Have I Chosen A Phenomenological Approach to Research?

There are four interrelated reasons which account for my having chosen a phenomenological approach to the study of children of cancer patients. First, phenomenological research acknowledges the special nature of human existence: that human beings are always in relation. A phenomenological perspective, therefore, seems to be the framework of choice for a phenomenon which threatens the very heart and nature of the parent-child relation.

Second, "being" and "nonbeing," two major themes in existentialism, are particularly relevant to the topic I am studying. Other existential issues such as anxiety and human suffering are also central to my topic. Phenomenology has become the methodology of choice (actually a collection of methodologies) for studying existentialism (a collection of philosophies about "lived experience").[6]

Third, we all live with some uncertainty and ambiguity in our lives--this is the human condition. Feelings of uncertainty and ambivalence come to the fore for cancer patients and their families. In this study, I did not want to reduce the dynamic nature of that uncertainty by using structured, empirical means of investigation:

> This research approach acknowledges that we will probably never know all that can be known about humankind; there will probably always be some mystery to the question of being a human being. This is not a popular idea in a computerized age of certainty, an age of seeking to measure, control and predict all aspects of human existence. It makes some people nervous that certainty might be an impossible goal. . . .The mystery of being human is addressed in the studies of education, psychology and other social science disciplines, but it is also the ultimate question that each one of us faces in living out our humanity. (Wood, 1982, p. 58)

All human research, particularly psychological research, is a mode of existential psychotherapy" (Colaizzi, 1979, p. 69). In doing phenomenological research, I can rely on my perceptiveness. I can also reflect upon my skills as a clinician and improve them by disciplining myself to truly listen to and understand another person's world. As a result of first understanding the world of the child whose parent has cancer, I am then in a position whereby I can offer these children the types of services they want and need.

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[6] See Colaizzi (1979) for further elaborataion.

4. <u>How Will I Suspend My Judgements?</u>

The research procedures were designed so as to minimize my judgements during the interviews. I allowed each participant to speak about the phenomenon before asking for clarification of what I interpreted to be essential elements of the cancer experience. I did not go in with prestructured questions, but rather allowed each child to explore and communicate his/her experience through drawings and storywriting. Their responses to these tasks provided the direction to our interview. Once themes were crystallizing, I proceeded with direct questioning to validate these themes as our spontaneous dialogue drew to a close.

C. Procedures

Critical Review of Existing Studies: Implications for the Methodology of the Present Study

As we saw in the literature review, the existing studies with children of cancer patients are exploratory and preliminary in nature. My study builds on their shortcomings by considering the following:

1. <u>Varying Ages Of Subjects</u>

Five of the studies focus on adolescents only. The participants in my study vary in age from three to fourteen years. This will allow the researcher to search for developmental patterns as evident in the children and in literature on death. Looking for developmental patterns is useful but, especially with small sample sizes, can by no means be exclusive and definitive. Furthermore "schematic stages. . .are at best approximations, and at worst, obstacles for individualization" (Weisman, 1972, p. 111).

2. <u>Child's Perspective</u>

While the existing studies, for the most part, consist of interviews with children, their conceptual frame of reference is not children. That is, either they translate the child's experience into behavioural descriptions ("promiscuity," rebellious behaviour," "decline in school performance") or into psychological jargon ("psychosomatic symptoms," "dysphoric mood," "cognitive difficulties"). Such terminology removes the "child" from the lifeworld of the child and prevents the adult from entering. In two of the studies (Cancer Care Inc., 1977; Grandstaff, 1976), the researchers rely on parental reports of the children's behaviour. Looking at behavioural concomitants of children's behaviour as described by parents is not an objective measure (as is assumed by empirical methodologies). Parents' judgements are likely to be distorted because they, themselves, are stressed and distressed. Much of their children's behaviour would not be seen as problematic in a more "normal" context.

The remaining five studies base their findings on data collected from children but they do not use the children's own words to exemplify the findings. In my study children are interviewed and trusted as perceptive observers of their own worlds. Their statements are reproduced to highlight and substantiate the research findings, and to involve the reader in the research endeavor. The reader is then able to question the findings and may even draw some additional, personal conclusions.

3. Home Interviews

In one study (Rosenheim & Ichilov, 1979), the interviews were conducted with children in their homes; the others were conducted in university and clinical settings. According to Sartre (1968), to understand, the researcher must immerse himself or herself into the "landscape" of the subject's experience. "To divorce the act, word or gesture from its context is, for the phenomenological researcher to lose sight of significance" (Bogdan & Biklen, 1982). In the present study home interviews were conducted, except in three cases where it was more convenient for the families to meet in the hospital (two cases) or in the researcher's home (one case).

4. Children Without Psychological Difficulties

Two researchers (Cancer Care Inc., 1977; Wellisch, 1979) study children whose adjustment difficulties predate their parent's cancer diagnosis and two use clinical populations (Adams-Greenly & Moynihan, 1983; Grandstaff, 1976). In the present study, none of the children had psychological problems which predated their parent's cancer diagnosis. Children who were experiencing problems as a result of the cancer diagnosis were included. If the children were already experiencing psychological difficulties even before they knew of their parent's diagnosis, the answer to the research question "What is the experience of children who have a parent with cancer?" would be needlessly complicated.

5. Retrospective Study.

Rosenfeld et al. (1983) conducted a retrospective investigation to find out how children were doing three years following their parent's active illness. This idea was incorporated into the present study. Ten of the twenty-three children had parents who were already deceased and one child's mother was considered "cured." These children's experiences were explored currently and retrospectively.

6. Heterogeneous Sample.

Attempts were made in the existing studies to make the samples of children homogeneous on some variable, for example, age of child, cancer type, time since parent's diagnosis. In my study a heterogeneous sample was used so that I could explore various examples of what it is like to be a child of a cancer patient.

7. Research Instruments.

For most of the studies reviewed, interviews were the sole source of data collected; except for Arnowitz and his colleagues (unpublished manuscript, 1984) who utilized both subjective and objective measures. In the present study, since the subjective experience of the child is the focal point, the researcher is the main "instrument." Other subjective, projective measures (drawings, stories) are also used.

A comprehensive outline of the research procedures utilized in the present study follows.

Participants

The participants were twenty-three children of fifteen cancer patients. The children ranged in age from three to fourteen years. The families were referred by staff persons, or self-referred to the psychology department of a regional cancer center in Western Canada. The patients were experiencing difficulty in adjusting to the disease process, treatment, and/or impending death. In some cases they were seeking help for their families. It is hospital procedure to refer families of terminally ill patients to the department. Families also sought assistance in helping their children cope with the recent death of a parent.

The sample of participants varied on many family and personal characteristics and no attempt was made to obtain a "representative" group of children. Having rich and varied examples of the phenomenon is characteristic of phenomenological research (Polkinghorne, 1983). The main criteria were that the parent have or had cancer, and that both parents and child agreed to participate. All of the children who were bereaved had a parent die from cancer up to five months prior to the first interview. One child whose parent was cured of cervical cancer was included in the sample because he provided many retrospective insights deemed useful for the purposes of this study. Ten of the children were female, thirteen were male. For six of the children, the ill parent was the father, and for seventeen the ill parent was the mother. Metastatic breast disease was the cancer most common to the group of parents (seven cases), but there were also three cases of lung cancer and one case each of cervical cancer, sarcoma, myeloma, and leukemia. Seven of the parents were recently deceased, three were in the terminal phase of their illness, one was considered a cure, and the others (four cases) were on a low, downwardly spiralling course, where death was not predictable in terms of weeks or months.

In Table 1, a summary is presented of the sex, ages, and sibling status (number of siblings, and birth order of child) of the participating children, and the marital status, sex, type of cancer, and stage of illness of their parents. The names used for the purposes of this table, and throughout the body of the dissertation, are fictitious.

Table 1

Identities of Children and Their Parents

Child			Parent				Siblings	
Name	Sex	Age*	Sex	Marital status	Cancer type	Illness status	No. of	Birth order
A. Patricia	F	3	M	married	leukemia	deceased, 2 mos.	0	1
B. Melanie	F	3	F	married	breast	deceased, 1 mo.	1	2
C. Christine	F	4	F	married	myeloma	2nd remission	1	2
D. Dawn	F	5	F	single	breast	deceased, 2 wks.	2	3
E. Mickey	M	6	M	married	breast	deceased, 1 mo.	1	1
F. Don	M	6	F	married	breast	terminal	3	4
G. Joey	M	6	F	divorced	breast	1st remission	2	3
H. Peter	M	7	M	married	myeloma	2nd remission	1	1
I. Mark	M	8	F	married	sarcoma	2nd relapse	2	1
J. Stephanie	F	8	F	married	breast	2nd relapse	2	3
K. Tina	F	8	F	married	breast	deceased, 3 mos.	1	2
L. Sam	M	8	F	Married	breast	terminal	1	2
M. Karen	F	9	F	Married	breast	terminal	1	1

N.	Marianne	F	9	F	Separated	breast	deceased, 2 wks.	2	2
O.	Ricky	M	9	M	Married	lung	terminal	3**	4
P.	Elizabeth	F	10	F	Separated	breast	1st remission	0	1
Q.	Jeremy	M	11	M	Married	lung	deceased, 5 mos.	1	2
R.	Steven	M	11	F	Married	lung	deceased, 2 mos.	0	1
S.	Darryl	M	12	F	Divorced	breast	1st remission	2	2
T.	Cindy	F	13	M	Married	lung	deceased, 5 mos.	1	1
U.	Tom	M	13	F	Married	breast	deceased, 3 mos.	1	1
V.	Jerry	M	14	F	Divorced	breast	1st remission	2	1
W.	Stan	M	14	F	Single	cervical	cure	0	1

Note. * = age to nearest year
** = step siblings

Generating Data

> The less life experience the phenomenologist has developed, the more crucial it is that one gains the experiential understanding from extensive and time consuming field work: interviewing, playing, talking with subjects, case studies, participatory work, and so forth. For example, one gains real life experiences about children not by observing them from a distance by way of test instruments, or through a one-way mirror, but by living with them, striving for the kind of contact and dialogue that helps us to understand what a certain experience is like for children. (Van Manen, 1984, pp. 50-51)

I contacted the parents by telephone to arrange a time in which I could have at least one hour with the parents and one hour with each of the children. Many of the interviews were conducted on weekends so that the children would be alert rather than tired after a full day of school. The interviews were held in the homes of the participating families for the family's convenience. This allowed the researcher more of an opportunity to understand the child's experience of living with parental cancer. In three cases the interviews were held outside of the participants' homes at the family's request (In one instance the father was seriously ill in hospital and in the other situations the families lived out of town). Two of these interviews were held in the hospital and one child came with her mother to the researcher's home.

After the details of the study were explained to all members of the family, an opportunity was given to ask questions, and then the parents and children signed separate consent forms (see Appendix A). The children were asked to complete a couple of tasks in the privacy of their bedrooms. Children from the same family were encouraged to work in separate rooms so as not to influence each other's responses. During the time it took the children to finish the tasks (approximately 45 minutes) the parents were interviewed. They were asked to address their experience of living with cancer (their spouses or their own) before structured areas of inquiry were pursued (see Appendix B for parent interview schedule).

Interview Tasks

The tasks the children were asked to complete were structured in a way which ensured that their responses would be a direct reflection of their experience of parental cancer. The tasks--puppet play, a story about cancer, drawings--were adapted to the age and personal interests of each child. The youngest children were encouraged to play out themes with puppets they chose from a collection of human and animal puppets. Typically, the children would include me in their play so that I was both a participant and an observer.

Children seven years and older wrote stories about cancer, except in a few cases where the children preferred to talk instead. The task was to write a story about cancer--what it meant to him/her (the facts, their feelings, and thoughts).

I designed the temporal continuum drawing technique to explore the child's world at various times during the parent's illness. Each child was instructed to draw four pictures of himself/herself, alone or with others (parents, siblings, friends). The first picture was to portray the time at which the child became aware of the parent's diagnosis and the fourth picture was to portray the child's present situation, in general. If the child was too young at the time of the parent's diagnosis to remember the experience s/he was asked to draw what it might have been like. The second and third pictures were to depict any important times in between and these could have been "good times, bad times, fun times, sad or mad times." "The child's decision about what to draw and how to draw it frequently provides a clear representation of his impressions that go unexpressed on the conscious level. . .A child records in his extemporaneous drawings his unverbalized feelings and thoughts" (Firth, cited in Kubler-Ross, 1981, pp. 65-66). Some of the youngest children had difficulty with the concept of the temporal continuum drawing task and they were encouraged to draw whatever they wanted to draw. Much of what the children drew was a function of their recollections: "Recollection refers to that function of memory which enables us to bring into awareness events most intimately part of our history. Recollections have about them the quality of 'meness'" (Kuhns, 1970, p. 83). It was this "meness" that I was trying to delve into and understand for each child.

Children's Interview

The drawings and story provided the foundation and direction for the initial interview. In all of the home interviews I was invited by the child into his/her bedroom. Immediately I was shown special and favoured objects. We talked about the child's hobbies and friends and I took my cues from posters on the walls, photographs, memorabilia, and toys scattered through the room. After we had established a rapport (usually about 20 minutes) I asked the child to explain the first drawing to me. In instances where the child could not do this, I asked him or her to "Tell me a story about the first picture." Dialoguing about each of the four drawings, and about the child's story, kept our conversation focused on their experience of living with parental cancer. Once the drawings and story had been discussed, and conversation started straying onto other matters (what was on T.V. at 7:00 p.m., for example), we terminated the interview. At the end of the interview I recapitulated our interview (privately with the child) and had the child confirm whether or not I was understanding his/her experience. I met with the first eight children for a second interview. In the interim, I transcribed the tape from our first interview and made a list of all the statements which were pertinent to the phenomenon. I then interpreted what I understood these statements to mean. I reviewed the transcription, the drawings, and the story for details which were previously unaddressed or still unclear to me. During the second interview, I asked the child about how things had been for him/her since our interview, and then I proceeded to seek clarification and validation for my interpretations. For example, I asked eight-year-old Mark: "Was the reason you were asking me all about Terry Fox because he had cancer, and if you could learn more about Terry Fox you would understand more about your mom's cancer?" He responded "yes" which validated my interpretations of his intended meaning.

By making follow-up phone calls to parents and/or children two weeks after our second interview, I could check on how the family was responding to my intervention in their lives. All reports were favourable.

Interpretation of the Data

"Phenomenological research requires not only the description and reconstruction of experiential data but also the critical and reflexive analysis of it" (Wood, 1982, p. 74). Following now is an outline of the stages I proceeded through to critically and reflexively interpret my data.

In phenomenological analysis the researcher searches for common themes in the transcribed material and then uses written language to capture the essence of these themes. In the analysis phase itself: "the purpose is to discover the moments common to all individual experiences of the same kind" (Van Kaam, 1966, p. 339). As Baritt and his colleagues (1984) purport, there is no fixed formula for phenomenological analysis, the researcher must design methods which suit the data collected: "There is no right or wrong about any of this. We are trying to use our language to understand and appreciate the meaning of experience for other people. Some do that more insightfully than others. We claim no special powers" (p. 7).

Data analysis is an ongoing process in phenomenological research and proceeds throughout the data collection process. For example, in the previous section on data collection, it was demonstrated that the initial interpretations were made and validation for them was sought during what was essentially the data collection phase of the research. It is during the post-interview stage of the research, however, that the researcher concentrates most on analysis and interpretation. The formal data analysis phase is an opportunity to create some distance between oneself as researcher and the participant, in order to see the data from a wider perspective. The process entails an effort to formally identify themes as they are suggested by the data (children's words, drawings, and stories). The seven steps of data analysis used in this study are based on a compilation of suggestions from the work of several phenomenological writers (Baritt *et al*., 1984; Colaizzi, 1979; Polkinghorne, 1983; Van Manen, 1984).

Stages of Data Analysis

1. I transcribed the tape recordings from all thirty-one interviews. These transcriptions, my participant observation notes from each interview, the children's drawings and stories, and my "research log"[7] all comprised my recorded experiential data.
2. I read and reread all the childrens' descriptions, and the other experiential data, to begin to make sense out of them.
3. I read the transcriptions line by line and I underlined phrases and sentences which struck me as being essential to the phenomenon. This procedure is known as *"extracting significant statements"* (Colaizzi, 1979) and as "highlighting" (Van Manen, 1984).
4. I tried to spell out the meaning of each significant statement known as *"formulating meanings"* (Colaizzi, 1979). In cases where significant statements had not been taken back to the children to be validated, I used "creative insight" to make the jump from

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[7] I documented my perceptions, feelings, and thoughts in a diary as I reflected on each interview.

what the children said to what they meant (Colaizzi, 1979). I repeated this step with the experiential recorded data from each child. In reading and rereading the significant statements I began to find clusters of these formulated meanings which formed core themes, themes that appeared to penetrate the "essence" of each child's experience. The essence of the phenomenon has been reached when the lived experience of the child is revealed to us in a way that we can grasp the nature and significance of the experience in a previously unseen way (Van Manen, 1984).

5. I selected out other significant details from the children's drawings, and from the other experiential data (observations, research log), that also formed or supported themes.
6. I described the children's experience using the core themes as guideposts. "To take a fixed language and re-create the dynamic process of human life so that a child whom you have known and cared about 'lives' for the reader as s/he lives for you is a painstaking process" (Wood, 1983, p. 76). I constantly reflected on my writing and on the original data so that my descriptions became a true reflection of these children's experience of living with parental cancer.
7. In the final step I referred the descriptions back to the original data to validate them; to check if there was anything contained in the data that wasn't accounted for in the descriptions, or anything proposed in the descriptions that was not implied in the original protocols. The descriptions were embellished with quotations from the interviews with the children, and with samples of their drawings and stories. The transcriptions, stories, and drawings were viewed and reviewed, read and reread, many times during the course of research.

"Bits of our lives surely remain open to analysis, but the totality of a single emerging soul ultimately defies interpretation and begs, instead for the right to be heard" (Cottle, 1972, p. 52). The lives of the child participants were filled with far more depth and complexity than I could ever convey through words. To provide an understanding of the steps of analysis and at the same time introduce the reader to three child participants, three case presentations follow the descriptions of the themes. In this way, the reader can grasp a little more of what the individual world of a few of these children was like.

Interpreting Children's Drawings

The temporal continuum drawing technique was devised as a means of providing the children with some direction for expressing thoughts and feelings about the experience of living with cancer in a parent. The drawings were used mainly to generate dialogue and communication. As the children spoke about each of the four drawings (most children drew four, although some drew more or less) the meanings they intended to express to me through them began to emerge. In this sense my interpretations were based on a kind of mutual understanding as described by Merleau-Ponty (1973) and McNuff (1976):

> It's a question of suggestiveness, of whether (the interpretation) seems to fit both your sense of what is going on and, of course, the sense of the person who has made the production. If somehow that works and enables the two people to understand themselves on paper, or between themselves as two human beings. That's what it's all about. (p. 72)

In agreement, Merleau-Ponty views drawing interpretation as a process in which the child's attempt at expression must be understood "precisely as the juncture between he who perceives and the perceived" (Merleau-Ponty, cited in Sardello, 1974, p. 408). In this way, drawing interpretation maintains the same "fusion of horizons" between researcher and participant which takes place during the research interview.

Since drawings of young children are self-projections, in that they reveal feelings that otherwise remain unexpressed and thoughts that go unspoken, one may detect and interpret deeper levels of meaning in them. Valid depth interpretations, however, are not possible without knowledge of how children express themselves graphically and without training in drawing interpretation. The interpretations I have made in this study are based on my years of accumulated experience with children and their drawings. My background includes: teaching school-aged children drawing and painting, working in the area of art therapy, using drawings as diagnostic aids with children in psychiatric and clinical settings, and training in projective testing with children and adults.

In the case studies, interpretations are made of the children's thoughts and feelings based on their drawings. The rationale, and some empirical support for many of these kinds of interpretations, can be found in work by Buck (1948), Burns (1972), Di Leo (1970; 1973), Kellog (1969), Lewis and Greene (1983), Machover (1949), and in Schildkrout, Shenker, and Sonnenblick (1972). The interpretations I made based on what I know from the literature and from personal experience, were synthesized with what I learned about each child, his/her family, and what the child expressed verbally.

We can learn from a child's choice of subject, preference for a particular colour, use of space and shading, the way images are placed on the page, the way in which lines are drawn, the details they decide to include or prefer to leave out or exaggerate (Lewis & Greene, 1983). Once one has learned to identify the hidden language of drawings, it becomes possible to better understand a child's dreams and fears, hopes and despairs, conflicts and confusions.

Often there is no final interpretation about what the child means to say or what s/he is about: "This is a field where ambiguity and irony, inconsistency and perplexity, are not only the rule, but ought to be desireable" (McNuff, 1976, p. 129). For the purposes of the study, the interpretation of children's drawings are only one part of a comprehensive evaluation process, and only one person's interpretation.

IV. PRESENTATION OF THEMES AND CASE STUDIES

At this point in a research study one would expect a presentation of supra-ordinate categories to organize the findings. However, "categories assigned for the purpose of universal meaning are in the consciousness of the theorist, not part of the self-understanding of the agents being studied" (Sullivan, 1979, p. 92). The aim of the study was to present the children's sense of the world without making them answerable to structures imposed by an adult researcher. No "a priori" structures have been proposed, doing so would have severed the link with the intentions and feelings of the participants and would be anti-phenomenological. In this chapter, as in previous chapters, an attempt has been made to resist conceptual articulation.

Instead, the data presented are descriptions and interpretations of aspects of the childhood phenomenon "living with parental cancer." I was able to identify eighteen common themes in my interpretations of the children's statements about parental cancer. By "common" I do not mean that each child gave evidence of every theme in his/her interview. Rather, I was able to find common patterns of meaning across several of the children's statements and these patterns made sense to me as comments on the experience of "living with parental cancer." The eighteen themes provide a comprehensive, though not exhaustive delineation of the phenomenon: "A phenomenological description is only one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer description" (Van Manen, 1984, p. 40).

Chapter four begins with a theme which is a statement on how participating children initially responded to the inte[illegible] the interviewer, and to the interview topic, in particular (see "Responding and No[illegible]onding to [illegible]s"). I open with this section to demonstrate, that even though these children [illegible]ch, so deeply, so eloquently; and even though each and every one of them value[illegible] experience in the end (see "Benefitting from Interviews"), at the outset, many were reluctant to participate, and a few even averse to doing so (even after they had given their formal consent). This I believe to be one of the more important findings with strong implications for research and practice, and so I present it first.

The second theme, "Communicating Through Symbols and Metaphors" is a description of the type of indirect communication that characterized the spoken and unspoken dialogue during the interviews. This theme is given primacy for its very strong implications for practical work with children of cancer patients, and with children in difficult circumstances in general. It is also important as a "megatheme" in that the child's use of symbols surfaces in the discussion of many other themes.

The children's social, emotional, and conceptual worlds while a parent has cancer and also how they manage to cope and adapt are revealed through the remaining sixteen themes. Quotations from the protocols and samples of the children's drawings and stories are used to vitalize and substantiate the themes. A listing of all eighteen themes is presented in Table 2. Each theme title has two components: the first is my description of the theme; the second is a selected quote from a child which captures the essence of the theme. The section concludes with a summary description of the themes.

Children of different ages, personalities, and family backgrounds express many of the same experiences, and may express them in similar or different ways. But the experiences that are uniquely their own are still valid expressions of the phenomenon. To highlight both the unique and common experiences of the participants, three cases are individually presented. Each case includes some information on the family background of the child, interview dialogue with interpretations, the child's drawings and / or story about cancer, along with a summary and discussion. The case presentations end with a summary which compares and contrasts the three cases.

Table 2

Presentation of Themes

1. Responding and Not Responding to Interviews
2. Communicating Through Symbols and Metaphor
3. Being Parental
4. Feeling Different From Peers
5. Sustaining the Symptoms
6. Being Confused About Cancer and Its Treatments
7. Obtaining Information About Cancer
8. Experiencing Fear and Anxiety
9. Feeling Angry
10. Enduring Deep and Painful Sadness
11. Mourning Past, Present, and Future Losses
12. Adapting to Changes in Daily Living
13. Making a Connection Between Life and Death
14. Looking At the Lighter and Brighter Sides
15. Resorting to Internal Dialogue
16. Seeking Refuge in Activity and Fantasy
17. Advising Other Children of Cancer Patients
18. Benefitting From Interviews

A. Presentation of Themes

Theme 1. Responding And Not Responding To Interviews: "I Have an Earache"

The children s responses to my initial contact with them were reflections of how the topic of cancer was broached in their homes and has implications for how an outsider--teacher, counsellor, family friend--would be received should s/he attempt to discuss the parent s cancer with the child. The youngest children (three to six-year olds) were excited by participating in the research and enjoyed colouring, playing with puppets, and they especially enjoyed playing with the pocket tape-recorder. Don went out into the hallway of the hospital to secretly "catch the voices" of unknowing hospital staff. These children were keen to draw their experiences but were less enthusiastic about discussing them. They were excited about talking to me but seemed disinterested in speaking at any length about their parent s illness, impending or recent death, or were unable to do so. For a couple of children their lack of enthusiasm seemed to stem from a discomfort with the topic as manifested by their overall anxiety and "silly talk" whenever the conversation was directed to elaborating on cancer-related issues. For all of the younger children, their short attention spans, boredom and impatience with the repetition of the topic, limited discussion of the phenomenon. Don feigned earaches every time he was encouraged to talk more about his mother's terminal illness. To establish rapport with Don, I played "X's and O's," among other games, with him. He maintained total control throughout our game play and would rarely allow me to put my crayon to the paper. Losing control of the game meant giving me an opportunity to take control and to broach the dreaded topic with him. The best clues to his world, and to the worlds of all the three to six-year old children, were in the symbolic nature of his drawings and play.

The older children (seven- to fourteen-year olds), too, immediately retreated to the privacy of their bedrooms and eagerly got underway with the research tasks. Once they were done they took me into their private places and began sharing their favorite things with me--dolls, photographs, new clothes, and toys. Stephanie (eight years) brought out two boxes of miscellaneous objects to show me which she had given her mother for a "welcome home from hospital" party and for her mother's birthday. Tina "adopted" me as her mother for a short while showing me her fancy new dresses, wanting me to put ribbons in her hair. She was initially reluctant to engage in conversation about her mom and cancer. By our next meeting, however, she had a Valentine for me and her words came much more readily on subjects related to her mother s cancer. Darryl, who initially agreed to complete the tasks, presented me with the drawings in Figure 1 and a story which read "Cancer is a malfunction of cells. It causes a lot of pain." It was unclear whether his story and drawings were eflection of the quiet type of person he is, or whether he was indeed reluctant (or even resentful of having to) to talk about his mother s illness. It was very difficult to strike up a rapport with Darryl. The figures in his drawings are uniform and small, his description of them short and evasive. His replies to any inquiries were abrupt. I was reluctant to force myself into his private world by questioning him, but I did. After about an hour with Darryl, it became clear that he was a quiet type of person and he was reluctant about discussing the painful issue of his mother s illness. Once he trusted me, his defenses lifted, he enjoyed and sought comfort in talking about his situation.

Steven, too, had difficulty in the initial part of our interview. His father had told him that I was an art teacher (which is something I had communicated over the phone when his dad told me of Steven s artistic interests). Although Steven knew the actual intent of my visit, in his extreme anxiousness, he postponed any discussion of his mother by showing me his sketchbooks of drawings and by having me draw for him. In two other situations the children were confused about my professional role which complicated the onset of our visit. Stephanie thought that I was a nurse and would ask only medical questions and Tom thought that I was his dad's girlfriend: "I thought you were my dad s girlfriend and he was going to introduce us and you were going to get married and that would be fun!".

After the initial confusions were clarified, and the children became comfortable with my presence, they began to share openly and unendingly their deep, as yet unshared, feelings about living with their parent s cancer. They had already communicated one message. While some were overwhelmed with excitement at having someone to talk to about their experience, others found that they had covered up for so long that it was difficult to share, even though deep down they wanted to. Some were too frightened to share and still others had been misled by their parents about my intentions; their parents too, were afraid for me to have their children speak about their painful experience.

Figure 1. Darryl s drawings.

a. "Mom telling me that she has cancer--happy."
b. "Me with my friends--happy."
c. "Me with my friends--still happy."
d. "Me and my family--happy."

Theme 2. Communicating Through Symbols and Metaphors: "Acid Eats Through Things"

By attending to what the children were communicating through their symbolic and metaphorical words and images, a wealth of information was collected which could be integrated with information communicated through more direct means.

Symbols

In reviewing some contemporary issues related to cancer in Chapter I, I focused on the cancer legend: a collection of "myths" and misunderstandings that characterize adult views about cancer. When there is anything beyond the range of our understanding--anomalies of nature, unexplored realms--or something which is emotionally overwhelming, our naive perceptions take over. When something is unknown to us and it does not fit into our structured perceptions of the world, symbolism begins to operate. A symbol is the best possible expression of what is unknown to us (Jung, 1961). Adults and children alike employ symbolic language when attempting to articulate what they know and do not know about cancer. Because there are innumerable things beyond the range of a young child's understanding, and because s/he is just beginning to master conventional language with its many nuances, s/he employs symbols with more regularity than adults. The word "cancer" itself has become a symbol for the children in this study like it has for their parents. The definition of symbol makes this point very clear: "an image which embodies a web of interrelated meanings or which evokes a complex of emotions"[1]. To the children, in this study for example, cancer is a symbol of danger, destruction pain and suffering, the end of the happiness of everyday life, uncertainty and ambiguity, all of which evoke sadness, anger, guilt, fear, and anxiety.

In the world of symbols, development proceeds backwards; the adult regresses. In Jungian psychology, the analysands (adult patients) attempt to recover the adult's original ways of perceiving the world as a child. In symbolism it is the very simple elements that have the greatest impact and as we learn conventional ways of seeing and labelling the world we lose our naive, immediate perceptions. The symbols adults use are often

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[1] New Webster's Dictionary. Deluxe Encyclopedic Edition. New York: Delar Publishing Co., Inc., 1984, p. 994.

unconscious symbols[9], while the verbal symbols children use are often conscious with manifestly intended meaning.

Symbology is the art of interpreting symbols. To interpret children's symbols (those used in speech or drawings) one needs: an understanding of the child whose language or drawing is being interpreted, knowledge of how children present themselves linguistically, graphically, and projectively; and an intuitive sense based on both a natural skill and one which is derived from having accumulated experience with children. Jung (1964) supports these notions: "Intuition is most indispensible in the interpretation of symbols. . .When we attempt to understand symbols, we are not only confronted with the symbol itself, but we are brought up against the wholeness

When interviewing a child with the intent of understanding his/her symbol, I ask, what does this (symbol) mean to you?" I then ask myself, "what could the symbol mean to him or her?" Finally I ask "What has the symbol meant historically for others (archetypically) and what has this symbol meant for other children?" The general, archetypal symbolic interpretations become useful in enriching the interpretation when they fit with what I know of the child, and with what the child himself/herself has expressed. There were few common symbols for cancer amongst the children. Each child had their own individual symbol or metaphor to express cancer, or to articulate other elements of the parental cancer experience.

<u>An example</u>. Since communication through symbol is basic to each drawing and to many of the verbal statements of each child, examples are replete throughout the presentation of themes. An example will be given now of how one child's symbols were identified and interpreted in his drawing. One of Don's first session drawings appears in Figure 2. It is very unusual for young children to avoid drawing figures in their picture (Di Leo, 1973) and this is a cue to the fact that six-year old Don is struggling with difficulty in his personal relationships; his mother is dying. He has emphasized heaven in the top of his drawing with dots, dots often being representative of anxiety. The four penguins[10] seem to represent he and his siblings, the reindeer and his dog, his parents. They are surrounded

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[9] Meanings which lie at deeper levels of understanding of which they themselves are not consciously aware.

[10] His choice of penguins are interesting since they are animals that can live in two environments and he has been struggling with his own concerns of mother living in heaven and on earth.

by a cliff[11] (a symbol of danger) beyond which there is water and he, the youngest, is closest to the edge. They are all walking towards the hole in the ice--dangerous and unknown territory. The family is walking on "thin ice" and they could fall through at any moment. There is a bird, a spiritual symbol, flying above them.

The bird as a symbol incorporates simple elements of spirituality like "up high" and airiness; proximity to the sun, a source of light; and freedom from earth. The bird escapes the limits of the human body as does the spirit; the bird is an archetype of transcendence in Jungian psychology (Jung, 1964). Etymologically symbol means "thrown together."[12] All the descriptors above are not spirituality, but "thrown together" they give us a sense of what spirituality is.

Don was very much concerned with the spiritual life after death and constantly questioned his parents about heaven. Including a bird in his drawing is one more reflection of his concern. He drew a picture for mom to take to God. He would see them both later, or so he hoped.

Metaphors

A metaphor is defined as a "figure of speech in which a name, action, or descriptive term characteristic of one object is applied to another to suggest a likeness between them."[13] Metaphors are important because of their ability to provide alternative or new ways of "seeing." Many metaphors were used by the children in their dialogue and that is why one of these metaphors, shadow, has been given precedence in the title of the dissertation. The children did not directly say "cancer is like acid" or "my life is like a windstorm," but rather their metaphors emerged in the course of our conversation. For example, two children used flowers as metaphors for what was happening to their parents. Christine (four years) spoke of a "flower growing and kind of dying but it's not" (see Case #1 for the complete dialogue). It became clear as our discussion unfolded that she was indeed speaking of her father who may appear extremely ill (wilted) one day and healthy (fresh) another, but whose death was nonetheless approaching. She was telling me that he was "kind of dying." Dawn was obviously speaking of her bereft father when she

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[11] Water is also reminiscent of birth and the intrauterine environment, which is one of many references to "birth" made by the youngest children. See Theme 13: "Making a Connection Between Birth and Death."

[12] From the root syn "together" and ballein "to throw"; Funk & Wagnall's Standard College Dictionary. New York:

[13] Scribner-Bantam English Dictionary. New York: Bantam Books, 1979, p. 568.

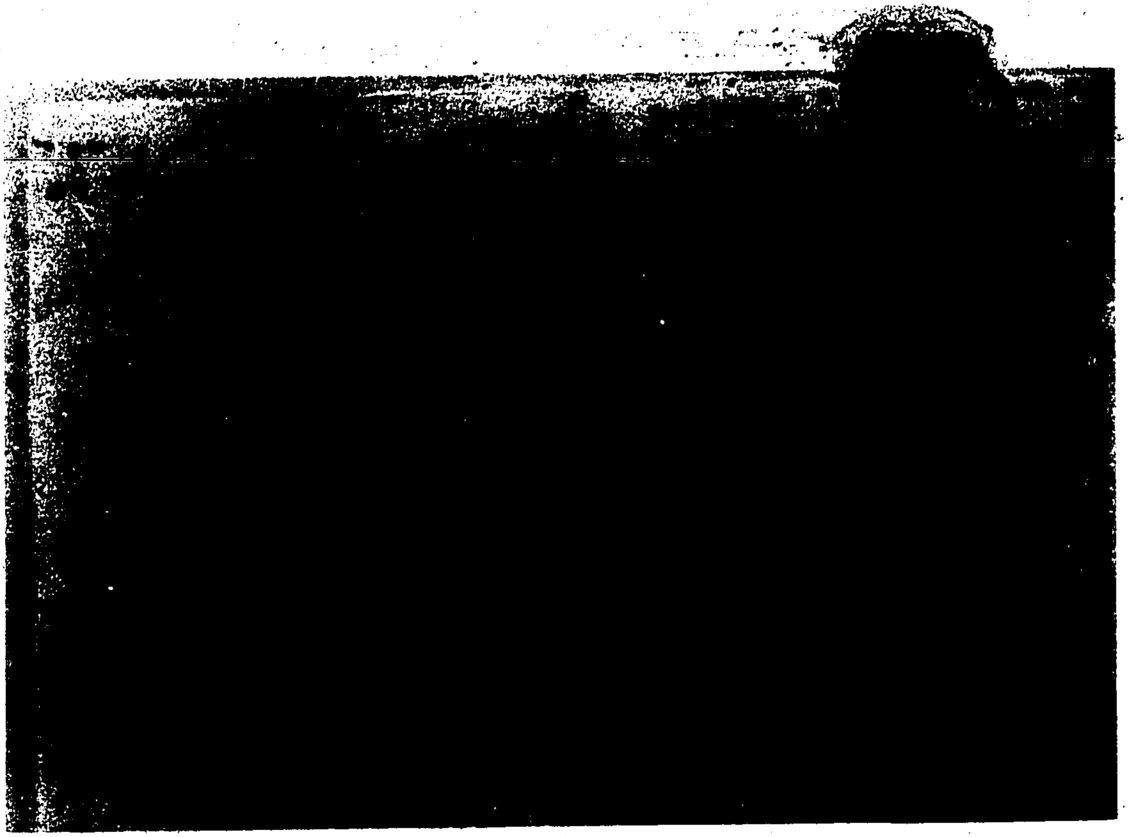

Figure 2. Don's first session drawing

remarked "the flower is crying 'cause the house blew down.'" Her father was crying and for him, like for her, it felt like the whole house blew down after his wife's death. A couple of children spoke of Terry Fox (eight-year olds Mark and Stephanie), metaphorically representing their understanding about cancer and its fatal implications for each of their sick parents. Terry Fox had cancer and he died, so would their mothers (see Case #2).

Nine-year old Sam used the metaphor of windstorm for how he was feeling about his mother's prolonged disease process and impending death. "I wish the windstorm would go away and it would be a nice day," he said in response to his drawing of a tornado. Other children gave metaphors for cancer itself. Christine (four years) spoke of "acid" in a way which made it [illegible]ous that she was expressing her understanding of cancer: "Acid eats through thing[illegible] also spoke of "poison garbage" voicing her view that cancer was both dangerous and "useless" (see Case #1). Steven (eleven years), knowledgeable about the cancer disease process, spoke of "bugs creeping through his food" just as cancerous cells crept through his mother's body. Elizabeth (ten years) drew a picture of cancer and described it as a "birthmark". A birth mark is a mark of birth, while cancer, in her view, was a mark of death. The metaphors the children developed to describe cancer, and their experience of it, reflected their knowledge of its dangerous, destructive, and potentially fatal properties.

The most potent metaphor for me in that it both communicated and embodied so much of the phenomenon (what all the children described as their experience of parental cancer) was the metaphor of "shadow" offered by eleven-year old Steven. "Living in the shadow of mom's death" says so much in so few words (refer back to "Prologue").

Listening to and dialoguing spontaneously with the children were important things to do during the interview. However, in reading and rereading the transcripts following the interview, it was important to attend to symbolic and less direct means by which the children were communicating. Many of the intended meanings of the metaphors and symbols could be understood during our dialogue; some could not. The method of understanding the "recorded experiential data" was indeed a reflexive interpretive process. I had to read and reread [illegible] and review the children's words and drawings over and over again. Furthermore, what became obvious in retrospect was often obscure in the immediacy of the situation. The implications for the way in which the child communicates about the parental cancer experience (that is, through symbol and metaphor in addition to more direct means) will be addressed in the next chapter.

The first two themes ("Responding and Not Responding To Being Interviewed" and "Communicating Through Symbols and Metaphors") are essentially "megathemes" in that they have intimations for the sixteen remaining themes. For example, the children all eventually responded openly and uninhibitedly to the interview and so it can be assumed that the themes which emerged are representative of the phenomenon. Had the children felt reserved and constrained throughout the interviews, much less of the phenomenon would have been available to me. Similarly, had I not considered each child's use of symbol and metaphor, much of the parental cancer experience would have been left untapped. Secondly, since the child's symbolic and metaphorical communication characterizes much of their communication about the phenomenon, the discussion of the remaining themes contains many references to symbolic communication.

Theme 3. Being Parental: "It's Okay To See You Crying, We Cry, Too"

The children became "parental" in varying degrees during their parent's illness. They became what some researchers call "pseudoparents," a term which refers to the tendency for children to become caregivers when a family member has cancer.

There are many aspects of the theme "Being Parental" which emerged during the interviews. First the children demonstrated a deep compassion for, and understanding of, their parents. When parents were unable to cater to their needs, the children understood that it was because the ill parent needed care and attention. Instead of being nurtured and taken care of, the children tried to nurture their ill or distressed parent:

> She just sits there and cries. I sort of cuddle up to her. . . And help her along. . .comfort her. (Jerry, thirteen)[14]

> Well, after my mom got sick I kind of feel I have to be here to help her. . .so I

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[14] the age of the child, to the nearest year

> stay home. (Stan, fourteen)

Elizabeth's (age ten) story exemplifies the intense desire all of these children had to help their parents (the significant statements are underlined):

> I think cancer is a big sad thing I do! I have been good to my mom. I hope it will be like that all the time. I do think it will help. I do get sad in bed thinking I am all well and my mom is sick in bed. I do hope my mom will not be dead. I am sad, too sad, I think sometimes. I have hope for my mom and all the time will. And try to help. And I am scared and sorry. I am trying to be helpful and I am trying. I love my mom. And she loves me. And I hope I can help. And I think I am. I hope so. I hate cancer and I hope I don't get it I do.

The low frustration tolerance and moodiness of each parent was accepted by the children. They recognized that mom's crying, yelling, and demanding behaviour were a result of her pain and that dad's was because he missed mom while she was in hospital and especially once she was gone forever. They were extremely understanding:

> And then there's the "mad days" when it hurts so much she yells at us for the little things we do. (Darryl, twelve)
>
> I understand when she gets mad. I can tell that it hurts her a lot and that she has to let it out somehow. So usually it's us that she lets it out on. (Jerry, thirteen)
>
> The next closest person to them's feelings and temper changes. Well like she gets edgy fast now. . .Like every little thing she yells at me. (Cindy, thirteen)
>
> But I say he's (his father) mad 'cause mom passed away. (Tom, thirteen)
>
> I saw mom crying and she said she didn't know why she was crying. I said (to her mother) "maybe you were thinking about cancer without knowing you were thinking about it." (Karen, nine)
>
> I just said (to his mother) "it's okay to see you crying, we cry, too." (Sam, eight)

A state of mutual protection existed between the parents and children. The adults were not sure of what to say for fear of disturbing their children so they said nothing. The children modelled their parents' protective behaviour for they, too, were afraid of burdening their already grief-stricken parents. The children were aware of their parents' attempts at protecting them and they also recognized their parents' attempts at minimizing the severity of the situation:

> Then they went in their rooms 'cause they didn't want us to see them cry. (Karen, nine)
>
> Like I told her "I think you might die." and she said that she won't but I don't know if she won't. (Elizabeth, ten)
>
> But she seems to be getting okay. But you know I don't think she would really tell me 'cause she wouldn't want me to worry. (Stephanie, eight)

> She said "It's okay I'm not going to die, I'm just gonna' get real sick." That's not true. (Mark, seven)

Knowing how much emotional distress their parents were already undergoing because of the illness, the children would hide their sadness from their parents so as not to disturb them further:

> I never usually sit in the room. I always wanna' get out 'cause if I do sit there I'd just break out and that would make him feel worse. (Jeremy, eleven)

> I left the room 'cause I thought I was gonna' cry and I didn't want dad to see me. He'd worry about me and he's already got enough to worry about. (Ricky, nine)

The children refrained from questioning their parents about the details of cancer and the details of their illness in particular, for fear of irritating them:

> I didn't want to ask her about her cancer 'cause she was really sick and I would just aggravate her. (Stan, fourteen)

> If we talked about cancer it would just make her sicker. (Sam, eight)

The tendency for children to pseudoparent with all that being parental entails--nurturing, giving unconditional understanding, and caregiving; being protective, being perceptive in identifying the others concerns and feelings, being helpful in meeting needs--was an attempt to gain control in a situation where, in fact, they had very little control. They were trying to create some predictability for themselves while experiencing, as will be demonstrated in future themes, so much ambiguity, uncertainty, and unpredictability. The next theme describes the nature of the child-peer relationship during the parental cancer experience.

Theme 4. Feeling Different From Peers: "I Felt Like I Was a Freak or Something"

The children did not discuss their predicament and attendant feelings with their peers for three reasons. First, they could sense that open discussion of cancer was basically taboo:

> People try to keep cancer quiet and just ignore it hoping it will go away. Keeping it quiet doesn't help anybody but those who keep it quiet. (Cindy, thirteen)

> It's a bad thing cancer and people don't want to hear it. (Sam, seven)

> You're not supposed to talk about cancer. It upsets people when you bring it up in front of them. (Jeremy, eleven)

Second, they feared insensitive responses from their peers so they did not even broach the subject with them. And third, playing with peers was a welcomed reprieve from their stressful home life. Some children felt that being secretive would enable them to maintain a sense of normalcy in at least one area of their lives.

For the children seven years of age and older, choosing not to share the family secret tended to isolate them from their peers.

> At first I thought that I was the only kid that had their father in hospital. I felt like I was a freak or something. (Cindy, thirteen)

The children tended to become more emotionally mature and sensitive through their experience and were alarmed by the insensitivity of their peers. The children's peers, with their own misunderstandings and fears of cancer, did not know how to react--so either they did not, or they did so inappropriately. Nothing was more hurtful than some of the insensitive rumours and comments. Pity and special favours made the children feel even more separate and different.

> Most kids nowadays are pretty dumb. They say "what is that?" (he is referring to cancer) They act like a bunch of dopes. Even the smart ones. You have to experience it first. Most people I know they don't really care they just care about themselves. I'm the way I am and they're the way they are. (Stan, fourteen)
>
> And then I sometimes get mad 'cause they tease me at school. They say I probably killed my mom and all that. ...Because I'm different from them. 'Cause I don't have a mom and they do. (Tom, thirteen)
>
> Kathy, she said my mom was dead[13] and she didn't even know. (Tina, seven)
>
> They treat me special 'cause my mom had cancer. They (his friends) would say "Oh you can have this, you can have that." 'Cause they're all feeling sorry for me. . . .Well they always want to buy me stuff and that. I said "I got money I can buy myself stuff" and they always like being nice to me. . .Kind of made me mad. Everybody was pitying me. They're friends they're not supposed to pity me and all that stuff. . . .I prefer good friends. . . .To tell jokes, make me laugh and all that. (Tom, thirteen)

When encouraged to explain their situation to their peers following the initial interview, they did, and were surprised to find out how interested and caring their friends were. Stephanie (eight years) rallied the support of her friends to make a welcome home party for her mother.

The children trusted, or thought they could trust, peers who had endured similar experiences.

> I only talk to one friend. He's a real good friend. He had the same thing. . .And

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[13] before Tina's mom actually did die

> me and him would talk. . .And we just think about the positive and negative things people say. (Sam, nine)
>
> Maybe if I knew someone whose parent had cancer but I couldn't find out. But I'm shy so I wouldn't really ask. (Stan, fourteen)
>
> Not many people really know how serious it is unless they, themselves, have dealt with it or know someone who had it or died from it. (Cindy, thirteen)
>
> Jason understood. His auntie died from cancer. (Stephanie, eight)

The children had to contend with changes in the parent-child relationship, changes in their relationships with peers and were also subjected to societal taboos which changed how they interacted with members of society, in general.

Theme 5. Sustaining the Symptoms: "It's the Same Mom It's Just She Has No Hair!"

Pain was the disease characteristic that had the strongest and most pervasive impact on all of the children. Physical pain and suffering were things they, themselves, could relate to from personal experience. "I know what it's like to get needles," Elizabeth remarked. Children could not remain in the presence of their ill parent while his or her pain was intense:

> When I went to the hospital to visit my dad I always had to go somewheres else because I didn't like to see my dad suffer. (Ricky, nine)
>
> A few weeks before he died he was really yelling and screaming in pain and Cindy and I had to close the door. (Jeremy, eleven)

Pain and suffering were things they themselves feared most about dying.

Fatigue and immobility, experienced increasingly by their parents as the disease progressed, significantly affected the child-parent relationship. Activities and conversations with the ill parent were minimized until there were none at all:

> We couldn't do anything 'cause she was sleeping all the time and in pain. (Jeremy, eleven)
>
> I remember when my mom walked me to kindergarten then she couldn't do it 'cause she was sick. (Marianne, eight)
>
> I could talk to her but she couldn't talk to me 'cause the cancer spread to her voice box. (Steven, eleven)

The children would closely monitor the daily progress of their parents during relapses. Their mood would very much depend upon whether or not there was any noticeable sign of improvement in their parent's health. Small signs--father smiling, mother getting dressed in the morning or eating more, temporary cessation of back pain--were interpreted as indications that the parent would get well again.

> She ate quite a bit. She ate a whole watermelon. Then I felt better. (Tina, thirteen)

> Her back hurts only right now. I'm happy. She was always in her housecoat. Now she gets dressed. I feel better. (Stephanie, eight)

Dawn, five years, was happy whenever her mother yelled at her, a sign that she was getting better.

While discussing their parent's symptoms during the interviews, the children would mention their own physical complaints which included sunburn, stomach pain, colds, and recent injuries (concussion, for example). They seemed to want to understand and empathize with their parents. Three children had symptoms which paralleled those their parent was experiencing. Three-year old Patricia would limp around the house when she was two, Tina feared that she had cancer because she was losing some hair, and Stan had stomach pains. The youngest children created their own symptoms. They represented cancer by drawing dots all over the faces and bodies in the drawings of their sick parent (see Figures 3a and 3b) and Christine put round stickers all over a puppet she was playing with. Measles and chicken pox are symptoms they were familiar with from personal experience.

Even though individual children mentioned, in passing, many of the visible aspects of the disease (e.g., hair and weight loss, mastectomies, laryngitis, jaundice, physical aids including canes, wheelchairs, and prostheses) it seemed as though these were things they temporarily wrestled with and then passed off as having little, if any, significance in the parent-child relationship:

> Well I really didn't mind 'cause she had a kerchief on most of the time. Well, I said to myself "It's the same mom it's just that she's got no hair." I said "She's got the same thing for caring for us and that." So I really didn't mind. (Tom, thirteen)

> In the time from when my mother's cancer was detected to now I've noticed a change in my mother's physical appearance. . . .In the last two years my mother has physically changed. She has slimmed down and doesn't have the strength she used to. (Stan, fourteen)

[redacted]

[redacted]

Figure 3. Dawn's drawings.

First drawing:
a. Mommy with dots on her cheeks and arms
b. Dressing up for playschool
c. Mommy and a rainbow
d. "The mom's angry at the little girl."

Second drawing:
e. Mommy's birthday
f. Daddy crying 'cause mommy died
g. Flower crying 'cause the house blew down
h. Mommy with dots all over

Theme 6. Being Confused About Cancer and Its Treatments: "Medicine is Supposed To Make You Better"

The children offered their own views of disease etiology even when they had received the medical facts by the time of the first interview. They searched for the cause of the disease. Some children thought they, themselves, were responsible, some thought God was responsible while others thought the cancer was caught from someone else

> [I thought mom got cancer] by somebody else who had it. . . .I thought it was spreading the cancer. . .and it would be spreading through the whole family. (Mark, eight)
>
> It's my fault like when I play with him I could have played too rough and hit him in a spot that could have hurt him, could have caused cancer. I could have moved the cancer cells to another part of the body. (Jeremy, eleven)
>
> I thought that every time I made her mad it like kinda' got on her nerves and made it worse. (Tom, thirteen)
>
> I know God meant her to have cancer. He might want her to die. (Marianne, eight)

Other children thought something that their mother or father did as a child was responsible, and a few thought a virus or bacteria caused their parent's disease

> I always thought that there's always a seed in your body when you're a kid and sometimes something you do will make it break when you grow up, and that's how cancer starts. (Ricky, nine)
>
> How does cancer develop? Is it because you ate something? Or is it because you got a cut when you were little and all sorts of bacteria got in. (Cindy, thirteen)
>
> Cancer is a degenerative disease in which a virus attacks a human cell. (Steven, eleven)

The nature of the disease process was confusing for the children. They could not understand the history of relapses and remissions and why their parent could be disease free for a long period, seemingly cured, and then the disease would reappear. The pattern of relapses and remissions lead to expectancy of recovery following relapses; therefore death came as a shock even though the possibility had been considered.

> We thought she'd get better in a month or so and then it will be back the same. After a couple of months, then we thought she might be sick for a little bit long. Then after a year we knew she was really, really sick and we just helped her and everything 'till she'd get better, but she didn't. (Tom, thirteen)
>
> Well actually I'd like to know what kind of cancer my mom has? Do you know why I want to know "why"? Because she's always getting sick, right? First day she's sick next day she's not. First day she's sick, and it goes on. Then it's strange that when I was three-and-a-half and she had cancer, then until I was

> eight-years old it stopped. (Stephanie, eight)

> I'd like a miracle to happen. It happened, like when he had liver cancer, once they had a X-ray then there was liver cancer and then a few weeks later or so they had another X-ray and it was completely gone. Then it started again. (Jeremy, eleven)

The capricious nature of the disease process left the children living in limbo:

> Mom's in hospital and you don't know if she's gonna die or what, you know. I couldn't handle it. (Stan, fourteen)

> I'd think 'is daddy gonna live, is daddy gonna die?' (Jeremy, eleven)

> Is mom gonna live or die or what? (Elizabeth, ten)

> The doctor said there was a small chance she would live. So we didn't know what would happen 'til she died. (Mickey, six)

The children also questioned the nature of the treatment and could not understand why medication and procedures designed to restore health would cause so much unhealth in the short term, with no cure in the long term.

> And then I'd like to know why they have to use radiation because it makes a person's hair fall out and then it comes back anyways. . .the cancer. (Tom, thirteen)

> I thought medicine was supposed to make you better. Why is mom always sick after she has her chemotherapy? (Stephanie, eight)

> I thought pills make you better but my mom's hair fell out after she took them. (Mickey, six)

Theme 7. Obtaining Information About Cancer: "Terry Fox Had Cancer and He Died"

The children each knew of someone who had cancer and this formed the basis for how they viewed their parent's situation and how they reacted to it. These people served as "cancer models." Most of these models were people who had died of cancer. The youngest children spoke of aunts, uncles, grandparents, and other close relatives who they knew had cancer. The school-aged children had an extended network of cancer models which included peers (Marianne and Karen each had a friend who died of leukemia) and relatives of peers, characters on television programs, and, the most renowned model, Terry Fox. Inquiring about Terry Fox, for Stephanie and Mark, was a way of indirectly obtaining information about their parent's situation. During our interviews they would ask about the type of cancer he had, his symptoms and would compare the answers with what they knew of their parent's illness.

> Terry Fox had cancer and he died. What kind of cancer did he have? Why did they cut off his leg? (Tina, eight)

> Well my friend in my class, his auntie had cancer and she died in her sleep and that's why I'm scared. (Stephanie, eight)

> Yeah I've got an uncle that died and he had cancer. I think he had a tumour and he went to lift something and it just blew open. (Ricky, nine)

> I only know one person and he used to be my classmate and died of cancer. His name is Marcel. . . .Well I just felt sorry for him. Well I was sad about it cause he was a very good student and has funny jokes to tell the class. And one thing he always talked with a smile. Even though he has pain. . . .Every time I say a prayer in school I always think of him. . . .I just say that I wish he didn't die. That he could still be living. (Marianne, nine)

> Cause I saw this show that a little boy he got to go to his mom's funeral. His mom had cancer. Well he started to cry. That made me think that my mom might die 'cause she's got cancer. . . .But then the father told the little boy that she's very, very sick. My dad said my mom is very, very sick. That's why I'm really scared. (Stephanie, eight)

The oldest children extended their reference sources. They learned about the reality of their parent's situation from documentaries and news specials in addition to learning from relatives and friends:

> I'd have to say that most of the stuff I've learned about cancer I've learned on T.V. . . .the good parts and the bad parts. Like they show cures and new drugs. They tell you what they think of the disease. So it's almost like reading a book. Better, really. (Stan, fourteen)

> Well T.V. informs you 'cause I always watch these medical shows and everybody's talking about how bad cancer is. I think the way I perceived it was by what they say on T.V. (Cindy, thirteen)

The children were ambivalent about wanting information about cancer and about wanting to know their sick parent's feelings:

> Sometimes if I was really upset and I wanted to know if my mom was going to get better and I was wondering but I was scared to ask. (Sam, eight)

> I was afraid to ask 'cause I didn't know if the answer was going to be good or bad. (Tina, seven)

> I don't know how my mom's feeling but I'm afraid to know. What if she's sad? (Stephanie, seven)

Stephanie reluctantly asked for information through notes:

> I wrote her notes. . .I only wrote two. The first one said "I hope you understand that I don't understand about cancer." The second note said "Please come see me."

As long as the children did not know the facts of their parent's situation they could hope for the best; more frequently than not, however, they feared the worst--death.

The younger children understood cancer in terms of its symptomatology. To them cancer was a sickness, "mom's sore breast" or "lumps" and "a sickness which makes dad need canes." Many of the children reported learning about the state of their parent's health through overhearing conversations between their parents and doctors or family friends. In some instances parents made attempts to share the "facts," though they did not share the fatal implications until death was imminent in terms of days or weeks.

The oldest children had the most knowledge of cancer which they obtained from their experience with others who had cancer, from parents, and from documentaries. Their definitions about cancer reflected their understanding of many of the physical aspects of the disease and its treatment, and they stressed how rampant the disease is ("Hundreds of people die from cancer each year") and how serious. Steven's definition of cancer has already been presented (see "Cancer: A Definition, Chapter II). Here are Stan and Cindy's definitions, which are excerpts from their stories:

> Cancer is a degenerative disease in which a virus attacks a human cell and then the cell spreads the virus to other cells in a specific area such as: lung, breast, etcetera. If this disease is found in its early stages it can be drastically decimated. If that was to happen the person would be in remission. That does not mean the person is cured but that the disease has been decimated but it can build up again. Some of the kinds of cancers are lung, breast, skin, cervix, uterus, bone (Leukemia), rectum. (Stan, fourteen)

> Cancer is an uncontrollable disease that takes thousands of lives each year. It is a disease that most of the time is fatal. It destroys different organs in the human body. There are all sorts of treatments such as Kobolt, Kemotherapy, and radiation. These treatments do not cure it, but try and slow down the fast growing disease and get it under control. (Cindy, thirteen)

The older children (nine to fourteen years) had an understanding of many of the physical aspects of the disease and its treatment, and in their stories they stressed how rampant the disease is ("Hundreds of people die from cancer each year") and how serious.

Theme 8. Experiencing Fear and Anxiety: "I'm Afraid to Have Cancer"

Fear and anxiety, both latent and manifest, were expressed by all of the children. The children spoke of fears of the dark, being alone while parents went out and being alone permanently after parent died. They also feared relapse of cancer in their parent, developing cancer themselves, and death--their own, their sick or remaining parent's. Physical descriptions of feeling afraid included feeling "shakey," "cold," "nauseous," and having "stomach pains." Some of the older children were overwhelmed with anxiety during the times they would be alone thinking of their sick parent and described themselves as "being in a stupor," "unable to move," and "feeling numb." These feelings were most intense following diagnosis, after hearing word of a relapse or of death. Steven experienced an acute phobic reaction during the terminal phase of his mother's illness. He would not eat because there were "bugs" in his food. While discussing these symptoms with me, he exclaimed: "I was channelling all of my fears and anxieties about my mom's dying into seeing bugs!"

Their anxiety was chronic--becoming strongest at night and being suppressed to a "worry" during the day. Ricky (age nine) commented: "I worry about dad mostly all the time. I worry pretty alots." The children would worry most about their parent after diagnosis, after a relapse, and especially during the terminal phase. Even once a remission lasted for a number of months, the children would become fearful with any signs of illness. The children put on a brave front and sought comfort from their parents only when the feelings became overwhelming. Following are some of the reports of their fears and concerns:

> My mom said her other breast is starting to hurt and I get worried that it might have cancer in it, too. (Elizabeth, ten)
>
> I'm afraid to have cancer 'cause I'm afraid of suffering and I'm afraid of dying. (Jeremy, eleven)
>
> I think what am I going to do if my mom dies? (Karen, nine)
>
> I can't sleep 'cause I have bad dreams that mom is dancing with me. (Marianne, nine)
>
> I couldn't be by myself here at home you know. I was good up until a little bit before she died staying here alone but I couldn't after that. . .My dad couldn't stand it any longer 'cause I'd be terrified and all that. (Steven, eleven)

The fear experienced by these children is most poignantly illustrated in Steven's drawings (see Figure 4). He chose to draw four fearful situations. Fear is manifested in the sketchy line quality of his drawing, in the facial features he draws on his self portraits, and by the fact that he drew himself "alone" in all four drawings. He explained the first in his series of drawings with the following description (see Figure 4a):

> There's this family called the Rimby's and I guess you can say they take care of me until dad came home from work and this is the first time I went and I was scared. I didn't know what was going to happen. This the first time this has ever happened. The first time I've gone somewhere after school.

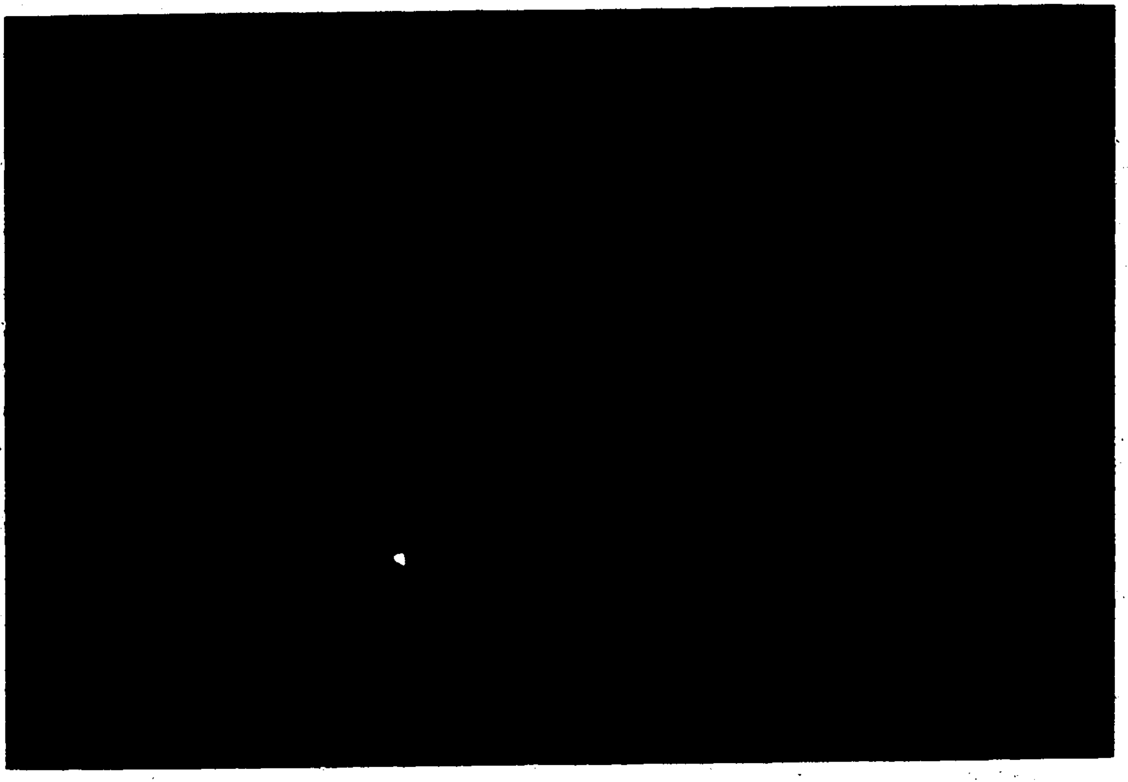

Figure 4. Steven's drawings.

a. First day at the Rimby's
b. Being hit by a snowball
c. Schultz and "a little guy" barking at Steven
d. "Living in the shadow of mom's death"

His explanation about the second drawing was (see figure 4b):

> And this one, again is at the Rimby's. Across their neighbors have this big dog Schultz, this one. And a little guy. . . .And the first time they just--and he can bark so loud. Schultz, the big one and I just was walking by and all of a sudden he went "Woof! Woof!"

And his remarks about the third drawing were (see Figure 4c).

> And this one here, it's just this kid from this hockey club. He threw a snowball at me. . .Because he's bigger and I'm a smaller, fat kid and he just wants to have dominance over smaller kids.

In his fourth drawing (see Figure 4d, a larger version appears at the beginning of the dissertation) he depicted himself as being overwhelmed while "living in the shadow of mom's death." His hands are pushing back the cancer--the word haunts him. His body is leaning back as though he is trying to avoid the experience of his mom's illness and subsequent death. There is attention to shadows everywhere, shadows seemingly a symbol of fear (he is terrified of the dark). His fear is associated with his unfamiliarity with the whole experience and he emphasizes that many "first" experiences were happening for him. His fear was also associated with feelings of vulnerability (as represented by his being attacked by dogs, snowballs, and cancer) and with the isolation that he felt.

Theme 9. Feeling Angry: "Why Couldn't It Be Someone Else?"

The children were angry that it had to be their parent who had to have cancer. They became angry at school and with friends when work or conversation would interfere with their need to think and daydream about their sick or deceased parent. Peter and Christine (siblings, ages four and seven) would shoplift and Joey threw temper tantrums. The older children admitted to displacing their anger onto teachers, peers, and extended family members. Some of the older children voiced their rage indirectly by speaking angrily about the neglect of the doctors during their parent's treatment and Stan (fourteen) spoke about how everything happened to his family because they were poor. Often their anger was directed inwardly in the form of depression as the children sought refuge in their bedrooms. Here are some of their remarks:

> I was mad 'cause it was my dad who had to have it. (Steven, eleven)
>
> Then at night I got mad. I thought why couldn't it be someone else? (Tom, thirteen)

> Why me? I always ask the question but I never get any answers. (Cindy, thirteen)
>
> I got so mad I got in a fight with my cousin. And I hit him over the head with a wrench. 'Cause I was mad. He wasn't even bothering me. I was just really mad. I'd think why did they invent dumb ol' cigarettes? Why didn't they just leave what it is--a plant? (Tom, thirteen)
>
> Usually I take it out on the teacher. (Jeremy, eleven)
>
> But I was angry, too. 'Cause it seems like people who have a lot of things in life, stuff never happens to them. . . .It just seems that the rich are all right and the poor everything always happens to them. (Stan, fourteen)

The children manifested the human tendency to search for a scapegoat. It was easier for them to blame other's rather than to accept that life is unpredictable and their own future uncertain.

Theme 10. Enduring Deep and Painful Sadness: "When I'm Sad I Feel Pain"

The children were understandably sad about their parent's diagnosis, suffering, changed family situation, and impending or recent death. Their sadness was manifested by the tears which they drew (see Figures 3, 5, and 9) but managed to contain (sometimes with difficulty) during the interview(s). Without exception all of the children related feelings of sadness.

> My first thoughts were sad when I heard my dad had cancer. I thought I'd never see him again. (Jeremy, eleven)
>
> I always had dreams about my mom suffering and I'd always want to cry. I'd wake up and cry. (Marianne, eight)
>
> I think about daddy in the night and then I couldn't sleep. I cried. (Patricia, three)
>
> When I feel sad I don't want to speak to anybody, you wanna get away from the world. (Ricky, nine)
>
> That's me and the gray represents sadness. (Cindy, thirteen; see Figure 5)

children related what they felt physically while they were experiencing the

> My body feels slow and I don't want to move my feet. (Jeremy, eleven)
>
> When I'm sad I get a funny feeling. . .pain. Up here in my heart. Kind of feels like you can't talk. (Tom, thirteen)
>
> When I'm sad I feel pain. . . .It's kind of a sickening feeling. It's something like if you put on a parka and maybe for three hours you stay in a hot room. It's a horrible feeling, really. (Steven, eleven)

Figure 5. Cindy's drawings.

a. Hearing about dad's diagnosis
b. The hospital
c. Dad's funeral
d. Mixed feelings at Christmas

Children would repress their sadness, not only out of fear of disturbing their parents, but out of a concern for how others would conceive of them. The children were influenced by societal and cultural norms which discourage any public display of weakness vulnerability, especially amongst males:

> I was afraid to cry at school 'cause the kids would call me "crybaby." (Tina, eight)
>
> Because I'm a guy I'm not supposed to cry. I tried to keep it in at the funeral, but I just couldn't. (Tom, thirteen)
>
> I cried inside. . .I was embarassed for people to see me cry. (Jeremy, eleven)

Theme 11. Mourning Past, Present, and Future Losses: "I'm Kinda' Scared That Dad Will Happen The Same Thing"

During the course of their parent's illness the children seemed to become sensitive to the phenomenon of loss, in general. They would recount past losses--death of a pet, relative, or friend, moving, parents' separation or divorce, their own near-death experiences--and anticipate future ones--death of a sick parent, well parent, their own death, marriage of family members, special times with sick parent. Sometimes pining past losses was a safer way for the child to deal with the anger, guilt, and loneliness the present loss incurred. When past losses were unresolved, the impending loss provided the impetus to bring these to the fore. Promises left unfulfilled by the ill or deceased parent were also mourned. Here are some of the children's descriptions of past, present, and future losses:

> When I was ten months I nearly died. (Jeremy, eleven)
>
> Last week I got a concussion and had to go to hospital. I was afraid I was going to die. (Ricky, nine)
>
> I miss when we lived in Nova Scotia and we used to go to the beach. (Tom, thirteen)
>
> I think of Peppy and how angry I was when daddy gave him away without even telling us. (Marianne, eight; see Figure 6a)
>
> I remember when Ginger ran away. I saw a cat lying dead on the road and I think it was her. I miss her. (Stephanie, eight)
>
> Me and Tina talk and I ask her "When are you going to get married?" and all that. (Tom, thirteen)

Figure 6. Marianne's drawings.

a. Mom and Peppy
b. The whole family jumping together
c. Mom in hospital
d. Playing with Heather

I felt angry with my dad a few times. When he promised me he'd that when I'm eleven or twelve that he'd take me to those go karts and didn't because he was sick and he went to hospital. Now we can never go. (Jeremy, eleven)

I'm kinda scared that dad will happen the same thing. (Sam, eight)

All of the children knew of the possibility of their parent's death and in cases where death was imminent in terms of days or weeks the children sensed this whether or not they were told. This did not seem to make the situation any easier to grasp. It's hard to comprehend even if you know it's going to happen. You don't believe it 'til it happens. (Steven, eleven). Six-year old Don, whose mother was in the terminal phase of her illness knew his mother was dying but did not want to think about it.

M Do you know why your mom and dad come here?
D 'Cause my mom's sick.
M What's wrong with your mom?
D She's dying.
M She's dying?
D No. I mean she's losing weight and stuff.
M How come, do you know why?
D No.
M Do you think about that a lot?
D Yeah sometimes.
M So tell me about your mom. Why did you say she's dying?
D She wasn't dying (he changes the subject).

It is not surprising to learn that children who have a parent with cancer constantly worry about the possibility of their parent's death. Most children thought about their parent dying frequently after diagnosis and during remissions. The prospect of the parent's death, whether distant or imminent, was omnipresent in these children. Thoughts of their own death from cancer, and thoughts about their remaining parent's death, also preoccupied them.

When the children spoke of their parent's death, impending or recent, to them it meant separation which entailed the cessation of special times with the parent. Reflecting on this separation the children spoke about what would be missed or what would change after death of the parent. They recognized the uniqueness of each of their parents and thought about what would be irreplaceable once the sick parent died:

It'd be hard for my dad 'cause he doesn't know how to brush my hair, like he doesn't even know how to get my barettes in. (Stephanie, eight)

There wouldn't be any more fun. Mom plays with me lots. She takes me to the park. (Mark, seven)

It would be hard 'cause we wouldn't learn how to cook. (Karen, nine)

It'll be hard if my dad gets another wife 'cause we won't learn as many things.

> He'd be too upset to teach us to do things. (Sam, nine)

These children associated the cancer experience with ending their daily happiness.

> Before she got sick we had lots of fun. But when she got sick, we didn't have very much fun and hardly ever done anything. (Tina, eight)
>
> The disease ends the happiness of everyday life. (Jerry, thirteen)
>
> It just wouldn't be very happy. (Darryl, twelve)

The children were experiencing many losses and experienced many more as their sick parent became terminally ill and died. Their parent's illness and/or subsequent death incurred many changes in the children's lifestyles. Every change involved a loss, of sorts.

Theme 12. Adapting to Changes in Daily Living: "I Have No One To Hug and Kiss Goodbye"

In their drawings and interviews the children expressed longings to return to the "good ol' days" (see Figure 7d) before the illness or during remissions. The important times in between diagnosis and the present were occasions when the family was together on vacation or at home. The children felt like pieces of "broken" families, trying to be whole again.

Family rules, roles, and routines were in flux and the children were constantly in the process of adapting and changing.

> When I came home mom was home and I could tell her what's happening. (Marianne, nine)
>
> I have no one to hug and kiss goodbye. (Mickey, six)
>
> When I get home dad's still at work and I have to pick Tina up from across the street. (Tom, thirteen)
>
> I go to the Rimby's until dad comes home from work. (Steven, eleven, see Figure 4a)
>
> Like we used to sit at the table and now we just sit at the counter and eat. No use dirtying up the table. (Tina, eight)
>
> Sometimes we have to stop doing things like she might be hurting and we won't go uptown. (Jerry, thirteen)
>
> My aunt or grandmother would go shopping. It works okay but it's a change. (Stephanie, eight)
>
> Before she had cancer we had supper. Now sometimes we have suppers, but not really. We all do our own thing and make what we want. (Jerry, thirteen)

[redacted]

Figure 7. Tom's drawings.

a. Finding out about mom's diagnosis
b. Hiking with mom and dad back in New Brunswick
c. Mom teaching Tom how to cook
d. Remembering the "good ol' days" (hiking and mom's cooking lessons)

Tom found it difficult at times to keep pace with the changes

> Because one or a couple of times I'd forget and say 'Mom are you home?' because I wasn't used to it. She was always home. Now when I come in it's kind of strange it's so silent.

Depletion of family financial resources paralleled emotional depletion in the aftermath of regular hospital and clinic visits over prolonged periods. The children spoke of activities they could no longer do together as a family--not only because the family was no longer together, but because of lack of finances.

Children anticipated other family changes such as their parent's remarriage (even among children whose parent was still alive). For some, thoughts of remarriage brought fear ("Maybe his new wife won't like kids?!") and for others excitement ("I thought you were my dad's girlfriend and he was going to introduce us and you were going to get married and that would be fun!").

Either children became so preoccupied with their parent's illness that they could not concentrate on their school and homework, or they would immerse themselves in their work as an escape. For some, homework was just an added stress to their already burdened homelife while for others it provided temporary relief from their current reality.

> I know everything. I just don't apply myself. I'd be an honour student. I'm kind of bad since my mom got sick. I have lots of stress. (Stan, fourteen)

> When I got homework I hate it. I can't do it. I got lots of stuff to do. (Jeremy, eleven)

> 'Cause the teacher even ~~told~~ me before I was good and when he was suffering my marks went down, and just after he died, they came up slowly. (Tom, thirteen)

> I'd do things wrong 'cause I'd be thinking of cancer. (Ricky, nine)

For these children, school, which was usually the central focus of their everyday life, was viewed as interfering with their new focus: their homelife and their sick parent. It was by no means as enjoyable as it was when their life was not complicated by parental cancer.

In Joey's drawings (Figure 8) he depicts how things were before mom "got a sore breast" and how things have changed. He drew mom in the kitchen making supper (Figure 8a), mom pushing him on the swing in the park (Figure 8b), and his whole family together (Figure 8c). His fourth drawing (Figure 8d) reflects the current reality--"Mommy's all by herself in her room. Mommy's sad." Mommy no longer cooks supper, she does not take Joey to the park, and each member of the family keeps to himself or herself.

Figure 8. Joey's beginning of session drawings.

a. Mom in the kitchen making supper
b. Mom and Joey at the park
c. Joey's family all together
d. Mom all by herself in her bedroom

Theme 13. Making a Connection Between Life and Death: "There Are Two Babies Inside Mommy's Tummy"

Although the youngest children spoke about their parent's dying or death, they communicated only fragments of information about their understanding of it. Christine's confused response "body up up and soul down down" and Melanie's monotonal, stereotypic "Mom's never going back again" seemed to be a parrotting of what they heard from others. Dawn (five years) acknowledged that she did not understand what it meant to die:

D Daddy was crying.
M Why?
D 'Cause mommy died.
M Why would he cry about it?
D Because daddy wants her to be alive.
M And how about you?
D I wasn't crying.
M You weren't crying?
D I don't understand.
M What don't you understand?
D When daddy was talking about mommy was dead. I don't understand.

I became intent on obtaining an "answer" as to what her thoughts about death were. Eventually she put things in perspective for me:

M You must think something. You have to have something on your mind.
D I don't have it on my mind.
M So where's mommy now?
D In heaven.
M What's she doing up there?
D I don't know.
M What happens, you don't know?
D Do <u>you</u>?
M I'm not sure.

I continued in a much more humble fashion for the remainder of our time together, and in future interviews with the other children.

The youngest children (three- to six-year olds) all drew flowers. They have watched flowers grow, bloom, and die. Their subject choice, therefore, may represent attempts at understanding the life cycle. As previously discussed, both Dawn and Christine used flowers as metaphors for what was happening with their parents ("The flower's growing and kind of dying but it's not," "Daddy's crying 'cause the house blew down").

The theme of birth surfaced in numerous situations with these children. Melanie and Micky suggested that maybe their mother would come back as their baby, Dawn drew a picture of "mommy's birthday" and of "mommy's birthmarks" (Figure 3a, 3e), and the dots in Melanie's drawings were "bellybuttons." Three-year old Patricia drew a picture of "two babies inside of mommy's tummy" and Don said to me "My mom's dying. She's sick. My sister's sick. She's going to have a baby." Mark (eight years), asked "What if babies get them [cancer] as soon as they're born?" Elizabeth (ten years) drew a picture of what she thought cancer looked like and explained it as a "birthmark that grows." At some level these children seemed to be attempting to make a connection between birth and death and perhaps even rebirth.

From six years of age the children spoke of the burial of the body and children of all ages mentioned the concept of heaven. It was the older children (ten years and up), however, who were really challenged to think about death-related issues. Their reflections about nuclear war, the origin of man and God, what happens to the body after death, were generated by thoughts about their parent's impending death. The information they pondered came from discussions they had with their parents, information they read in books and from television specials. Excerpts from my dialogues with Jeremy (eleven years) and Elizabeth (ten years) have been selected to illustrate the variety of topics the older children thought about:

J: Well my dad told me that when you die you'll know all the answers; you'll know the answer for cancer. . . .The very second you die you'll know it all.
M: How do you feel about that?
J: Well a little relief that I'll know everything if I die before I'm old. Before I'm a teenager or something, like if something happens in a car accident. I'll know what will happen in a nuclear war if there is going to be one.
M: Do you think about nuclear war?
J: Yeah. . .I don't want to die. We're living in the most dangerous target. 'Cause we got all the oil tanks.
M: What part about dying scares you?
J: Like I want to live on the earth for a long time. I don't even want to grow old, I want to stay as a kid. I want to get to be an adult but I don't want to grow old. Over fifty. All the skin. 'Cause I've seen unwrapped mummies in our Egypt book and they look weird and that's how you'll look in over a hundred years. . . .After I die I'll watch after my sister and my mom and make sure they don't die.

Elizabeth had fearful ruminations about what her mother told her:

L: Yep, and that bad people go to hell. . .Well, mom was really making me scared. She said that in the Bible it says seven souls of the devil go in your body and now you know I'm thinking about the devil and everything and I can't get it out of mind.

She questioned the evolution of man and the origin of God:

L: Sometimes I think these are questions I think nobody knows, unless they came back from heaven, five years later.

> M What kind of questions?
> L Like, God just didn't come from nowhere I don't believe that. Maybe he comes from a different world or something. Flew up our something. Like maybe he was lonesome. But I don't know what to believe. that he made monkey and then human, or did he make Adam and Eve? But how can people say that we're made from monkey? . . . I believe both of them. I believe there was an Adam and Eve and I believe we came from monkey. . . . But anyways, you know, he came from a different world, and he was lonesome, and he made people and I wonder if God's so powerful, why didn't he just get rid of the devil?

After viewing a television special, Elizabeth considered the possibility of coming back to life and she wondered about what the quality of the new life would be like

> I'm not sure, I don't know what to believe, 'cause on the show they had people that died and then they came back again, you know. They interviewed people that died. . . they would go up in this black tunnel and they would see lights like in New York, New York, or Hollywood. . . . But I think about life in a world like that. It wouldn't be fun without T.V. . . . they said that animals won't go to heaven.

Theme 14. Looking At the Lighter and Brighter Sides: "I've Matured In the Last Two Years"

The children were able to look at some positive elements of their current experience, which facilitated their adjustment to it. Although they were enduring a constellation of stressful life circumstances, there were facets they could make light of, and the older children voiced benefits that ensued, from the ongoing challenges.

Many of their drawings had humorous details in them. For example, in one of Jeremy's (age eleven) drawings he depicted the limousine chauffeur en route to his father's funeral, smiling and honking the horn (see figure 9c). When asked about why he included this amusing detail, he explained that he enjoyed the limousine ride. In Tom's (age thirteen) drawing of a hiking excursion he portrays himself waving to the viewer (see figure 7b). Dawn's (age five) attempt at humour is manifested in a drawing of a little girl who is laughing at her angry mother (see figure 3d). Dawn remarked, in reference to the drawing, "the mother thinks the girl made the muddy footprints all over the floor but it was really the cat who runned away!" A fourth example is Steven's (age eleven) portrayal of his reaction to being frightened by neighborhood dogs (see figure 4c). He drew himself throwing his schoolbags up into the air. He explained that he did not actually react this way, but that he wanted to add humour to his depiction of a scary situation.

[redacted]

Figure 9: Jeremy's drawings

a. Finding out that dad has cancer
b. Visiting dad in hospital
c. Dad's funeral
d. Christmas without dad

Some of the children were able to articulate positive changes which resulted from meeting difficult challenges

> I think I've changed, too. Before I couldn't handle stress but in the last two years I've seen my mother almost die and that really affected my outlook on life and made me think that life can be taken away so easily. So I've matured somewhat in the last two years. (Stan, fourteen)
>
> I don't take my life for granted like I once did. I appreciate my health." (Cindy, thirteen)
>
> I guess dad cares a lot more. He looks after us. He makes sure everything's all right and all of that. He says "make sure you eat all your vegetables." He used to not mind if you didn't eat a couple of vegetables. Now he says (mimmicks his dad) "Make sure you eat those vegetables, they're really good for you." (T[illegible], thirteen)
>
> Well now dad really listens to what we say. Like before he listened but I didn't notice it then. He would say "Yeah." And now he kind of discusses with us. (Karen, nine)

There were some positive changes which resulted from the experience of living with parental cancer.

Theme 15. Resorting to Internal Dialogue: "I'd Talk to My Teddy Bear"

A web of silence enmeshed their social relations so the children resorted to imagined relationships and internal dialogue to problem solve about their experience, especially about disturbing aspects of it. Since they felt their friends would not understand, and since they wanted to shield their parents, they turned instead to invisible playmates, stuffed animals, and dolls. They also spoke to God, deceased parents or dialogued with themselves. For some of the children, the self talk was a habitual way of coping which increased from the time of their parent's diagnosis. For others, it began in response to a need to talk about cancer, but not knowing who to talk to about it.

> I'd talk to my teddy bears. Oh I'd tell them what happened to my dad and what I think is gonna happen. They say something back. I say to him "Do you know that dad has cancer and he's going to die very soon?" He said "Oh, I hope he doesn't die fast!" I said "I hope not, too." (Jeremy, eleven)
>
> It's sort of like talking to myself except I don't like talking to myself because then there's kind of nobody to answer to so I pretend there's an imaginary friend. And I kind of think "is my mom going to live or die or what?" (Elizabeth, ten)
>
> I talk to myself in my head. I just ask "Why? Why her?" (Steven, eleven)
>
> I usually talk to myself about it. (Ricky, nine)

> And I say to myself "Tom, don't cry now!" (Tom, thirteen)
>
> If I have a problem I just go through it in my head. I've always done that. But just found it more often lately. (Cindy, thirteen)
>
> When I'm alone and it's night time I say "Look mom, I got 100% on my test!" (Tom, thirteen)

Theme 16. Seeking Refuge in Activity and Fantasy: "They Call It Escape Fantasy or Something"

The children were able to self-regulate how much of the present reality they could face by seeking refuge in daydreams, play, television-viewing, novels, and homework, when they felt overwhelmed.

> I would just think about happy things. (Marianne, nine)
>
> I read stories, and get so caught up in the stories I don't remember anything. They call it escape fantasy or something like that. (Steven, eleven)
>
> If he was sitting there in pain I would [illegible] and do my homework. (Cindy, thirteen).
>
> When I got real down I'd just grab a toy and play with it. (Jeremy, eleven)

The youngest children created myths or "liberated convictions"[16] about a future reunion with the dying or dead parent which helped them cope with losing, or having lost, a parent. Myth is defined as ". . .any invented story. A fable or legend embodying the convictions of a people as to their [illegible]r divine personages, their own origin, or the origin of the world"[17]. Six-year o[illegible]ained

> My mom will die and go to heaven. After that there'll be dinosaurs and then the dinosaurs will die. And then there'll be Indians and then they'll die. And then there'll be people and then mom will come back.

Knowing that mom or dad was in heaven did not make everything okay:

> "Are you sad when you talk about mommy?" I asked six-year old Mickey who indeed looked very sad.
> "No!" he yelled. "She's in heaven and she's happy!"
> "So are you happy 'cause she's happy?" I inquired.
> "Yeah and I'd rather have her here anyway!" he pronounced.

For the young and older children alike, the concept of heaven did not provide them with

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[16] Piaget (1972) refers to a child's creation as a "liberated conviction" when s/he replies, after reflection, drawing the answer from the store of his own mind without suggestions from others.

[17] New Webster Dictionary. Deluxe Encyclopedic Edition. New York: Delar Publishing Co., Inc., 1984, p. 632.

total comfort. Many had uncertainties, questions, and doubts about heaven. Elizabeth was concerned that because she was bad sometimes that she might go to hell and would not see her mom again, because her mom would go to heaven. Don had similar concerns. He asked his father:

> "Will I meet mom in heaven?"
> "Yes you will." his father assured him.
> "Will she still be my mom in heaven?" he asked.
> "Yes." his dad answered.
> "Will I still be her son?"
> "Yes."

Most of the children (all ages) spoke about being reunited with their parents in heaven.

Mickey and Melanie spontaneously developed a myth together:

> "What happens to people when they die?" I asked Melanie.
> "They never go back again." she replied.
> Mickey stipulated "Unless they wind up to be somebody else's baby."
> "Sometimes they end up being somebody's baby?" I asked.
> "Then she'll be <u>our</u> baby!" Melanie exclaimed[18].

This fantasy seemed to please them and grant them temporary solace. "Myths. . .can be interpreted as a sort of mental therapy for the sufferings of mankind in general--disease, death, old age, war and hunger" (Jung, 1964, p. 68).

The older children pondered different possibilities of what heaven might be like. Of the families interviewed, none were regular church attenders so although there were references made to God and/or heaven, the children did not make any detailed comments about their religious beliefs. Stan was cynical about the usefulness of religion:

> Religion is to help people. Some people don't have the willpower so if you read the Bible they believe what it says in the Bible. If you believe in God you'll go to heaven and stuff like that. I seem to think that people who are really religious are with no will. They're kind of mental ones, they're not very strong and they have to depend on something else. They have a false belief in religion. . . .I believe in God but not to the point where I go to church everyday. Well, people who go to church are just--not all of them--but I have to say a fair amount of them are people who really don't have the will to believe in themselves. They have to hear it from someone else. . . .Religion is their crutch. (Stan, fourteen)

Stan believed in God and thought that he would go to heaven, but religion was not his "crutch" in helping him cope with parental cancer.

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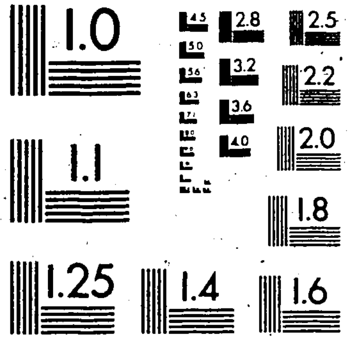
[18] Their myth is reminiscent of the eastern philosophy concept of Karma, the transmigration of the souls, where the soul appears and reappears generation after generation in different bodies.

2



Theme 17. Advising Other Children of Cancer Patients: "Make the Best Out of Times That They're There"

The children were asked for suggestions of what might help other children who are undergoing the same experience, based on what helped them. Some children offered suggestions spontaneously which gave me the idea for pursuing this line of inquiry. They suggested that it would be useful to get "practice at it" (at coping with their situation) either by talking to an experienced age peer or by reading about what happens in families when a parent has cancer. Children who knew their parent's illness was terminal emphasized that it would be important to take advantage of the time that remained with the parent by visiting frequently, kissing and cuddling them, and by doing the things the family always wanted to do. The children cautioned age peers "not to panic" as things would never be as bad as one might imagine them to be. The children realized that sometimes nothing helped and that only time would heal. Also mentioned was that certain memories would fade with time, that this was normal and helped with adjustment. A few children mentioned that it is important to always have hope, and to pray. Here are the children's own words:

> Well I'd tell him what happened to me, how I went through it, so he could have some practice at it. (Jeremy, eleven)
>
> To not worry about it and when it comes not to panic. (Tina, eight)
>
> I'd tell him about the funeral and how it went. (Jeremy, eleven)
>
> Just hope. That's the only thing you can do. There's nothing else you can do. Just have hope. There's nothing else. Hope and pray. (Ricky, nine)
>
> Well the best thing to do is just go on and all that and gradually it won't hurt so much after awhile. (Steven, eleven)
>
> And then one thing not to be alarmed is that well whoever it is that you've lost well, you won't remember them so well. (Steven, eleven)
>
> Well I think there should be a book like for kids like "how to prepare or something" or try to prepare youself and get a feeling what it's like. (Cindy, thirteen)
>
> When you're gone, then they're gone, you know, there's no more. You're never gonna' see them again Yes, so you gotta' make the best out of the times that they're there. It's not that terrible, you know. It's not that terrible as it seems. Let's say you've always wanted to go to a rodeo or something, don't put it off any longer, go <u>now</u>. 'Cause there might not be a next time. (Cindy, thirteen)
>
> Visit them as much as you can 'cause they won't be around ever again except maybe when after you die. (Steven, eleven)

The advice offered by the children seemed to be more practical and reality-bound than the advice offered to them by well-meaning adults. In a few situations children spoke with disdain of adults who talked about miraculous cures or about God choosing only the best people to have cancer or to die."

The older children were asked if peer support meetings would be useful for them. Most of them agreed that the idea was a good one. Ricky (nine years) rescinded his decision to participate and remarked "The other kids might not want me 'cause my father might die." It seemed that it was not sufficient in his view to be with other children of cancer patients--he wanted to be with others whose parents were also dying. Not only do children fear ridicule from inexperienced age peers, but they also fear reprisal from experienced peers whose situation is not as grave as their own. Two of the adolescents preferred to meet one-to-one with an experienced age peer but the remaining adolescents liked the idea of an ongoing group situation. Steven (eleven years) remarked that he liked seeing the hospital psychologist because she "speaks the truth." He qualified his statement, however, by saying:

> I liked talking to her (the psychologist) at first when my dad went into hospital and stuff and when he died. . . .I didn't like talking to her in between 'cause she talks about what I'd feel if he survived and all that. . .what I'd feel after he died. I didn't like saying and talking about the future, 'cause nobody knows what's going to happen.

Speaking to a psychologist after his father's diagnosis, and after his father's death, was helpful for Steven, but in between, he wanted to hope for the best. Speaking about the fatal possibility was an unpleasant reminder.

Cindy (thirteen) and Stan (fourteen) offered criticisms of the hospital environment and then gave suggestions for how it might be improved:

> You know in hospitals the rooms look so bland. People like doctors say like when you're having a baby you want to have it in a homey environment because it's good, you know. It's supposed to help. So why don't they make the rooms nice if it's supposed to make people happier. They just seemed cold and that. Colours would make it warmer. (Stan)

> If they would have books or games or something. . .Yeah, like cards. They had cards but they were hard to come by. You had to scavenge for them. (Cindy)

The hospital environment was appreciated by the younger children who could play with wheelchairs, who enjoyed eating off hospital trays and playing with syringes. But the older children needed something more. They wanted a more comfortable environment for their parents and for themselves.

Theme 18. Benefitting from Interviews: "I'm Kind of Happy To Get It All Out"

Having the opportunity to openly communicate with an adult, non-family member, had instant value for the children. They spoke about feeling happy following the interviews--once they talked about it "it wasn't as bad as it seemed." The children explained:

> I'm kind of happy to get it all out, tell you how I feel. I like that. I think it's better to get it all out into the open. Then once you realize it, it's not as bad as you think it is. (Tom, thirteen)
>
> I feel happy when I talk to you about my things 'cause it makes me forget about them. . . .Then you know that some of the bad things you think won't happen. (Peter, seven)

During the second interview or in the follow-up phone call, children and parents related experiences that happened in the interim which indicated improved individual adjustment, and openness in discussing their situation with siblings and friends:

> I talked to some of my friends. I didn't know that most of the kids in school were pretty interested. It was pretty fun to talk about it. Now they treat me the same. (Tom, thirteen)
>
> I'm getting along better with my friends. I got an award for doing any kind of work, no complaining and being friendly to the kids. It's a big one and I'm getting it framed. I'm better now 'cause you talked to me. (Jeremy, eleven)
>
> It's good to know that Alan (sibling who did not participate in interview) feels like me. He gets sad and cries by himself in his room. We never talked about how we felt before. (Marianne, eight)

Mothers of younger children reported fewer observed behaviour problems. During our follow-up phone conversation, Joey's mother insisted that I had performed "miracles" with him. The day after my visit, his fears of the dark and of being alone subsided, and he became toilet trained.

Second session and end of session drawings were good reflections of the children's improved emotional wellbeing. A couple of drawings (Figures 10 and 11) appear in the following two pages (refer to Figures 2 and 8 for a comparison with first session and beginning of session drawings by these same children). Initially, Don (six years) chose cold colours to depict his arctic scenes (Figure 2). In the second session he began to draw colourful spring and summer scenes and a lively fairgrounds picture (Figure 10). Before our interview, Joey drew small drawings of himself and others (Figure 8). At the end of the interview, he drew a full page drawing of himself smiling (Figure 11). Mark's drawings

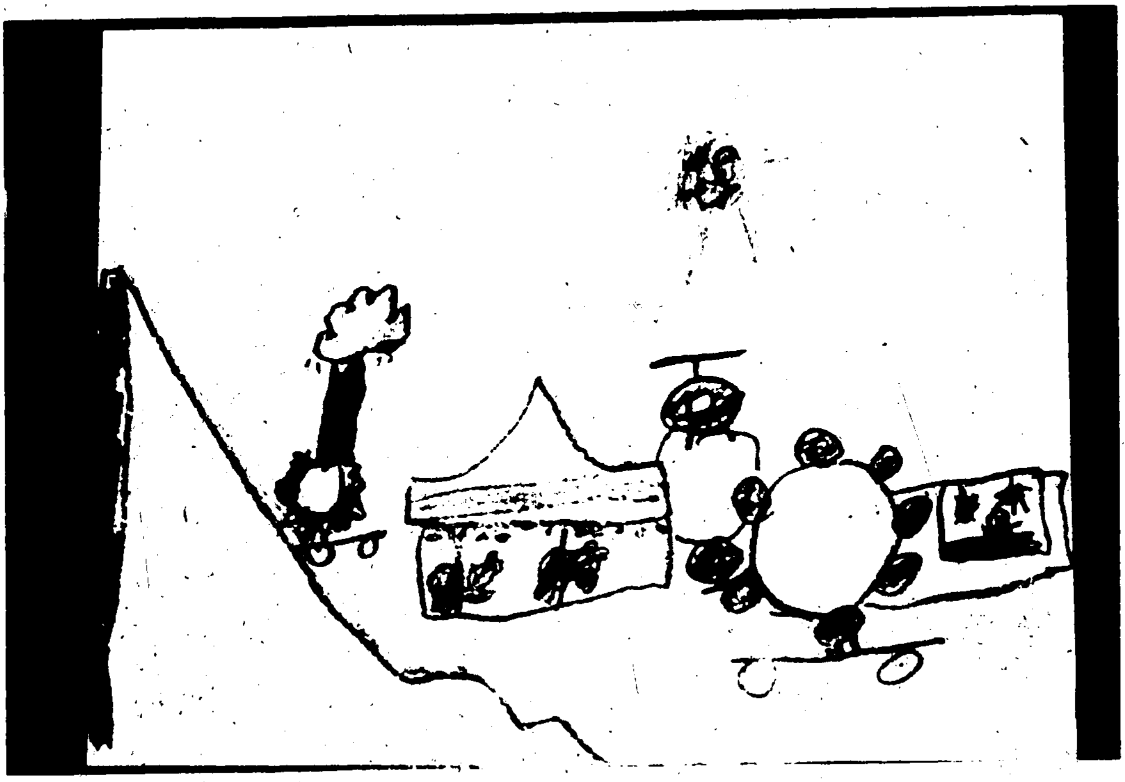


Figure 10. Don's second session drawing.

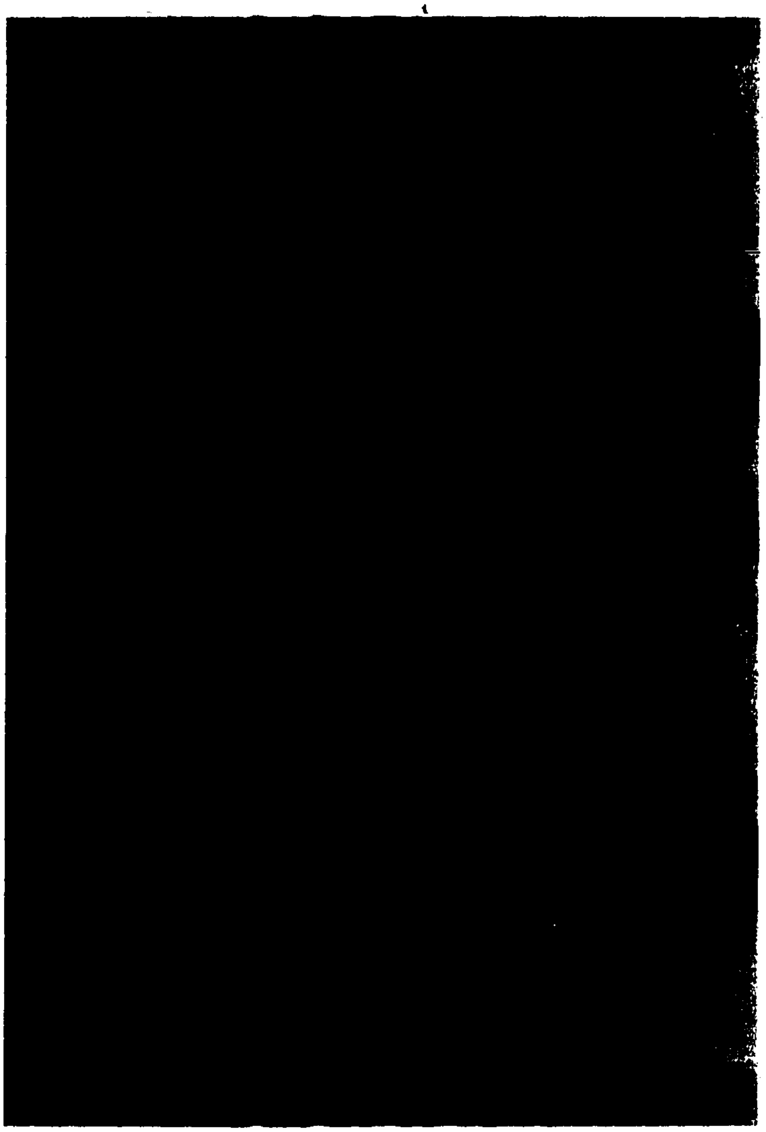


Figure 11. Joey's end of session drawing.

(Figures 13, 14, 15) depicted figures which were separate from each other and unhappy while his second session drawing was of his whole family, together and happy (Figure 17).

Summary of Themes

Parents and children alike commented on the value of the interviews. Improvements in behaviour and overall emotional wellbeing were demonstrated by the end of the interviews. Children who were initially reluctant to participate, eagerly awaited the second interview. The children's drawings and words were symbolic reflections of living with parental cancer and several important themes were revealed through them.

The children became extremely sensitive to their parent's needs and concerns by being nurturant, tolerant, and protective of them. The children became isolated from their social network--parents, peers, and societal taboos promoted a context of closed communication about cancer. They did not question their parents about cancer for fear of further burdening them, and did not talk to peers about it for fear of being ostracized by them. They did not talk to significant others in their social milieu because they were aware of societal dictates which discouraged open emotional expression and discussion about cancer.

The children were greatly affected by the pain, suffering, and fatigue their parents endured; the visible disease characteristics were not significant concerns for them. They would closely monitor their parent's physical progress and felt better when their parent was better. Some of the children had adopted their parent's physical symptoms, others felt physically ill from the chronic stress of the situation. Children spoke of their fear, anger, sadness, and anxiety. Major fears were of getting cancer themselves, of relapse or death in their parent. These fears became fears of the dark and of being alone. Their anger became directed against teachers, doctors, God, and relatives.

Losing their parent slowly to cancer meant a gradual decrease in shared activities and conversation, and a general lessening of family togetherness. Family roles, rules, and routines changed and children longed for the "good ol' days" and the "good ol' ways." Their current losses reminded them of past losses and triggered thoughts of future losses.

Children understood some of the medical facts about cancer, but in seeking the cause of cancer, substituted their own. They blamed themselves, others, God, and some thought it was caused by something the parent did, or by a virus or bacteria. The series of relapses and remissions, and the ineffectiveness of treatment in preventing future reoccurrences, led to a general state of confusion about the nature of the illness. The children lived with ambivalence which led them to question the certainty of their parent's future as well as their own future. Although they knew about the fatal likelihood of their parent's illness, each remission brought renewed hope and thoughts of miraculous cures.

The children learned about cancer, even before the parent became ill, from cancer models. Cancer models included other family relatives, peers who had cancer, media personalities, and television characters. The models they chose were people who had died from cancer, and not people who had survived. The children were uncertain about whether or not they wanted to confirm their beliefs by asking parents about the illness. They would suspect that things were not going well, but as long as they did not hear this directly from their parents, they could maintain hope for their parent's survival.

The youngest children had an understanding of the cyclical nature of life and death. They made many references to birth, rebirth, and life after death. They created myths about afterlife. The older children pondered details about what heaven might be like, as well as other death-related issues such as nuclear war, what happens to the body after death, and the origin of God and human beings.

Being left alone to cope with their concerns and fears enabled the children to capitalize on inner resources which would have otherwise remained dormant. Participating in parental care brought out their nurturant qualities which was one means of coping. They used self-talk to comfort themselves and to dialogue about their situation. When they became overwhelmed they sought refuge in fantasy and play. The youngest children created myths about afterlife which granted them temporary solace. All of the children valued being involved in the hospital experience, though the older children felt that the hospital environment could have been more comfortable for them and their parents. The children made suggestions of what would be helpful for other children going through a similar experience and these included: making optimal use of remaining time; talking with experienced age peers, realizing that fading memories and time would help in the emotional healing process.

Finally, the children could find some positive elements to their difficult life experience. Their sense of humour came through in drawings. They were able to enjoy everyday out-of-home activities. Some of the older children were able to articulate how their experience matured them and resulted in quality changes in themselves and in their well or surviving parents.

B. Presentation of Case Studies

The case studies of three participants have been chosen for presentation. The children are: four-year old Christine Albertson, eight-year old Mark Sanderman, and fourteen-year old Jerry Slavens. Each of these children had a preferred mode of communicating (through puppets, writing, drawing, and/or speaking) about the experience of living with parental cancer. The three cases combined provide a good cross section of various themes, and the children each demonstrate unique ways of expressing the same themes.

Each case study commences with some information on family background of the participant. Next, a table is provided which presents an abridged version of our interview(s). Also included are reproductions of the child's drawings and/or story, and a commentary on the outstanding and unique features of the case, with implications for understanding and working with children of cancer patients, in general.

Case #1. Christine Albertson: "Flower is Growing and It's Kind of Dying But It's Not"

The Albertson Family

When I met Daniel Albertson, a thirty-four year old computer programmer, and his wife, Darlene, I had difficulty believing that he was enduring a terminal disease. On the day of our meeting he looked slightly tired but otherwise well. When Daniel went for a routine medical examination two years ago because of a feeling of fatigue and of vague back pain, he was diagnosed with multiple myeloma, a disease which is rare for men under fifty. To date, no one has ever been cured of multiple myeloma: "They all ultimately relapse and become refractory to further therapy. The current overall figures for duration of life span for all patients with this illness is approximately three months." (Doctor's progress notes)

Since his diagnosis, Daniel has been hospitalized twice for one-month periods and in between has had pain-free periods and has returned to work full time. Spontaneous bone fractures, characteristic of myeloma, necessitates his wearing of a corset and he walks with canes. Daniel was referred by his doctor to the psychology department for self-hypnosis in stress management. In talking to the psychologist, it became evident that the Albertsons had some concerns centering on their two young children--Christine, four years, and Peter, seven years. During their dad's most recent hospitalization mom discovered that the two children were shoplifting various stationery articles while shopping with her in a local department store. When the Albertsons heard about my study, they decided it would be valuable to take the opportunity to find out about their children's experiences and gain some insight into what the shoplifting may have been about.

During my interview with Christine's mother and father, they voiced concerns about their parenting techniques and wanted advice on child management. The Albertsons shared with me that they adopted both of their children as infants. Managing the children had become a mounting concern with Daniel's frequent absences from home (multiple myeloma patients require regular medical check-ups and tests even while they are in remission).

First I met with Peter who spoke about his involvement in peewee hockey and showed me a photograph of his baseball team. He excitedly reported on his hospital visits where he enjoyed everything from riding around in wheelchairs to eating off dad's food tray. He defined cancer as an illness that made dad tired and made him need canes to walk.

Christine was very eager to have her turn to meet with me, so much so that she would check up on my progress during my interviews with her parents and brother. She took an immediate liking to the fluffy dog puppet I brought with me and named him "Ruff Ruff." By the end of our interview I was behind Christine's bed with her while we both put on a puppet show. She was anxious throughout our discussion of her drawings. She would repetitively carve circles in the carpet and added "scribbly dibbly" to her completed drawings. She spoke "baby talk" and used "Ruff Ruff" as her intermediary, initially. It became clear that she wanted to speak to me but that the themes of illness, danger, loss, and death which she herself generated, were disturbing to her.

At the end of our visit the two children skipped with me to the nearby bus stop and there was a deep sense of connection between us.

Following now, in Table 3, is an abridged version of my interview with Christine. Dialogue which was considered directly related to "living with parental cancer" (the significant statements) is presented on the left, and my interpretations (formulated meanings) appear on the right. Accompanying the formulated meanings, in parentheses, are the corresponding themes. Following the table is a commentary on special features of Christine's experience with some implications for working with young children of cancer patients.

Table 3

Abridged Version of Interview with Christine Albertson: Significant Statements, Formulated Meanings, and Themes

Significant Statements (M: Michelle; C: Christine)	Formulated Meanings and Themes
M: Who do you play with? C: My invisible friend. . .Timmy. M: What do you talk to Timmy about? C: Dangerous things. (She begins to talk "baby talk" and continues to do so throughout most of the interview.)	She has an imaginary playmate, Timmy. *(Theme 15: Resorting to Internal Dialogue)*
M: Dangerous things? Like what? C: Acid. M: What does acid do? C: Eats through things.	Acid has some cancer-like qualities: it's dangerous and eats through things. *(Theme 2: Communicating Through Symbols and Metaphors)*
M: How did you find out about acid? C: My friend Timmy told me. M: What other dangerous things do you talk about?	Christine dialogues with Timmy about dangerous things like acid.
C: Poisonous garbage.	She has angry feelings about cancer. It is harmful like poison and useless like garbage. *(Theme 2: Communicating through Symbols; Theme 9: Feeling Angry)*
M: Now this is you (referring to her first drawing, see Figure 12a). Who is that? C: Scott. My friend Scott, . . .he's three. M: And what's happening in that picture? C: I'm smiling. M: Is there anything else you want to tell me about that picture? C: Yeah, blue sky.	She has fun and is happy when she plays with her friend Scott. *(Theme 4: Feeling Different From Peers)* [The theme title "Feeling Different From Peers" is incongruent with what Christine is trying to express. However, the idea of playing with friends as a reprieve is discussed under this theme. Similar discrepancies occur in a few other instances].
M: How about this picture? (Figure 12b) C: That's a flower. M: And tell me about the flower. C: Little flower growing. M: That's a pretty flower. Do you want to tell me more about the flower? C: Flower is growing and it's kind of dying but it's not. M: It's kind of dying. . .What does it mean to die?	She knows that although dad continues to live, he is also deteriorating and slowly dying. *(Theme 2: Communicating Through Symbols and Metaphors; Theme 13: Making the Connection Between Life and Death; and Theme 11: Mourning Past, Present, and Future Losses)*
C: You're very, very sick. M: You're very sick, and what happens?	People die when they're very sick.

C:	Like you broke your brain all up.	People can't think any more and then they die. They die because their brain doesn't work. *(Theme 13: Making the Connection Between Life and Death)*
M:	You broke your brain all up?	
C:	Flowers don't have brains.	
M:	So do people die?	
C:	Yes.	
M:	When do people die?	
C:	When they're very, very sick and they break their brain all up.	
M:	Do you know people who are very sick?	
C:	Daddy (she screams a few times).	She has been telling me that it is daddy that's growing and kind of dying. She knows that dad has cancer but does not know what cancer is except that it is harmful and makes dad sick. *(Theme 6: Being Confused About Cancer and Its Treatments)*
M:	What's wrong with daddy?	
C:	Cancer.	
M:	What's cancer? (she shrugs her shoulders).	cancer but does not know what cancer is except that it is harmful and makes dad sick.
M:	So you were telling me about daddy and cancer. How do you know that he has cancer?	
C:	'Cause he told me. And I have sunburn on my shoulders.	She relates dad's sickness to her own physical symptom--a sunburn. *(Theme 5: Sustaining the Symptoms)*
M:	Does it hurt?	
C:	Yeah.	
M:	What happens to daddy when he has cancer?	
C:	. . . .He needs canes.	Cancer makes dad need canes. *(Theme 7: Obtaining Information About Cancer)*
M:	You went to visit him in hospital didn't you? Do you want to tell me about that?	
C:	I forget all about, all I know is a little bit. . .T.V. .	
M:	Do you ever worry about daddy?	
C:	Only when he hurts himself badly.	She worries about her dad when he has his spontaneous bone fractures. *(Theme 8: Experiencing Fear and Anxiety)*
M:	Do you know anybody who died?	
C:	Yeah. Abba. Mommy's daddy.	
M:	Did you know him?	
C:	No mommy told us.	
	Mr. Colby. . .he died.	She remembers Mr. Colby's death and she misses him very much. *(Theme 11: Mourning Past, Present, and Future Losses)*
M:	Do you miss him?	
C:	Lots and lots and lots and lots.	
M:	What do you think happened to him after he died?	
C:	His soul down, down, and his body up, up.	She is confused about what she has been taught about afterlife. *(Theme 13: Making the Connection Between Life and Death)*
M:	How about this picture? (referring to figure 12c)	
C:	That's daddy. . . .He has his canes.	Canes are the prominent part of dad's illness to her.
M:	Why doesn't he have his canes now?	

C:	'Cause he doesn't need them. He walks without them.	She monitors how he is doing on the basis of whether or not he is using his canes. *(Theme 5: Sustaining the Symptoms)*
M:	What's this you're drawing in? (She's adding something to her picture).	
C:	Grass.	
M:	What's this here?	
C:	Scribbly dibbly. (She's scribbling on top of her drawing).	She appears extremely anxious while talking about her dad's illness with me. *(Theme 8: Experiencing Fear and Anxiety; Theme 11: Mourning Past, Present, and Future Losses)*
M:	Daddy's happy.	
C:	He's laughing.	
M:	What's he laughing about?	She likes to cheer dad up. *(Theme 3: Being Parental)*
C:	He's laughing about me being funny.	
M:	What does cancer make you think about?	
C:	Danger. . .poison.	I want to validate my earlier hypothesis that she believes cancer is dangerous and poisonous. She confirms it.
M:	What happens to people when they can't think anymore?	I want to validate a second hypothesis, that Christine believes people die when they can't think anymore.
C:	Their brains blow up and they die.	She validates it.
	During the rest of the interview she gives me a puppet to play with which is one which she has covered with big round stickers as though it has the measles. The stickers come off before we start playing. During our play session the puppet cannot come out to play because he is very ill.	Illness is a theme she is very preoccupied with and she enacts this theme with her puppets. One of the puppets has measles which is an illness with overt symptoms which she is familiar with. *(Theme 5: Sustaining the Symptoms)*

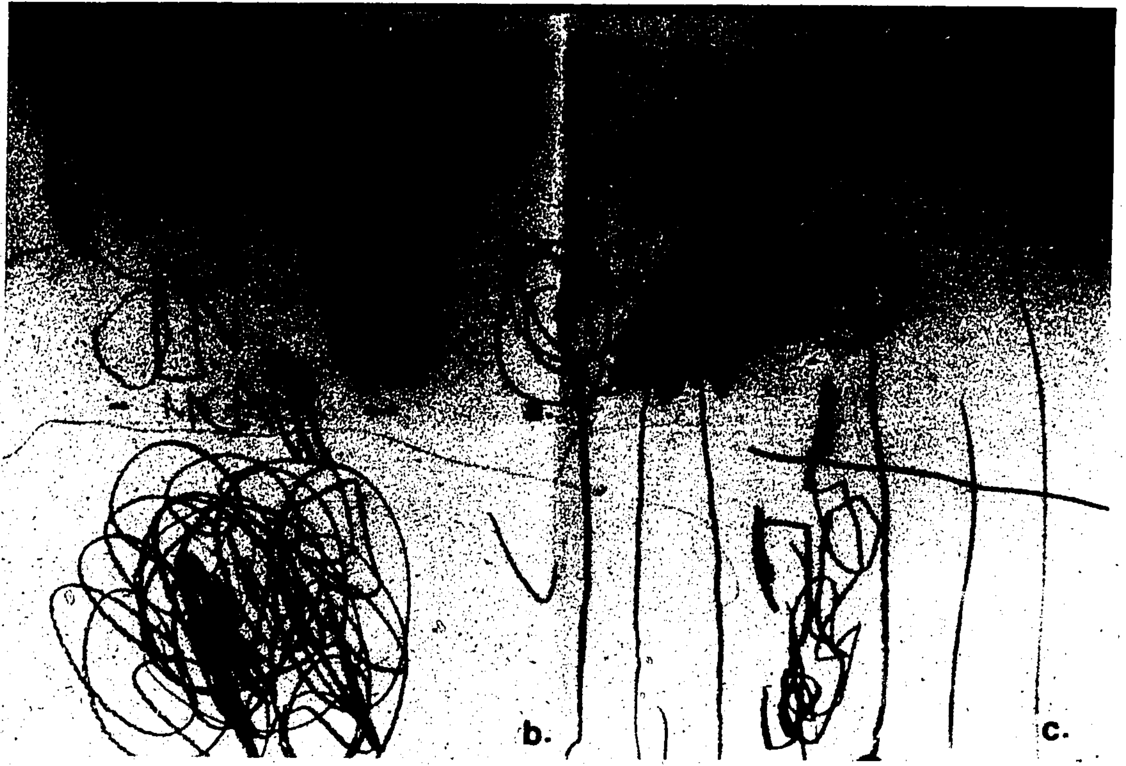


Figure 12. Christine's drawings.

a. Christine and Scott.
b. Flower which is growing and kind of dying.
c. Dad with canes. He is smiling at Christine.

Commentary

Significant features of Christine's interview include the acute symbols and metaphors she uses to represent cancer, and the fact that she was able to discern that her father's illness is terminal. "Flower is growing and it's kind of dying but it's not" penetrates the core of her father's situation. His series of relapses and remissions give a sense of "kind of dying," though not dying yet. The fact that she was able to determine her father's prognosis, even though her parents had not discussed it with her, reflects how adept children are at reading messages and picking up signals from those around them. They are able to perceive what is happening at a feeling level. Christine could tell whenever her father "hurt badly" and when her parents were reacting to bad news (e.g., negative prognosis, relapse, the need for more treatment, complications, etc.).

As children begin to learn language, they rely heavily on symbols and metaphors. Christine's chosen metaphor of "acid" succinctly represents the cancer process. Similarly, "poisonous garbage" tersely depicts her strong, aversive reaction towards the disease. When Christine mentioned "acid," "poisonous garbage," and "flower. . . kind of dying but it's not" it was initially difficult for me to interpret confidently whether she was referring to cancer. However, as we dialogued together and played for awhile, I began to understand the significance of her words. During our play she used round stickers on her puppet who was sick and who could not come out to play. Through her play, she was communicating to me that she was preoccupied with themes of illness. I could also interpret that mentioning her sunburn was her way of empathizing with her father's pain. When we want to learn about the experience of young children in crisis, we must listen to what they communicate symbolically through their words and images.

Case #2: Mark Sanderman: "It's Spreading Through The Whole Family!"

The Sanderman Family

What is a family?
It's a father's strength and wisdom
It's a mother's tender love
And the innocence of childhood
Soft and fragile as a dove.

It's a source of joy and laughter
Joke's and secret smiles and tears
And a wealth of treasured memories
That grow dearer with the years.

It's a constant lifestyle that guides us
And when anything's amiss
There's comfort in its steady glow
But, more than all of this

It's a warm and special feeling
Binding heart to heart forever.
In a spirit of belonging
Neither time nor miles can sever!

The above poem, carved in a wooden plaque, adorns the wall of the front hall entrance in the Sanderman duplex. Sherry, twenty-three, answers the door sporting a kerchief to cover the hair she has begun to lose and enthusiastically ushers me into her home. Her three children: Mark, eight years, Billy, three years, and Cory, one and a half years are nestled side by side in front of the television, undisturbed by my entrance. Three pairs of angelic eyes stare out from their portraits which hang carefully above them in the living room. When meeting the young couple--Sherry, and Keith, twenty-five years--there is an instant attraction, a "warm and special feeling." As their dog scoots off to the basement and their cat snuggles into my lap, I sit down to speak with the Sanderman couple.

Sherry had a lump on her left thigh which she thought was a muscle she developed from doing the "Jane Fonda Workout." When Mark accidentally kicked Sherry, it started bleeding and she was in unbearable pain. She was admitted to hospital in October of 1983 as a day case and had the mass removed. Her diagnosis was Alveolar Soft Part Sarcoma which is an extremely rare tumour of the cells which form the connective tissues. Her doctor reports "only 90 cases have been reported in the world literature up to 1981." He also gave a poor prognosis stating that "the course is slow and indolent but invariably has ended in death from metasteses, mostly to the lungs." There is a 50 percent survival rate after five years. In September of 1984 multiple metastatic lesions were found in her lungs. She has received three of six chemotherapy treatments over the past three months. She is nauseous the entire day following her injection. Over the past year she has experienced low energy and malaise. After her most recent treatment she developed anxiety attacks and wanted to terminate all subsequent treatments: "What's the use of suffering through all this if I'm going to die anyway!"

"All males die of heart attacks in my family and all the females die of cancer!" she responded to my inquiry regarding the family history of severe illness. Both of her grandmothers died of cancer. Her family--three sisters, one brother, mother and father who are divorced--all live in Winnipeg where Sherry and Karl grew up. Karl's family--his parents and one sister--live in Edmonton. All family members reacted hysterically when Sherry told them of her cancer diagnosis and her mother and mother-in-law cried incessantly over the phone. Karl was frightened initially but claims "it's a part of our life now!" Between visits Sherry and Karl started reading up on her illness and they now understand that it is a rare type and that it is likely to be fatal.

Karl's work in aluminum siding is slow during the winter months which allows him to spend much of his time with Sherry and the children. Sherry works two nights a week as a waitress part-time at a local restaurant. "Living without my kids is like cutting off my right arm!" claims Sherry who adores her children. The couple rarely go anywhere without taking the children.

Mark was born when the Sandermans were very young, before they were married, and they feel he is an extremely nervous child as a result of all of their arguments during his early yeras. He has a visual impairment in one eye and wears corrective lenses, and has an auditory impairment which has recently flared up again in one ear. He plays hockey on a league and has always been one of the top pupils in class. He is obviously his parents' pride and joy. The three items on the wall of his bedroom clearly indicate that Mark is very much a child with contemporary interests. A poster of Michael Jackson hangs adjacent to a pendant reading "Oilers--1984 Stanley Cup Champions." He beams from ear to ear as he shows me the classroom chart of "Math Superstars" where beside his name only, there are three stars. Mark is very fond of his younger brothers and plays beautifully with them and takes responsibility for them. Mike has accompanied Sherry on one of her clinic visits and watched while she received her treatment.

The Sandermans had initially decided not to tell Mark about Sherry's cancer, but reversed this decision once they noticed a radical change in his behaviour. He became absent-minded, physiclly assaultive with his brothers, and became increasingly defensive and sensitive. He would cry readily and was getting into frequent fights with friends. Sherry asked him "Mark, are you upset with mommy 'cause mommy's sick?" His lack of response indicated to her that she had zeroed in on the right issue. After listening to Sherry's explanation of her illness he replied "Mommy that's what Terry Fox had and he died. Are you gonna' die?" She answered "No." with a nervous laughter as she recounted this e[illegible] to me. He was so visibly upset with the possibility of her dying that she replied "Mommy's not going to die of cancer. Mommy's going to be very sick and mommy's going to lose all her hair. You're gonna laugh at me having no hair!" Mark could not appreciate his mother's attempt at humouring him. After this discussion, Mark was temporarily angry but then "he turned out to be a different kid after that." He would constantly approach his mother and embrace her. "Now he's back to normal."

Sherry had been meeting with a psychologist at the hospital under Karl's insistence. He felt she was responding "too cooly and unemotionally" to her diagnosis. She mentioned to the psychologist that she would like some assistance in dealing with Mark's inquiries, so the psychologist asked permission for Mark's participation in the study.

During our two visits together, Mark was eager to share his experience with me. When he was encouraged to ask questions he could not get the words out fast enough and listened attentively to each of my replies.

His story about cancer was brief:

> Five weeks ago my mom talked to me--she had cancer. We talked about how we were feeling. I was sad and I didn't know how mom was. I was playing football and I thought she might die.

He elaborates on his story during our interview (and so the formulated meanings and related themes are presented there) which follows in Table 4. Table 4 contains segments of our dialogue which were considered significant to the parental cancer experience. Included is one lengthy excerpt in which I answer some of Mark's questions about cancer. This was incorporated to illustrate Mark's curiosity with disease-related information, and equally important, to demonstrate some ways of answering children's concerns about cancer, at their level. I also include a section to demonstrate the typical manner in which I would validate interpretations.

Following Table 4 are Mark's drawings along with a summary of my interpretations of them. At the end of his case study I provide a commentary in which I discuss some features of our dialogue which have implications for parents, teachers, and others who are in a position to help children of cancer patients.

Table 4

Abridged Version of Interview With Mark Sanderman: Significant Statements, Formulated Meanings, and Themes

First Interview

	Significant Statements	Formulated Meanings and Themes
	(MA: Mark; MI: Michelle)	
MA:	(Referring to drawing in Figure 13 and to his story) She said she wanted to talk to me and I thought she was going to ask if I wanted to go somewhere, and then she said "I have cancer."	The news of his mother's cancer was totally unexpected.
MI:	What did you first think when she said that?	First thoughts after hearing about mother's diagnosis were about her dying. He is still concerned about mom dying. *(Theme 11: Mourning Past, Present, and Future Losses)*
MA:	I thought she was gonna' like die.	
~~MI:~~	Do you still worry about that?	
~~MA:~~	Just a bit.	
MA:	I think they get put in a thing and then they get put in a graveyard dug underground then if they're bad they go to the devil and if they're good they go up to heaven.	Knows about burial and traditional Christian view of afterlife. *(Theme 13: Making the Connection Between Life and Death)* ✓
MA:	Yeah, when I was over here (in mom's bedroom) I asked her (if she was going to die) but she said "no."	
MI:	Do you believe her?	Disbelieves mom's assurance that she won't die *(Theme 3: Being Parental)*
MA:	No. She might die.	
MI:	How do you know?	
MA:	'Cause like Terry Fox has cancer, he died.	Compares mother's fate to that of Terry Fox. *(Theme 7: Obtaining Information Ab[illegible]ncer)*
MA:	(Referring to his second drawing, Figure 14) It's at school time. We were having a little soccer game and we were playing against a different team of school kids. I got some goals and so did. . . One of the kids who kicks, fights, and trips.	After hearing of [illegible]'s cancer diagnosis he becam[illegible] sensitive to kids fighting. (He inv[illegible]s this interpretation later [illegible]
MA:	(In referring to his story) We talk(ed) about how we were feeling. I was sad; I don't know how mom was.	Felt sad about mom, was [illegible] hear about mom's sadness *([illegible]eme 3: Being Parental; Theme [illegible]: Deep and Painful Sadness)*
MI:	You don't know how mom was feeling.	
MA:	No.	
MI:	Do you wonder how she's feeling?	
MA:	Yeah.	
MI:	What did you think she might say if you asked her.	

MA:	Sad.	
MI:	When do you think about mom?	
MA:	When I'm at school and stuff. And when we're having the Terry Fox Run.	Terry Fox Run is a reminder to him of mom's illness. *(Theme 7: Obtaining Information About Cancer)*
MA:	She gets drugs put in, it's not kind people smoke. It's a different kind and it's taking her hair away and I don't know how--her hair's falling out.	Mom's hair loss doesn't bother him. He understands it is caused by anti-cancer drugs but doesn't know how this happens. *(Theme 5: Sustaining the Symptoms)*
MI:	What do you think about that?	
MA:	I just think it's the cancer.	
MA:	What if you get cancer all over?	Is curious about terminality of mom's disease *(Theme 11: Mourning Past, Present, and Future Losses)*
MI:	And then there's no more good or healthy cells you mean?	
MA:	Yeah.	
MI:	Well then the person dies.	
MA:	Is that the kind, did Terry Fox have it all over?	Uses Terry Fox as an index or metaphor through which to talk about mom's cancer and to judge her prognosis. *(Theme 7: Obtaining Information About Cancer)*
	In the following section I answer Mark's questions about cancer.	
MI:	Do you have any questions about cancer?	
MA:	How do people get cancer?	
MI:	Um hmm. And what other questions?	
MA:	That's all.	
MI:	You want to know how they get it? (Yeah) Well sometimes cancer, they're not really sure how people get cancer, where it comes from. But what happens is that it's a small cell, and then it becomes two cells, then three, and more and more. And they take up the room of the healthy cells. Do you know what a cell is? The cell is a little teeny weeny thing and a whole bunch of them, millions and millions, make up the whole body. And if doctors find a special cell in the body that doesn't look like the normal cells,(Yeah) it's probably a cancer cell. And it starts eating the food of the other cells and then there becomes more and more of them. . . you know what I mean? (Yeah) They take up all the food and there's no room for the other cells. They're like little wee, wee, things, you can't see them without a microscope.	
MI:	Well right now mom's getting drugs right? You know the drugs you were telling me about? (Yeah) And what happens is sometimes it kills some of the healthy cells, too.	He was confused about why mom's hair was falling out. *(Theme 6: Being Confused About Cancer and Its Treatments)*
MA:	Why?	
MI:	Because it's very strong medicine.	

MA:	What if it doesn't kill any and it just kills the cancer. . . .What if it kills cancer though.	
MI:	What if it kills all the cancer. That's good. Then there's no more cancer.	
MA:	If it only kills some, then there's some more, right?	
MI:	Yep. That sometimes happens, too.	
MA:	. . . what if you get cancer all over? And then there's no more good cells?	
MI:	Healthy cells, you mean? (Yeah) Well then the person dies.	
MA:	Is that the kind, did Terry Fox have it all over?	Is curious about Terry Fox. *(Theme 7: Obtaining Information About Cancer)*
MI:	Um humm.	
MA:	Where was his leg? (can't get the question out fast enough, he's very involved in conversation)	
MI:	What do you mean?	
MA:	Like his leg. . .	
MI:	Came off--how?	
MA:	How?	
MI:	Well what happens is sometimes the cancer gets all over and it gets into the leg, (yeah) and some parts of the body get worse than other parts of the body. You know when you're sick sometimes you feel sick more in one place than in another place? When you have a headache or a stomach ache? Well when people have cancer there's usually one part of the body that's worse than the other parts. And with Terry Fox his leg was bad. It had a lot of cancer in it. They wanted to stop the cancer from spreading to other parts of his body.	
MA:	Did they cut it about right here?	He is particularly curious about the amputation of Terry Fox's leg. This is partly due to his fascination with the amputation process, and partly because the first symptom of cancer in his mom was a tumour in her leg. *(Theme 7: Obtaining Information About Cancer)*
MI:	Yes.	
MA:	How come they cut the bone?	
MI:	What should they have done? What do you think they should have done?	
MA:	I don't know why they cut off the bone here.	
MI:	You mean they think that they should have taken off the skin and everything without the bone?	
MA:	No 'cause it would be bloody. But how come they cut off this bone? It had cancer, too? Was it hard to cut it?	
MI:	They have special tools to cut it.	
MA:	Yet but how do they cut it.	
MI:	With almost like a saw.	
MA:	Do they use one of those big saws that they go shhh shh (demonstrates use of a manual saw)	
MI:	No they use an electric saw and it would go through the bone easier so it wouldn't be that hard for the person.	
MA:	What if it was a real saw?	
MI:	It would probably hurt more. It would take longer, too.	

MA: He's sleeping.

MI: That's true the guy's sleeping so he wouldn't feel it.

He is telling me that a person is under anaesthetic so s/he would not feel the pain of the procedure.

MI: No they use a better saw than the saws people use to saw wood.

MA: Do they break it?--(again he demonstrates)

MI: No, no the doctors cut it right through.

MA: How do they get the other leg?

MI: (I misunderstand him) It didn't go to the other leg.

MA: No, that sort of steel thing that was on him.

MI: Oh what they do is it has something to hold it. Like it clips on the leg, here. So it'll stay on. He kind of puts his knee into it. Stand up for a minute, I'll show you. Pretend my hand was his leg. Put your knee right up. (I demonstrate how an artificial leg works by having him put his knee in my hands). Only it would be a smaller one so you'd be comfortable and then you would get used to it. So now you have an idea of how it might feel like for him. Do you understand?

MA: Yep.

MA: What about, I don't know. . .what are the drugs like?

MI: What do you mean? The drugs that take away the hair, in the needle?

MA: Yeah. What's it for and what's it look like?

MI: It looks like liquid. It's a liquid. It's just like when you get a needle only they put a different kind of stuff in.

MI: . . .what else do you want to ask?

MA: Why do they have to put the drugs in?

MI: Well what do the drugs do?

MA: They kill cancer.

MI: Um humm.

MA: And then why do they take away hair, too?

MI: 'Cause sometimes they kill healthy cells too. Remember I said that. They can't always recognize, they don't always know when there's cancer and not cancer. Usually they kill cancer but sometimes they kill other things.

MA: That's why the hair goes.

MI: Um hmm. It'll grow back though. It doesn't kill it forever and ever, it grows back when you're finished taking the medicine. Did you know that? (shakes head no) Did you think that your mom was going to be bald forever and ever. (Yeah) It grows back.

MI: What would happen if mom died.

MA:	There wouldn't be any more fun. Mom plays with me. lots. She takes me out to the park sometimes.	Equates mom's death with no more pleasure. *(Theme 11: Mourning Past, Present, and Future Losses)*
MI:	Why would kids be afraid to talk to their mom sometimes?	Afraid to talk to mom about cancer if she was ill for fear that the noise would disturb her and make her condition deteriorate. *(Theme 3: Being Parental)*
MA:	If they're laying in bed and they're really sick and they got cancer, I think that it would be too much noise and she would get more sicker.	

Second Interview

MI:	How did you feel after my visit, last time?	Having opportunity to talk about mom made Mark happy. The discussion relieved his inner pain. *(Theme 17: Benefitting from Interviews)*
MA:	I felt happy.	
MI:	Can you explain "why" you felt happy?	
MA:	Because it was hurting me inside and now it's not hurting me inside.	
MI:	It's not hurting you inside, now you feel happy. What changed? Why - before did you feel sad and hurt, and now you feel happy?	
MA:	Because of the talk we had.	
MI:	Why did you choose to draw a picture like this where your family's all happy?	He and his family are happy subsequent to the interview. Noticed family changes from the onset of mom's illness; especially in behaviour of siblings. *(Theme 12: Adapting to Changes in Daily Living)*
MA:	'Cause we're all very happy now.	
MI:	The whole family's happy now. And how was the family before?	
MA:	I was sad and Billy and Cory were.	
MI:	How could you tell that Billy and Cory were sad?	
MA:	'Cause when they were playing before they weren't playing before as they used to.	
MI:	What kinds of things were they doing differently?	
MA:	Before they were running, then (after mom got sick) they were walking. They were throwing the ball slowly.	He noticed that his siblings were moving slowly and he interprets this as a manifestation of their sadness about mom. *(Theme 10: Deep and Painful Sadness).*
MI:	That's interesting. What else were they doing differently?	
MA:	Like even on the bed they were jumping just like this (motions slowly with his hand).	
MI:	So everything is slow kind of? Is that what you're saying that everyone moved a lot slower?	
MA:	Yeah.	
MI:	How did you think your mom got cancer, before I explained it to you?	Saw cancer as contagious up until our interview. *(Theme 6: Being Confused About Cancer and Its Treatments)*
MA:	I thought it was spreading the cancer.	
MI:	You thought it was spreading? How did you think she got it?	

MA:	By somebody else who had it. . . .If I had cancer and me and my mom, I would be very sad. And it would be spreading through the whole family.	He believed that his mom got cancer from someone else. He thought that mom's cancer would spread throughout the whole family. *(Theme 6: Being Confused About Cancer and Its Treatments)*
MI:	You mean you thought that everybody could get it, in your whole family? You thought that people could just catch it? And how would they catch it?	
MA:	By being close to them and it's just coming right to them.	He believed that one could get cancer through close physical contact.
MI:	Touching them.	
MI:	You also said that you didn't tell any of your friends about your mom's cancer. Is there a reason why you don't talk to your friends about it?	
MA:	'Cause they might tell their other friends.	
MI:	What's wrong with that?	
MA:	Because they'll go to lots of people and they'll be telling jokes about it.	He is afraid to discuss his mom's illness with peers for fear of them teasing him *(Theme 4: Feeling Different From Peers)*.
MI:	Do you want to tell me more about that?	
MA:	Like they'd be saying "His mom's gonna' die." (He mimicks in a nasty, teasing voice.) And tease me and stuff.	
MI:	Did someone do that?	No one actually teased him but he fears that they would.
MA:	No.	
MI:	What makes you think that they would say that?	
MA:	'Cause it's not a very nice thing cancer.	He is aware that society discourages open discussion of cancer.
MI:	So you think that they'll start telling jokes, what kind of things would they say? (He snuggles up in my lap.)	
MA:	"My mom's gonna' die" and it's nothing very funny.	
MI:	(I explain to him why children tease like that, and give him suggestions of what to do)	
	(I begin to validate my interpretations from our previous visit, one week ago.)	
MI:	I am going to ask you things and you tell me if that's the way you feel or not. These are from our last talk. When your mom told you that she had cancer you were really surprised. You were kind of shocked. You weren't expecting her to say that. Is that true?	
MA:	Yep.	
MI:	And when you first heard it you thought she was going to die. And the reason you thought that was 'cause you knew Terry Fox had cancer and he died from it, right?	

MA: Yeah.

MI: If you think that what I'm saying isn't true and you want to correct it, please do, okay?. . . .When you asked your mom if she was going to die and she said no, you didn't believe her. Why? Didn't you think she was telling you the truth?

MA: 'Cause Terry Fox had cancer and he died.

Uses Terry Fox as a cancer model. *(Theme 7: Obtaining Information About Cancer)*

MI: When you were fighting with your friends, was part of the reason you were fighting 'cause you were angry about your mom having cancer?

MA: No, 'cause they were kicking and shoving and hitting.

MI: So it had nothing to do with you.

MA: Right.

MI: You were talking to your mom about your feelings about her having cancer and you were telling her that you were sad?

MA: Yeah.

MI: But you didn't know how she was feeling, right? Now, were you afraid to ask her 'cause she might say she was sad and you didn't want her to be sad?

MA: Right.

MI: And you also think about mom at school alot when you're away from her.

MA: Yeah.

MI: And you are reminded about your mom having cancer when you have the Terry Fox Run or whenever you hear Terry Fox's name you think about mom 'cause she has cancer too.

Worries about his mom having cancer. *(Theme 8: Experiencing Fear and Anxiety)*

MA: I think about her all the time.

MI: You think about her all the time, because she has cancer?

MA: Yeah.

MI: Why didn't you tell your teacher about your mom?. . . .For the same reason that you don't want the kids to know?

MA: Yeah.

MI: Did it bother you that mom's hair was falling out?

MA: No.

MI: What did you think when you first saw it coming out?

MA: I thought "why was it coming out?"

Mom's hair loss didn't upset him; he only wondered "why" it was coming out. *(Theme 7: Obtaining Information about Cancer)*

MI: Was the reason that you were asking me about Terry Fox because he had cancer and you felt that if you could learn more about Terry you would understand more about mom's cancer?

He was using Terry Fox as means through which to obtain more information about his mom.

MA: Yeah.

MI: And are you afraid to talk to your mom about cancer because you're afraid that it would make her more sick?
MA: It won't make her more sick but I think it's scary to me.
MI: Why?
MA: 'Cause I'm nervous to talk about it.
MI: Would you like to all of us to get together, now, to talk about your mom?
MA: I'd rather not.

He is not afraid to talk to his mom about cancer because it will make her condition worse, but rather because he is afraid to discuss it with her. *(Theme 8: Experiencing Fear and Anxiety)*

As our interview is drawing to a close, I thought it would help to relieve some of his fears by having the Sandermans meet together as a family. Mark, however, was not ready to do this.

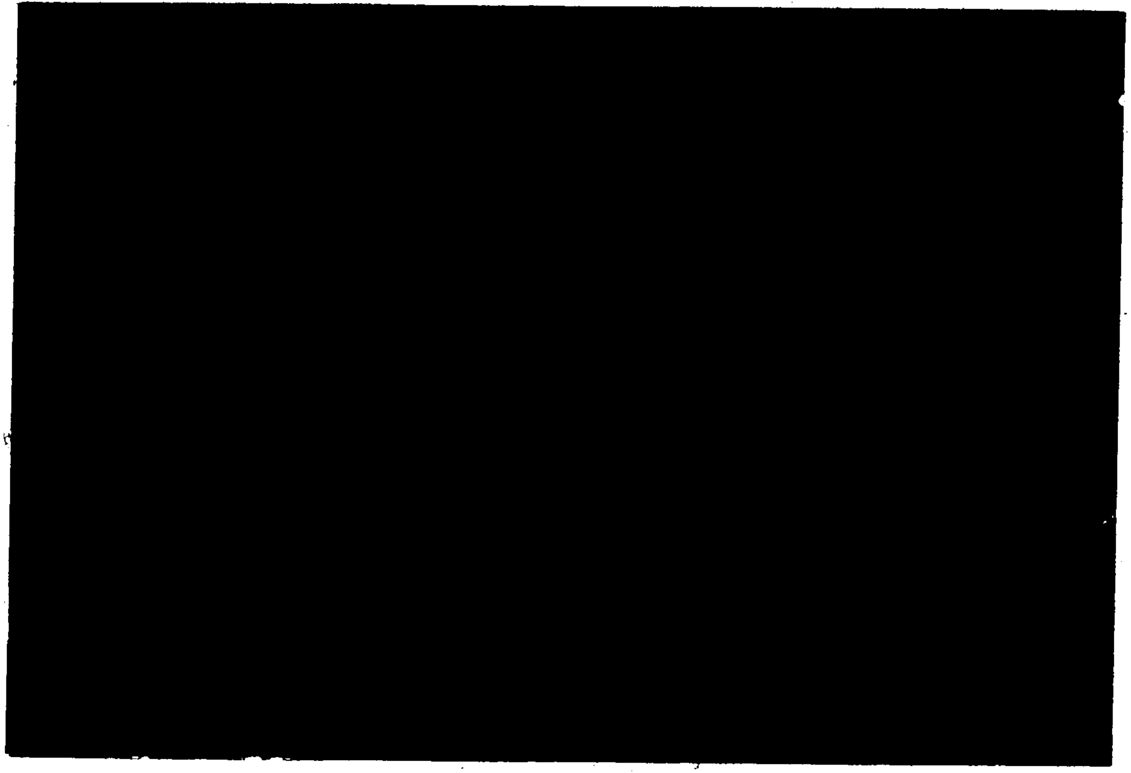


Figure 13. Mom talking to Mark about cancer.

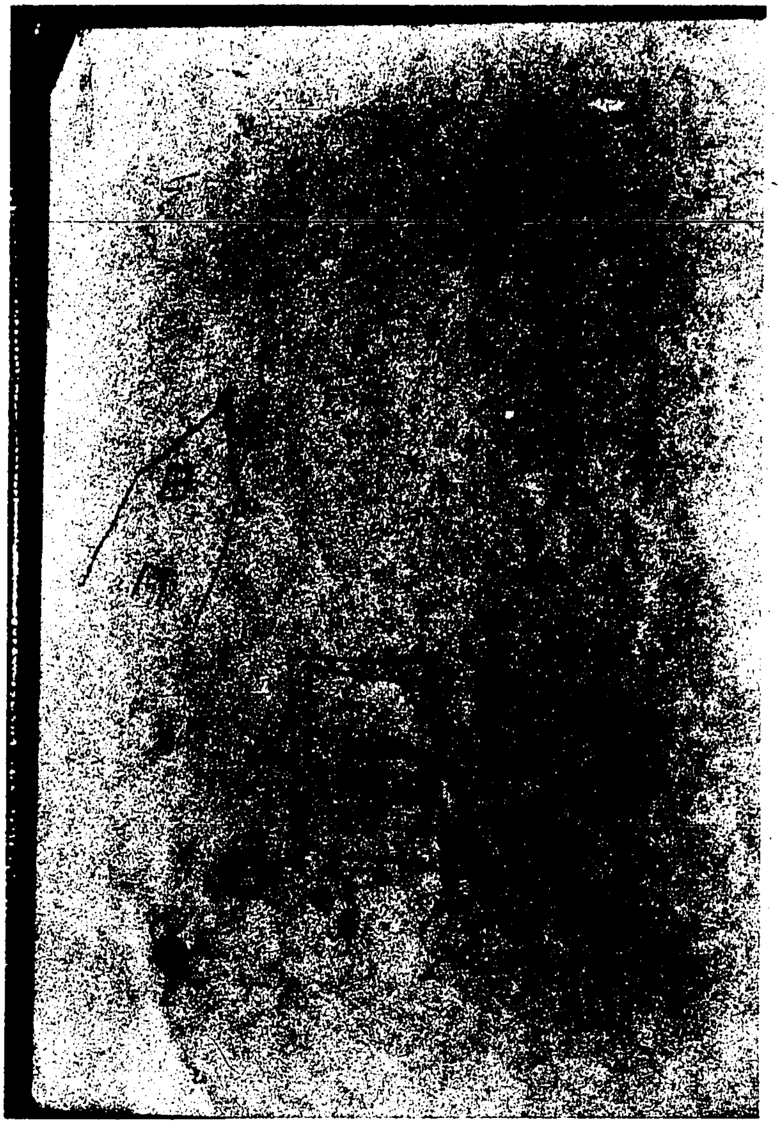


Figure 14. Mark playing soccer.

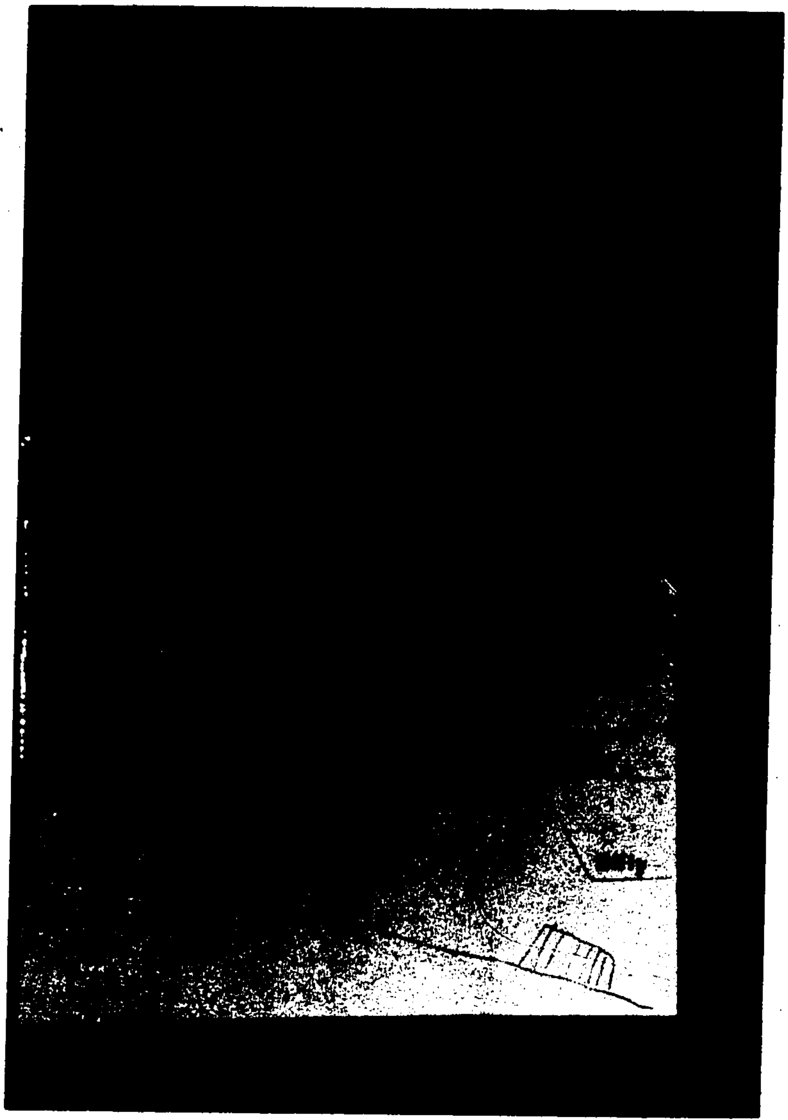


Figure 15. Mark, Cory, and Billy in the park.

Figure 16. Mark playing football with Ted.

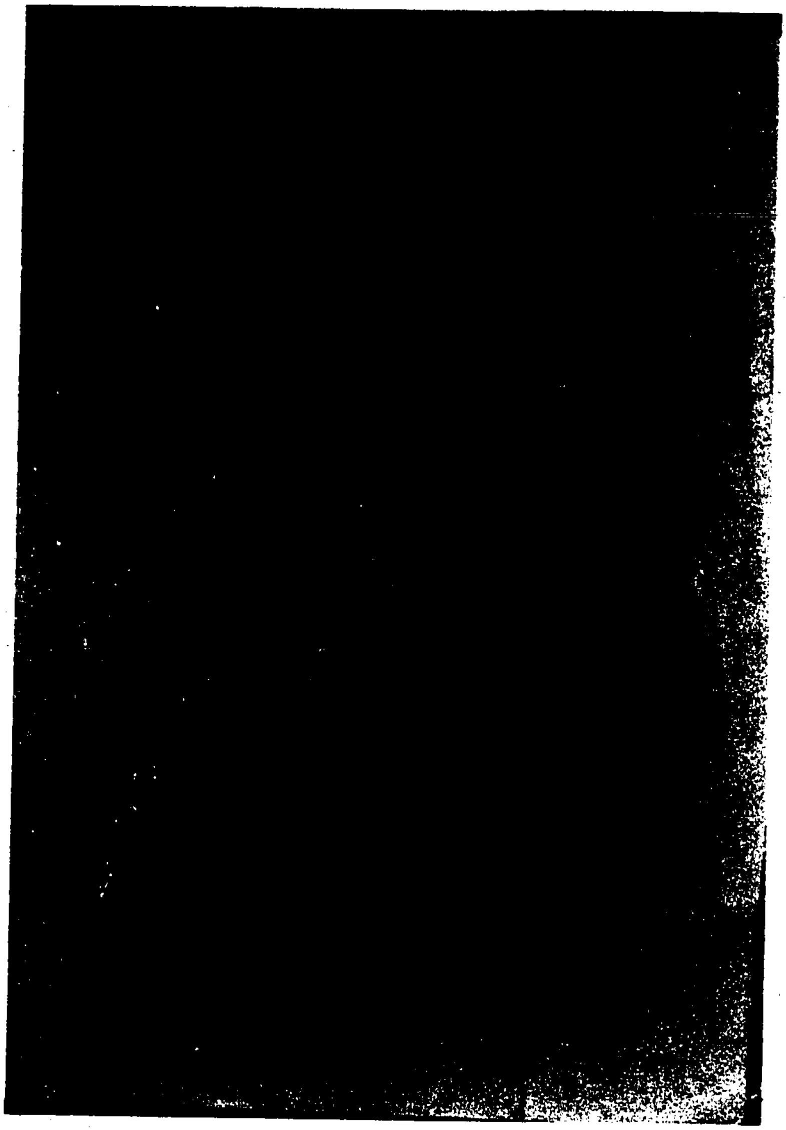


Figure 17. Mark's family.

Interpretation of Mark's drawings

Overall, Mark's drawings reflect his reserved, hesitant, nervous nature in that his figures are mostly stick figures and he chooses to use pencil and not colours. In his first drawing (Figure 13) Mark draws himself with his hand in his mouth which can be interpreted as either his pensiveness (as his mother speaks to him about her cancer) or the regression which his mother had commented upon. The doors leading from his room to his mother's room are finally open and the issue of mom's illness is open for discussion. His feet appear large and strong while his mother's appear small and weak. He is facing her "head on" while mom is facing sideways--she is not facing her feelings (nor is she facing Mark) directly. Mark's dresser drawers are showing in his bedroom, possibly indicating that there are still some family secrets and withheld feelings ("closed away").

In his second drawing (Figure 14) Mark draws himself in goal secluded in a box and isolated from his peers. His house has no foundation--he feels insecure. He has chosen to draw himself involved in a game of soccer, an aggressive sport which requires "kicking" and a sport where the ball is "out of his hands." The ball is away from him as his peers play. Mark communicates through this drawing that he feels isolated from his peers and angry about what is happening to his mother.

Mark's drawing of the playground (Figure 15) is extremely chaotic. There are barriers separating him from his brothers and each of them (he has two brothers, three years and one and a half years) is similarly separated from their surroundings. They are in the park alone and away from their parents.

During our second session together Mark did two more drawings (Figures 16 and 17). In the first of these drawings (Figure 16) he is separated from his friend, Ted, by a barrier. He is able to be with his friend but he feels different from him because of his mother's illness. The two of them are throwing a football indicating that things are more under Mark's control (as opposed to what is indicated in Figure 14 where the ball is being kicked, and is "out of Mark's hands"). He is participating in the "game" and he is happy. Even the sun is smiling.

In his last drawing (Figure 17), the whole family is together and they are happy. There has been more openness to the issue of mom's cancer between interviews and Mark has benefitted from being able to share his thoughts and concerns.

Commentary

Of particular interest in Mark's interviews are: his voracious curiosity about the details of cancer and its treatment; the way in which he uses Terry Fox as a cancer model; and, the secrecy he maintains about cancer with friends and family and the peer ridicule he anticipates such discussion would incur. Mark wants to know all kinds of specifics about cancer. He is curious about the kind of drugs that are used and how they are administered and why they cause hair to fall out. He is inquisitive about where cancer comes from and what exactly it is. He is intrigued by Terry Fox's illness partly because he wants to compare it to what he knows (and does not know) of his mother's cancer type; and partly because of his pure intrigue with the amputation process. He knows that his mother's cancer started in her leg; it was after he accidently kicked her that she discovered her tumour. His unvoiced question is "Will mom need to have her leg cut off, too?"

His belief that his mother caught cancer from someone else, and that it would be spreading throughout the family, is not such a gross misconception when one thinks of the many adults who believe (or act as though) cancer is contagious. The nature of the metastatic process contributes to the notion of cancer "spreading" from one person to another (like it does through the body). To think, however, that he held this belief and lived secretly with the fear, is indicative of what happens when discussion about cancer is not open, and when facts are withheld.

Mark was afraid of discussing cancer with his parents and with his peers. He anticipated the sadness he would feel in hearing of his mother's sadness, and in thinking he had precipitated it. At the end of our second visit together, Mark joined his parents in the living room to watch his favorite television program. I sat down with his parents and showed them Mark's drawings and story (with his permission). His parents cried quietly as they read his words. They had no idea, until that moment, of exactly what he was experiencing. When Mark glanced up and saw his parents' tears, he retreated to his bedroom to watch his program. He was sad, as were his parents; each was afraid to see or hear about the other's sadness.

Mark anticipated that sharing his experience with his friends would give them cause to ridicule him. His fear was rooted in the knowledge that cancer is not a desirable topic for discussion. He picks up this message from his interactions with his family, his own feelings, and from his general perception of societal taboos about cancer.

What came as a surprise to me was, that even though the school staff organized an annual Terry Fox run, and Terry Fox had been a topic of classroom discussion, the details of his illness were not discussed (not even something as crucial to the run as his artificial leg!). His teacher did not know about his mother's cancer. If the classroom teacher had inquired unto whether any of the children knew of others (besides Terry Fox) who had cancer, perhaps this would have encouraged Mark to mention his mother's situation. Teachers are in a position to provide a forum for children to learn about cancer and its impact on the families and, in doing so, can dispel contemporary myths about cancer. They can also teach children how they can be supportive to peers who are living with cancer in the family.

The indications are that cancer needs to be more of an open issue even though it is a difficult one, especially when there is an afflicted member in the family. As demonstrated with the Sanderman family, each individual family member suffers anyway--alone. Misconceptions were being developed and entrenched in Mark's mind in the absence of facts, from school or from his parents. He felt isolated from his social milieu and this was reflected in his words and in his drawings. He welcomed the opportunity to talk about his experiences with me; he hesitated to broach the matter with significant others. Families need help to discuss such an emotional topic with their loved ones. The benefits of discussing cancer-related issues honestly and openly were evident in Mark's words and in the words of the other participants.

Case #3: Jerry Slavens: "I Help Her Get Along"

The Slavens Family

Lena Slavens was diagnosed with cancer of the left breast which was biopsied in December of 1983. She commenced radiation treatment in January 1984 followed by four weeks of radical radiotherapy to the breasts and surrounding areas. She was then referred for chemotherapy and radiotherapy. She continues to have an open infected area in her breast from the radiotherapy. Healing has been slow because Lena is diabetic. Joey, her youngest child, would bang her over the breast which helped induce an area of infection. Lena was referred to Support Services at the cancer center to get a letter of support for financial aid from Social Services. A psychologist referred Lena to this study to obtain an assessment of the situation between Lena and her children.

When Lena heard that she had cancer she "couldn't cope with the word" even though she claims she had no thoughts related to the possibility of dying. Her maternal grandfather died of throat cancer, her father who had cancer died in an accident, her maternal aunt died of breast cancer, and her mother had bone cancer but is still alive and staying with the Slavens family. Lena, thirty-three years old, has been a single parent for the past three years. The family has had no communication with her husband since their separation. Sometimes Joey (Lena's youngest child) asks about him but the older two boys--Jerry, fourteen years, and Darryl, twelve years--do not inquire about their father.

Lena describes Jerry as a "good child" who will probably settle into a "clean job." He currently works part-time for a fast food chain. Darryl, Lena predicts, will be a mechanic. Five-year old Joey is a very "nervous child" who has frequent temper tantrums and has never been toilet trained. He was of toilet training age when his parents were going through the process of separation[19]. Joey enjoys grade one but Lena reports that the "boom hits" when he comes home. Joey sleeps in bed with Lena. Lena's mother has always lived with the family but she did not join us at any point during my visit.

Lena explained to the children that she had cancer and that she was going for radiation therapy. The children did not seem to react when she told them, and they "were never concerned if I'd die from it or anything like that." She knows that the children are

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[19] The day after I visited the Slavens in their home I made a follow-up phone call. Lena claimed that I performed miracles with Joey. He became toilet trained. He was the first one up in the morning and made himself breakfast. Prior to my visit he would spend all his time by his mother's side.

worried and confused when she sits and cries and Joey will hug and try to comfort her. She is regularly fatigued from the pain medication she was taking for her breast infection. Her disease is in remission.

She has grade nine education and has raised the boys on her own. She believes that "if you believe there is a God, He's going to help you" but has never introduced her boys to the Roman Catholic religion she, herself, was raised with. Lena was extremely receptive to my visit. She is a welfare recipient and has no involvements, work or otherwise, outside of the home.

The following passage has been excerpted from Mrs. Slavens' medical file with the permission of her doctor. It is included here to provide the context within which Jerry Slavens is experiencing his mother's illness. It becomes apparent in this passage why doctors cannot commit themselves to a definite prognosis: when they do and it is dismal, the patient becomes depressed; when they do not, the patient becomes extremely anxious because of the uncertainty with which s/he must live. Mrs. Slavens lives with the expectancy and fear of reoccurrence with an uncertain future and the resulting depression:

> Lena Slavens is becoming extremely depressed and it has not been helped by the fact that when she went one night to the Pinewood's hospital at the height of her reaction some well-meaning doctor told her that she should inform her children that she has five years to live! I explained to Sonia (Lena's sister) that unlike my colleague I have no idea how long Mrs. Slavens has to live. She might develop metastases in her vital organs within the next three months and not survive even five months never mind five years. On the other hand, I have seen patients like Mrs. Slavens who have gone on living surprisingly and gone on living for ten and fifteen years.
>
> She also states that Dr. M. on occasion told her that she had disease behind the breast bone and she is convinced there is something there that we have not treated which is going to kill her. She (Sonia) says that on occasion Lena spends her whole week in bed acutely depressed. I have spent a lot of time talking to her and I hope that she will convey some of this to her sister because, in my opinion, the depressed patient is the very one that gets metastatic disease. Every effort should be made to keep up the morale of this patient as none of us in all honesty knows how long she has to go. With encouragement (which I feel is the most important part of her treatment) she should at least be able to spend her time happily rather than in morbid depression. (Doctor's progress notes, August 17, 1984)

I walked down to the basement and entered Jerry's abode, posters of heavy metal rock groups and a button collection plastering his four walls in this retreat separate from the bedroom quarters of the rest of the family. His hair combed neatly, prepared at any moment for a call from his girlfriend who, sure enough, rings during our interview. Jerry is an easy-going adolescent, a grade nine student having failed his grade seven year. He is outgrowing his childhood interests of collecting--stamps, comic books, coins and paper money. He was friendly, enthusiastic and invited me into his domain. He did not know I was a psychologist (nor did he know what a psychologist was until I explained it to him) yet he gave me a complete psychosocial description when I asked him to write a story about cancer.

Table 5

Jerry's Story About Cancer With Formulated Meanings and Themes

Story	Formulated Meanings and Themes
Cancer is one of the most devastating diseases in the world today. Cancer kills thousands upon thousands of people each year.	He realizes how destructive cancer is. *(Theme 7: Obtaining Information About Cancer)*
But we have to remember that it doesn't kill you just like that.	Is aware that cancer is rampant and often terminal.
There is a "before part," that is, you have to go through a lot before your days are over or before it is healed. The disease ends the happiness of everyday life.	Knows about chronicity of disease.
When the disease strikes a person it not only strikes them but it also strikes the members of that family. They, your family, have to live with your pains too.	Cancer has an impact on the entire family.
Some days may be good and nothing goes wrong, but other days are terrible when the person with the disease starts feeling the pain.	There are good and bad days for patient and family. *(Theme 5: Sustaining the Symptoms)*
The pain wants to come out, but it can't so the person with the disease takes it out on you (as in getting mad). The diseased person has to go through hell each day. I don't know what the pain is like, but I can tell you one thing that it does hurt a hell of a lot	He understands that his Mother displaces anger onto he and his brothers. Understands severity of emotional and physical pain mom endures. *(Theme 3: Being Parental)*
because I have to go through each day watching one person in my family going through that hell. I hope that some day they will find a cure for this devastating disease so that all people with it can stop feeling the pain and start living normal lives.	He suffers, too. Lives in hope of a cure. Longs for normalcy.

Table 6

Abridged Version of Interview with Jerry Slavens: Significant Statements, Formulated Meanings, and Themes

	Significant Statements	Formulated Meanings and Themes
	(J: Jerry; M: Michelle)	
J:	It s a little different for me. I think I might understand it a bit more. I have a good idea of what's going on.	Because he is older, feels he has a better understanding of how his mom is reacting to cancer, than his siblings do.
M:	Okay, how about if we start by looking at your pictures. Which is the first one? Do you want to tell me about it.	
J:	Well like you said this is a picture when we first found out and this would probably be after she told me and she was crying and stuff like that. Around then I didn't have nothing. It just came, just like that.	He didn't have any feelings initially, when he first was told by mom about her cancer.
M:	What was your reaction?	
J.	It wasn't. . . .It was just like someone saying something. It was just there. I never felt anything.	
M:	It didn't have an effect on you either way. You put here that you were sad. Or was it your mom who was sad? (I am referring to how he has labelled his first drawing.)	
J:	Well I wasn't happy of course. It was just little feelings like it's there, that's too bad.	He felt mildly sorry for his mom. It didn't register for him right away.
M:	Do you want to show me the next one (his second drawing, Figure 18b).	
J:	Okay. This is happier days, a usual day, still with cancer. She's not hurting at all, she's just watching TV. That's about it. And this one here it's one of the Saturdays when she's crying in bed which she usually does.	There are good days and bad days. Sometimes mom is feeling okay and on those days things are happy for Jerry; unhappy days are when mom spends the day crying in bed. *(Theme 5: Sustaining the Symptoms)*
M:	How's that for you when it happens?	
J:	Uh. Doesn't make you feel great. She just sits there and cries.	It hurts him to see mom cry.
M:	What do you do when she cries?	
J:	I sort of just cuddle up to her, you know.	He cuddles up to her to comfort her and help her along. *(Theme 3: Being Parental)*
M:	That's good.	
J:	And I'll help her along.	
J:	This one's just a normal day again. See there's happy days and there's bad days. It kind of switches on and off.	Mom's health and mood fluctuates and as a result so does the family.
M:	How often does it switch?	
J:	Maybe a week. A week'll be good. And usually there'll be one day that'll be bad. And then there's the bad days when it hurts so much that she yells at us for little things that we do.	He understands that when mom is extremely ill she has less tolerance for him and his brothers; for the little things that they do. *(Theme 3: Being Parental)*

M:	How easy is it for you to show your feelings?	
J:	You mean towards my mom and my family? It's like we're the kind of family where we don't really let it out to each other. It's kind of inside of you and it stays inside and you work it out by yourself. I talk things out in my head.	In their family they cope with their feelings individually. Jerry uses self-talk to help him problem solve about his predicament. *(Theme 15: Resorting to Internal Dialogue)*
M:	Do you prefer that?	
J:	Yeah it's worked. For me anyways.	He realizes that this may not work for everyone but it works for him.
M:	Do you ever talk to your friends about it?	
J:	It comes up once in awhile. "My mom has cancer and I have to babysit, I have to do this. She has to go for treatments." Otherwise they don't like to hear about it.	He only mentions his mom's illness to friends when it interferes with his plans. *(Theme 4: Feeling Different From Peers)*
M:	How has it changed your life? Has anything changed in your family since your mom got cancer?	
J:	Usually every day was. . . .It's still not the same. You can tell now that it's not madness 'cause we're doing this wrong. It's 'cause she's sick.	Recognizes mom is angry that she is sick.
M:	And how do you respond to that?	
J:	I get angry but not really. I understand when she does get mad. I can tell that it' hurts her alot and that she has to let it out somehow so it's usually us she lets it out on. It's not heavy, you know, just little stuff. I can understand why she would do that.	He gets angry at mom but is very understanding about what is happening to her. He interprets her anger as releasing the pain. *(Theme 9: Feeling Angry)*
M:	(He has told me that he thinks there should be a book about the pain, "stuff sick parents can handle, the stuff they can't do", to "tell children how they can go about helping"). Is that something you still wonder about? How you can be helpful to your mom?	Feels a book which tells children: how they might better help their parents, about the pain their parents are experiencing and about their parents limitations while they are ill. *(Theme 18: Advising Other Children of Cancer Patients)*
J:	What can I do? . . . .Just comfort her and that's about it.	
M:	(advice for other kids)	
J:	I'd tell them that it's not easy going through this with your mom or whoever in your family has cancer. I'd tell them the sorts of things I went through, what I did. Depends on the person I guess. I'd give them some ideas of what they could do to help to make her feel better.	Would tell a peer going through a similar experience that: it won't be easy, he'd relate his own experiences and how he handled them. *(Theme 18: Advising Other Children of Cancer Patients)*
M:	Was there any point at which you thought about her dying? Or thoughts about her death?	
J:	Yeah my mind touched upon it. I thought about it. That it wouldn't be that nice. What would we do if she died?	Thought about the possibility of mom's death and what their future would be like without her. *(Theme 11: Mourning Past, Present, and Future Losses)*

M:	What do you see in terms of the future of your mom's illness, the progress of it?	
J:	I hope they can. Right now what they do to her and what they give to her to try and stop the pain doesn't work that good. It'll maybe stop the pain a little bit not that much 'cause you can tell that it hurts her an extreme amount. I hope that in the future that they'll have something better.	Sees painkillers as ineffective; hopes they'll develop something better. *(Theme 6: Being Confused About Cancer and Its Treatments)*
J:	Most of us are sad. While she's going through that pain we have to live through it, too. We have to take the pain that she's taking--mentally, you know. Sometimes we have to stop doing things like she may be hurting and won't go up town. Our aunt or grandmother would go shopping. It works out okay but it's a change.	They, too, are living through mom's pain and that makes them sad. *(Theme 5: Sustaining the Symptoms)* It restricts family activities and changes their routine. *(Theme 12: Adapting to Changes in Daily Living)*
M:	How else has your family changed since your mom's been sick?	
J:	We usually cook our own meals. We don't really have a supper around here. Anymore we used to. Before she had cancer we had suppers, we made them. Now sometimes we have suppers but not really.	
M:	How do you cope with the pressure?	
J:	It works out okay. It's not really. It doesn't really affect that much. Still in my mind it doesn't hit me real hard. It's not a thing that bothers me that much but it's always there. It's just like you're too young to understand what's going on.	He does not feel the full impact of his situation. Although he has a better understanding than his brothers, he still does not completely understand what is happening. *(Theme 6: Being Confused About Cancer and Its Treatments)*

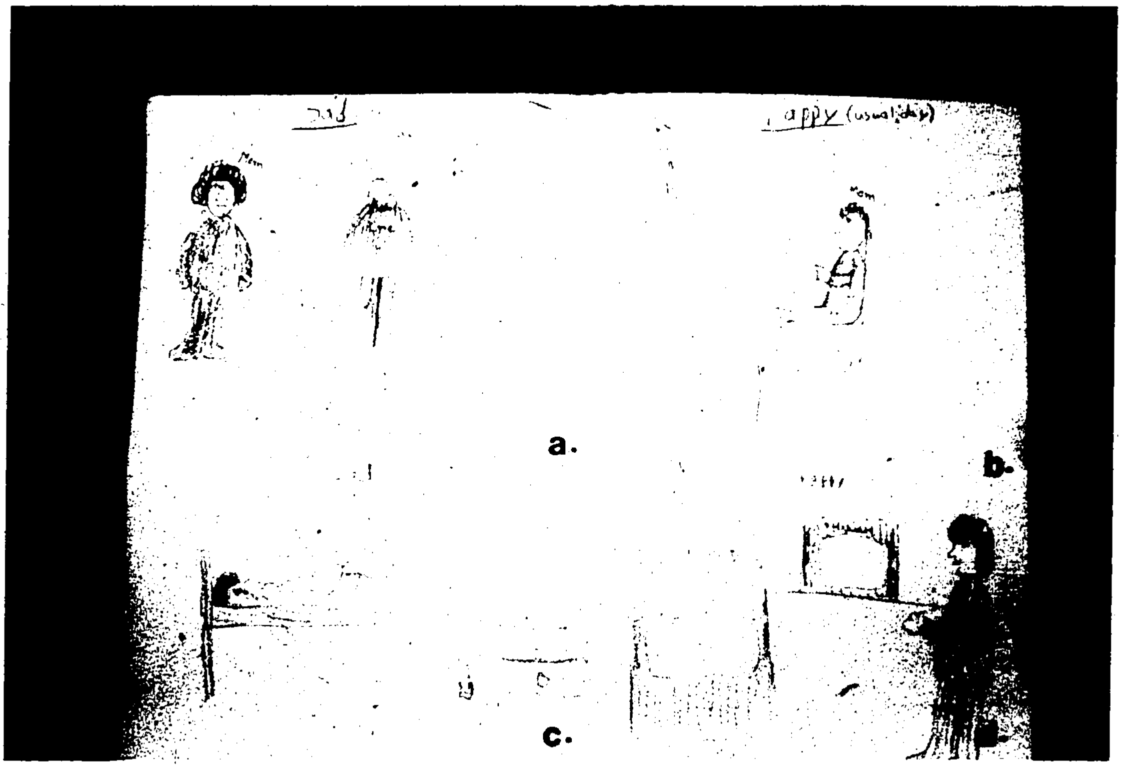

Figure 18. Jerry's drawings.

a. Mom telling Jerry about her diagnosis. Both are sad.
b. It's a usual day and mom is watching T.V. Things are happy.
c. Mom is lying in bed crying: it's a sad day.
d. Mom is in the kitchen: another happy day.

Commentary

Outstanding features of Jerry's story and interview are the contradiction between how he writes about cancer and how he speaks about it, and his extreme understanding of, and caring for, his mother.

In his story he speaks very powerfully about cancer using strong words ("hell" and "devastating," for example) to communicate a forceful message: "Cancer ends the happiness of everyday life" for both patient and family. During the course of our interview, however, Jerry understated the severity of his mother's illness (in terms of prognosis) and the impact it had on him. When I asked him whether or not he thought of his mom dying, he replied "My mind touched upon it" yet he wrote in his story that "Cancer kills thousands upon thousands of people each year" and "it doesn't kill you just like that." In conversing with me he used expressions ("It's not 'heavy' you know," "It doesn't really effect that much" and "It's not a thing that bothers me that much") which made it seem as though he was downplaying the impact to maintain an air of "bravado." Adolescents, especially adolescent boys, seem to deemphasize how they are affected by cancer for the sake of maintaining a brave facade. Jerry does acknowledge that the family suffers "mentally" but at the same time reassures me that "it's not that bad."

His understandingness towards his mother and his caring for her come across very clearly. He understands that she displaces her anger about her illness and that she discharges her pain by yelling at him and his brothers. He empathizes with the "extreme amount" of pain she endures and physically comforts her. When I inquired into what would help him through his experience, he responded that he would like to know what he could do to help his mom (as well as wanting to know about what "stuff sick parents can handle" and "what stuff they can't do.") He would advise other children in his same situation by giving them ideas on what they could do to help their sick parent. He continually emphasized his concern for his mom and his desire to learn more about how he could help her. Although most of the children became more solicitous and caring of their sick parent during the illness, for Jerry this seemed particularly so. Being the oldest son in a father-absent home seemed to result in his being extremely close to his mom. Elizabeth (ten years) and Stan (fourteen years) were both only children of single parents and they reacted similarly though more intensely than Jerry (They had more symbiotic ties with their mothers). To Jerry, losing a parent meant being left without parents; to Stan and Elizabeth, losing their mothers meant losing their family.

The implications from Jerry's interview are that for those who want to understand older children's experience of living with cancer, it is helpful to have them write about it and compare it with what they express verbally. We can also learn from his interview that it is useful to consider a child's position in the family constellation and the size of the family (number of siblings, and whether or not it is a single parent family) when anticipating the amount of responsibility a child may feel for a parent, and how intensely s/he feels it.

Summary of Case Studies

The case studies demonstrated that children of cancer patients, regardless of age, individual temperament, family background and constellation, past and current life adventures, share common as well as unique meanings of living with their parent's illness. Christine, Mark, and Jerry were all very attuned to their parent's physical and emotional reality. Despite the secretiveness (and denial) their parents maintained about the implications of cancer, the children sensed the fatal inevitability and had thoughts about death. Christine with her well developed repertoire of symbols and metaphors for cancer, Mark with his voracious curiosity for facts and his fascination with Terry Fox, and Jerry with his brave facade, revealed that different children have different ways of expressing their experience.

V. DISCUSSION AND CONCLUSIONS

After completing Chapter IV, I realized that the uniqueness of the present study did not lie in the number of discrete "facts" that the phenomenological methodology I had used enabled me to uncover, or the number of "facts" reported in the literature which I had been able to corroborate or confirm. I realize now that my findings are not dis coveries but un coverings of what we intuitively know about children of sick parents, if only we allow ourselves to stop, look, and listen to them.

Beyond this, it is necessary to reflect not only on the differences between children of cancer patients and other children and adults in crises, but also on the similarities. My findings, thus, are not always different from those in the literature, they are only more comprehensive. The more important contribution of this study arises from shifting the focus away from the question "What is different about children of cancer patients" to "How are these children the same as other children, and indeed the same as adults?" To this end, the first part of the discussion is a comparison of my findings with findings of research previously reviewed (studies on children of cancer patients and on children's conceptions of death). Some comparisons are also made with the literature on children and adults who are cancer patients, and on siblings of pediatric cancer patients. In the second part of the discussion some comments are made on the nature of our society as revealed through the children in my study. In the third section, some limitations of the study are outlined followed by sections on research and practical implications. The final section of the discussion is my personal reflection on the research process. The chapter and dissertation end with conclusions about the experience of being a child while a parent has cancer.

A. Discussion

1. Comparison With Existing Literature

Children of Cancer Patients, Adult Cancer Patients, Pediatric Cancer Patients and their Siblings

The findings of the present study confirm reports of other researchers who have found similar themes in their studies of children of cancer patients, and the patients themselves, child cancer patients, and their siblings. Following, now, are some comparisons with the literature, and a discussion which elaborates on the themes.

The tendency for children to become a "pseudoparent" during the illness experience, a central theme in my study, was also found by Grandstaff (1976) and Wellisch (1979) with other children of cancer patients, by Kubler-Ross (1984) with children who have terminal cancer, and by Lindsay and McKarthy (1974) and Cain et al. (1964) with siblings of cancer patients. By becoming a "parent," children can attempt to keep things in tow by caring for their parents and by protecting them. By keeping questions and emotional reactions to themselves for fear of disturbing and burdening parents, the children protect not only their parents, but themselves. Szasz (1959) explains: ". . .this has its basis in the bio-social fact that the child is dependent on the parent's integrated behaviour for his own survival and comfort. Hence, he has a pragmatic motive for keeping mother and father in good shape, so to speak" (p. 164).

The inclination children have to take responsibility by blaming themselves for a parent's illness has also been found by Grandstaff (1976), Adams-Greenly and Moynihan (1983), Rosenfeld et al. (1983) with their samples. Kubler-Ross (1984) and Sourkes (1980) have found children who are dying and their siblings to manifest this same theme. The readiness to assume responsibility for the other's distress might be explained by Piaget as being due to the basically egocentric logic of the child. But this same tendency, however, has been found among adult cancer patients and their spouses (Dunlop, 1985). Children, like adults, seek causes for cancer. Dunlop (1985) explains:

> Man is persuaded that to every effect there is a cause, so if cancer develops usually someone, or usually something must be blamed and these include habits, pastimes, previous illnesses or injuries. The family doctor is at times accused of missing symptoms or of delaying the consultant, of procrastination, or of inadequate or inappropriate treatment. Occasionally the family may be blamed, frequently God. Much of this is a search for a scapegoat. . . .It is often less disturbing to find someone to blame even themselves, than to accept the realization that life is uncertain and reasons for disease inexplicable. (p. 56)

Adults as well as children blame themselves for the cancer initiation and development. Children who are cancer patients and even adults feel they are receiving punishment for past wrongdoings. Siblings or children of cancer patients may have wished something bad upon their relatives during moments of anger and feel that the cancer is an answer to their plea.

Both the tendency for children of cancer patients to "pseudoparent" and their tendency for "self-blame" appear to be attempts to gain control, in a situation where in fact they have very little control. They are making an attempt to make predictable the capricious nature of life with cancer.

Although the literature does not reflect a concentration on positive elements of the child's experience while living with cancer in the family, Iles (1979), Sourkes (1980), and Fine (1984) give a few examples. Iles (1979), in her pilot study with five siblings of pediatric cancer patients, found them to be compassionate, tolerant, empathic towards parents and appreciative of their own health. Positive caring between patient and siblings was found by Sourkes (1980) and between parent and child by Fine (1984). In addition to being caring, empathic, and tolerant of their parents, the participants in my study were able to look at some of the "lighter and brighter" sides of their experience. They expressed humour and noticed growthful changes in themselves and/or their parents. Their resilience and ability to resort to inner resources for coping were remarkable.

Some other findings in the literature which were supported by the present study include children: fearing their own illness vulnerability (Adams-Greenly & Moynihan, 1983; McGuire, 1984; Sourkes, 1980) and death (Binger, 1973; Cain <u>et al</u>., 1964; McGuire, 1984); developing symptoms of the ill family member (Binger, 1973; Sourkes, 1980; Tessman, 1978); being ostrasized for having cancer or for having it in their family (Iles, 1979; Isenberg, 1981; Krell & Rabkin, 1979; Lavigne & Ryan, 1979); experiencing a decline in school performance (Rosenfeld <u>et al</u>., 1983; Rosenheim and Ichilov, 1979; Wellisch, 1979); having dysphoric mood and anxiety disturbances (Rosenfeld et al., 1983; Rosenheim and Ichilov, 1979; Arnowitz <u>et al</u>., unpublished manuscript, 1983) and experiencing improved overall functioning after being given the opportunity to talk about concerns related to cancer in the family (Adams-Greenly & Moynihan, 1983; Rosenheim & Ichilov, 1979).

Children's Conceptions of Death

Developmentalists who espouse Piaget's theory and apply it to research on children's death conceptions, propose that concepts of death proceed in an orderly sequence from "ignorance" (death is reversible; temporary state) to "limited understanding" (death is irreversible but not personally applicable) to "accurate comprehension" (death is a universal, natural process). The language of these psychologists is biased in the direction of adult structures (as outlined previously in the methodology section "Children and Phenomenology"). Their presuppositions are that childhood consciousness is incomplete or faulty adult understanding. In the tradition of "rationalism" (Chomsky, 1972) and Kantian categoricism, Piaget is interested in intelligence as defined by its purported endpoint:"intellectual maturity" as demonstrated by formal operational thought. The logical thrust of his "structuralist" formulations is the articulation of universal, abstract, formal structures (i.e., ideas) which are said to be underlying generative structures for the order of events (Sullivan, 1980).

What happens to young children who articulate very little about death at the level of words? We know so little about the extent to which statements made by young children are adequate representations of their thoughts and thinking processes. The implications of the present study are that the child's thoughts about death and cancer are far richer and more extensive than we estimate, as manifested by their symbols, metaphors, and perceptions. We can only "interpret" their intended meaning and check back with them whether or not our perceptions are accurate. But our interpretations need not be limited to a cognitive-developmental structure.

Wass and Corr (1984), based on their cognitive developmental presuppositions about death conceptions, make the following statement: "The cognitively advanced adolescents who have reached formal operations [12 years and up] fully comprehend death" (p. 13). The comments of two of the participants in my study challenge the assumptions of the above statement. Ten-year old Elizabeth remarked: "Sometimes I think there are questions nobody knows, unless they come back from heaven, five years later." In response to my question "What happens to people after they die?" five-year old Dawn replied: "I don't know. Do you?"

The point is that none of us knows for sure what happens after death. No one knows better than anyone else whether "Mom will come back after the Indians die" or whether she will be reincarnated. We are dealing with an unknown phenomenon, just like cancer, and we can create theological explanations, but how advanced, really, are these from a child's "magical-mythical" (what Piaget calls "prelogical") explanations? Three-year old Melanie's reference to her mom's death "Maybe she'll come back as someone's baby. . .maybe she'll be our baby" is parallel to a nine-year old girl's statement cited by Wass (1984): "I believe your soul goes into the next baby born." These statements are both equivalent to the Eastern philosophy of transmigration of souls. In Piagetian terminology, the first child, only three years of age, is organizing her thought according to preoperational structures. The second child, who is eight years old, should be functioning at the stage of concrete operations, and the abstract Buddhist philosophy would be reflective of formal operational thought. What value is there in categorizing children's death conceptions in cognitive-developmental terms when there is the potential for so much overlap across stages? All of the children in my study, regardless of age, believed in the permanence and irreversibility of death. The youngest children, too, knew that mommy would not come back and that they would see her again in heaven or after she was born again. They knew of their parent's impending death and mourned the threatened separation (and the actual separation once it happened).

In two studies by Wass and her associates, with 250 children ages nine through twelve (Wass, Guenther, & Towry, 1979; Wass & Towry, 1980), concrete operational children (9-12 year olds) gave "egocentric-affective" definitions of death including: "death is a scary thing," "something I don't like," "very sad," "something that hurts and I wish never happened." They also give religious definitions such as "mommy went to be with God." The researchers imply that "egocentric-affective" responses are limited to nine to twelve-year old children. I must admit that these have been my personal reactions to death: thoughts of my own, and deaths of those I have loved. It seems from the discussion so far that each of us incorporates fragments from all levels of cognitive functioning (preoperational, concrete operational, formal operational) thought when attempting to understand death.

Ten to eleven-year olds, in the above-mentioned studies, provided explanations that fell into the category of "general law and nature explanations" such as "death is a part of the life cycle." It has been my experience that children as young as three are able to conceive of death in this way. In my study children attempted to make connections between birth and death (Theme 13: Making the Connection Between Life and Death). They drew flowers and spoke of these flowers as metaphorical representations of their parents who were dying.

Wass and Corr (1984) claim that young children have no answer to the question "what is death?" and that they usually respond with "I don't know" or parrot answers given to them by adults. The young children in my study responded similarly. Melanie's stereotypic and monotonal "Mommy's never going back again" and Christine's confused "The body up up and the soul down down" were reflections of this. However, later on, during the course of our spontaneous conversation, they communicated fragments of their knowledge through images and words. Cognitive-developmentalists who adhere to Piagetian formulations assume that at the preoperational stage of intellectual development children have erroneous or incomplete understandings of death. Perhaps it is <u>our</u> understanding of children's death conceptions which are incomplete, and, <u>our</u> assumptions and the way in which <u>we</u> inquire about these understandings, erroneous (through direct questioning instead of spontaneous conversation)?! Furthermore, how can researchers refer to "incomplete" understandings of death, when our own understanding of the subject can never be complete?

Bluebond-Langner (1978), Kane (1978), and Carandang and associates (1979) report instances of cognitive advancement or deterioration as a result of children's experience with chronic illness or death (their own or a family member's). The younger children in my study did manifest thinking which, according to the cognitive developmental model, would typically not surface until the stage of concrete operations. I did not systematically study this phenomenon so I can only suggest that the generalizations of these researchers (Piaget's guidelines and the findings of Bluebond-Langner, Kane, and Carandang <u>et al</u>.) be used only as a frame of reference to guide our understanding. The various characteristics at the different stages should be viewed as themes, aspects of which can appear at <u>any</u> phase of development.

Generalizations about children should be complemented with sensitivity and responsiveness to the individual child with whom one interacts. A particular child may have many qualities and circumstances in common with other children but there are always characteristics which make him/her unique. This uniqueness applies to all aspects of growth and development, including conceptions of death.

2. The Nature of Society

> Critical reflection and dialectical knowledge require that one move beyond a search for themes within the internal structure and search for themes in the external structure to an anthropological statement about the nature of macro-society. (Suransky, cited in Wood, 1982, p. 77)

The discussion will move beyond the twenty-three participants to relate what "social-cultural arrangements" in Canadian society are revealed through them (Wood, 1982, p. 76). I was interested in analyzing how findings obtained from this study could be linked to more global issues. Three themes emerged as comments about society, in general. The first comment is the adult fear of speaking to children about serious issues like death and the second, the existence of cultural taboos which inhibit free expression of emotions and which alienate "cancer families." The third comment relates to the decrease in the size of the average Canadian family and the limited extended family network, which calls for more support from professionals for families dealing with serious illness.

Adults in our society have difficulty talking with children about the truths in their lives. In an age of impending nuclear war and global annihilation, mass starvation and murders depicted explicitly and regularly on the television, we are still fearful of broaching the subject of death with our children. In the present study children as young as three had thoughts about death. The prospect of parental death, whether distant or imminent, is present in the minds of children and omnipresent in the minds of children of cancer patients. Some parents were able to discuss death in abstract terms with their children but otherwise the topic of impending death from cancer was not mentioned until the last possible moment. In general, adults treat serious issues in a cursory or incomplete manner or ignore them altogether. We are so afraid of saying the wrong thing, or burdening children unnecessarily, that we say nothing at all. We <u>can</u> communicate openly and honestly with children about the painful, ominous, and frightening feelings that serious illness and the inevitability of death summons in all of us. The children in my study demonstrated the value of open discussion of serious issues by their improved emotional wellbeing. More than answers, these children wanted an opportunity to talk with a concerned adult; all they needed was someone who would actively listen.

With the transience and mobility of Albertans, and with the large influx of immigrants and Canadians from other provinces, there are many families that have limited local support in times of crisis. With the demise of the family as we once knew it, many families are now separated and many mothers and/or fathers are left alone to cope. Parents now have fewer options for care of their children when in the midst of family crisis. When relatives travel to be with sick family members this places an added stress, especially when the prognosis is indeterminate. There are smaller families, single-parent, single child families (Elizabeth, Stan, and their mothers, for example), and in these families the emotional stress is intense with fewer members to share physical and emotional support. A child in this situation not only stands to lose a parent, but his or her entire family. Professional caregivers and other adults can play surrogate family roles in families which are small and isolated from extended family members. Children step in and assume parental roles when grandparents are not available to do so.

Cancer is still very much a cultural taboo in Canadian society. Terry Fox and Steve Fonyo have run a long way to bring cancer out of the wards, but we still treat the issue in such a secretive manner. The "cancer family" learns to be secretive about cancer as a means of avoiding conflict with well-meaning and "not so well-meaning" friends. The social isolation and rejection, and fear thereof, is as common amongst cancer patients as it is amongst their children. Isenberg (1981) found the following six dilemmas to be characteristic of the experience of the adult cancer patient:

> 1. If I talk about what's on my mind friends will withdraw;
> 2. I want communion from friends but receive platitudes;
> 3. I face irritating incidents when I disclose I have cancer, or I feel isolated when I don't;
> 4. If I tell friends I have cancer I face rejection;
> 5. I would like to be valued in relationships while I am a cancer victim; and
> 6. I feel isolated and discriminated at work, yet I want to be a part of social situations and achieve my ambitions. (p. 98)

These six dilemmas parallel those experienced by children. It becomes clear that "mutual protection" and being secretive about cancer inside and outside of the family, is the family's way of adapting to a society where having cancer (or living in a family where a member has cancer) means being alienated from the mainstream of society. That is, to continue to be accepted, participants in society, the members of the family have to "keep quiet about the cancer."

Also taboo is allowing ourselves and our children open expression of emotions. Sadness is hidden in the privacy of bedrooms, fear and anxiety find physical outlets, and anger is displaced onto unwitting targets. Rarely do we allow ourselves to feel, acknowledge, and share these genuinely human and acceptable feelings. By denying ourselves this opportunity, we are also denying our children.

3. Limitations of the Study

Although several interesting and complementary themes have emerged in this analysis, no clear cumulative structure has evolved. I have developed a personal sense of what it is like to have a parent suffer and die from cancer, while one is still a child. I encourage others to share my journey by reading through the descriptions, but the journey will stop short of any final destination. There are a number of limitations to the study. First, this is a study of my experiences with twenty-three children of cancer patients. In many ways what I have found, or chosen to see, is a factor of who I am. My description of their experience is only one possible interpretation of the phenomenon "living with parental cancer." Second, my interactions with these children were limited to one or two meetings, enough time to gain an adequate slice, but not enough time to grasp the totality of their worlds. Third is the limit imposed by our separateness: Can we ever truly understand another human being's experience? Can we truly empathize with an experience we ourselves have not experienced? Cottle (1972) accurately describes this dilemma:

> Throughout the work, I have tried to hold to the notions that I could never fully know these young people I would "study"; that I could never totally articulate the impressions born from our contacts together. And yet, just as we learn that no one can speak wholly for us, so do we also realize that others' impressions, theories, words speak for substantial parts of us. And because they help to sort out the convergence of feelings and events that comprise our involvements, intellectual and social, they assist us in taking a step in overcoming error. (p. 26)

Fourth, although I interviewed the parents, I did not incorporate their experiences into the study. Interpreting the parents' experiences, (including their view of the child's experience), and then comparing these with the child's view, would have provided a richer context for my findings. Not having done so, I have, in a sense, separated the child and overlooked his/her "relatedness" to the family. Similarly, although I interviewed more than one child in each family, I did not explore the interrelationships between siblings. I have neglected to emphasize the reciprocal nature of the child's relationship to the world (or at least the immediate environment) which is central in existential-phenomenological approaches to the study of being human.

4. Implications for Research

Studies with controlled objective measures of children's behaviour throughout the illness experience must eventually be attempted. The effects of various independent measures such as sex of ill parent, stage of illness, type of cancer, length of illness, number of remissions and relapses, age and birth order of child, and numerous other variables, need to be studied.

This study has shown how creative investigative techniques are useful in helping children tell us what we want to know. It is unrealistic for a researcher to expect to obtain valid data about such an affect-laden situation using only objective techniques. Further development of the temporal continuum drawing technique as a research and diagnostic tool would be one way of bridging the gap between measures which are too subjective and "unscientific" and those which are too objective. A group of standardized questions, for example, could accompany each of the four drawings.

Research which explores the reciprocal nature of the child's relationship to the family (between child and parent, child and sibling) could strengthen research which focuses only on themes generated from interviews with children. Interviews would be conducted where parents are asked about the child's experience and the siblings are asked about each other. Children in the present study did not spontaneously generate conversation related to their siblings.

Included in Appendix C is the draft of a booklet which I have written and illustrated entitled "When A Parent Has Cancer." Presented in Appendix D is a draft of a second booklet entitled "Helping Your Children" and has been designed for cancer patients.[20] Pilot testing of these two booklets (both of which are based on the findings of the current study) with other children of cancer patients, would be another avenue for future research.

Bluebond-Langner (1978) provides a model for how dying children acquire disease-related information. The model consists of five stages which correspond to five stages in the child's disease process: child knows "it" is a serious illness (diagnosis); child knows names of drugs and side effects (first remission); child knows purposes of

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[20] A special acknowledgement to Dr. Ronna Jevne, who originally proposed the idea of a "cope kit" for children of cancer patients, of which these booklets will eventually become a part.

treatment and procedures (first relapse); child knows that there will continue to be a series of relapses and remissions, without death (series of relapses and remissions); and, child knows of terminal prognosis (peer death). Bluebond-Langner's model can be extended to, and tested with, children who have a parent with cancer. Such a model would have implications for when hospital personnel and parents can and should share certain disease-related information, to fit in with the child's natural acquisition of such information.

The themes that emerge from the present study, and from the studies reviewed in Chapter II can be translated into a questionnaire and used by researchers in longitudinal studies with these children. For example, we know from the study that children are preoccupied with thoughts of death. Do such preoccupations remain with the child with equal intensity throughout the parent's illness? By asking the same questions of children repeatedly at different stages of their parent's illness or of different children whose parents are in various stages of cancer, more specific information can be gained. Another area worthy of investigation would be comparing parental (both the patient and spouse) and child views of the cancer experience.

In the following section, the implications for practical work with children of cancer patients will be discussed.

5. Implications for Practical Work

Several suggestions for practice and clinical work with children of cancer patients can be gleaned from the results of the present study. Firstly, these children rarely make their needs known directly, nor do they ask spontaneous questions. Parents need to know their children's thoughts and concerns, many of which reflect or parallel their own. The pamphlets in Appendices C and D have been designed as exploratory projects to be used with patients and their children, and offers them something to act upon and / or respond to.

The value of observing children's drawings, and attending to both verbal and pictorial symbols depicted in them, has been demonstrated. To use drawings as a communication tool does not require professional expertise. Parents and teachers alike can make some initial hypotheses about children's experience based on their drawings and then discuss these suppositions with them.

A support group for school-aged children would be useful throughout the parent's illness experience. A peer network can be established in which experienced children become teachers and confidantes for the children of newly diagnosed patients; this would meet the needs of adolescents and others who prefer meeting an experienced peer on a one-to-one basis. Children in outlying areas can correspond with each other. Included below is Jeremy's correspondence with an age peer. The father of the child he was writing to, died in the interim, so Jeremy did not complete his letter:

> Dear Jeffrey:
>
> Hi my name is Jeremy Donahue. I had a father who died already. But I am unlucky because God take my father away from me. My dad died April 23, 1983. How are you? How are you taking it? How is your dad? I really miss my dad? Do you go to the hospital and visit your father? When I went to the hospital to visit my dad I always go somewheres because I didn't like to see my dad suffer. Have you talked to the psychologist. She talks the truth. I would like to meet you if you don't mind. I am eleven years old. How old are you? I heard that you have an older sister. I have an older sister named Cindy and she is thirteen years old. How old is your sister? What is your sister's name?

In his letter Jeremy communicates that meeting with another child, who is still going through what he has already experienced, would be beneficial for <u>him</u>, too.

Going into schools and speaking to children about cancer and how it affects children when someone in their family has it, would help to alleviate some of the ridicule and isolation children of cancer patients must endure. An experiential account of my first classroom visit is presented in Appendix E. Such a program could be given on the day of the Terry Fox run (which most schools participate in) or when a child in the school is affected by cancer in his or her family. Allowing children to bring a best friend to hospital with them or to the support group would also improve the child's support system.

Hospitals could become more child-centred, or at least provide a children's corner where children can read--about cancer or [illegible] pleasure--play games and just socialize with other children who are having similar experiences. More particip[illegible]vities by the children on behalf of the parent with cancer who is in hospital [illegible]ce the child's self-concept, and would respond to his/her need to be helpful and [illegible] contribute.

6. A Personal Reflection on the Research Process

"One couldn't, as I realized along my route, have hoped to reflect upon these painful interviews or write about them without touching the most defended, vulnerable, hurtful, hidden parts of one's own inner self" (Scarf, 1980, p. 198). There were many difficult times for me as a "participating observer" in the lives of these families. There was the time when Elizabeth's mother spontaneously and unexpectedly showed me her recent mastectomy scar. There were the times when I read Dawn and Marianne's mother's obituary notice and incidentally came across photographs of her radiation scarred body in hospital files. I watched twenty-three year old Sherry Sanderman lose her hair and thirty-six year old Daniel Albertson walk with canes, like a man twice his age. There was the hospital visit with Stephanie's mother when she had to summon up her energy to apologize for vomiting in my presence. All of this was important for me to experience although it was a very small part of what the patients themselves, and their children had to endure. Yes, they were living with cancer, but this living entailed so much more than anyone could imagine, or would ever want to.

As the children snuggled into my lap, as they excitedly ran to greet me at the door for our second visit, as they presented me with handmade cards, and as they hugged me goodbye or kissed me goodnight, I realized that our worlds had joined. I wondered about how things would be for them after I left--I knew in many ways thing would be better, but I could not help but wonder how they would experience yet another loss.

The listening, the learning, and the writing were very difficult, often painful, but one thing was certain--it was worth every minute! These children taught me about childhood pain and suffering, but they also taught me about human compassion and resilience.

B. Conclusion

The overriding theme of the present research is how children live and cope each day with the anxieties and uncertainties surrounding parental cancer. Their day to day lives have been dramatically changed, their understanding of life and loss and their meaning deepened, and their compassion for and understanding of/for others increased. Their lives have been altered by a disease which is overlaid with mystification and charged with the fear of inescapable fatality.

The themes which have been generated by these children's own words are human themes. The tendency to be angry when faced with tragedy and loss, the tendency for self-reproach when a loved one is suffering, the tendency to ponder life and death, the tendency to love another regardless of how changed physically or emotionally--these tendencies are not only children's tendencies, they are human tendencies. The importance of not severing these children from the adult world has been highlighted. These children's concerns are not only children's concerns. They are adult concerns and they are real human issues.

The tendency for adults to seek refuge in fantasy or religion, to deny the reality of their impending death to themselves and their children, the tendency to blame themselves for causing cancer, are not only adult concerns. Nor are they a regression to childhood tendencies. They, too, are human issues.

Children who are living with parental cancer are living with so much more than a serious disease. They are living with "diseased" attitudes and beliefs which separate them from others, even from other children. Cancer is still a modern day leprosy. Children of cancer patients are not only living in a strained family atmosphere, they are living in a stressful social situation. Children who are living with life-threatening illness in a parent need to be shown that they are part of a large, living social network for their own interpersonal network, as they once knew it, is dying. "Living while a parent may be dying" means continuing on with life in the face of death. Children have numerous personal resources for helping them live with the ambivalence and stress induced by living with parental cancer. They can be understanding and tolerant of their parents, they can look at the lighter and brighter sides of life even while their family is suffering. But they are human and need to be in relation to other humans when their most significant relationship is being threatened. We can learn so much from children of cancer patients. This study is only the beginning.

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APPENDIX A: INFORMED CONSENT FORMS

INFORMED CONSENT FORM

This research project to be conducted by MICHELLE GOODMAN of the UNIVERS OF ALBERTA'S DEPARTMENT OF EDUCATIONAL PSYCHOLOGY has been explained to me and my child. As the parent of ________________, I agree to let him/her participate in this research study. I understand that by participating in this study, my child and I will participate in tape recorded interviews, and that my child will be asked to complete drawings, write stories, and answer questions about his/her experience with cancer. I understand that the purpose of these procedures is to discover what it means to children to have a parent with cancer. I understand that this research may result in my child's increased thinking about, discussion of, and discomfort with cancer and cancer-related activities. I understand that my child may benefit from this research study by participating in these structured and emotionally supportive activities in which s/he will be able to express and clarify his/her thoughts and feelings about cancer. I understand that I may benefit and my relationship with my son/daughter may benefit from this study through Michelle's sharing with me information on my child's feelings, thoughts, and concerns related to cancer and its effect upon him/her. Michelle has explained to me that all information is confidential, and that my child's and my identity will not be revealed unless further permission is sought. I understand that interviews, drawings, stories, and anything that I or my child might contribute, will be used in the development of written materials which will compile a "cope kit for kids" of cancer patients. Any questions that I have about the project's procedures will be answered by Michelle. I am free to withdraw my consent and to discontinue my child's participation in this project at any time.

On the basis of the above statements, I agree to participate and to allow my child, ________________, to participate in this study.

________________ Date: ________________
(parent's signature)

________________ Date: ________________
(Michelle's signature)

INFORMED CONSENT FORM FOR CHILDREN

Michelle has explained to me what we will be doing together during her visits. I agree to let her use our taped interview, my drawings and stories in her research. If my drawings and stories are used in materials which will be published, she will include my name. Otherwise, no one except Michelle will know what I said and did during our time together.

NAME: ______________________

DATE: ______________________

MICHELLE'S SIGNATURE: ______________________

APPENDIX B: PARENT INTERVIEW SCHEDULE

PARENT INTERVIEW SCHEDULE

(where applicable, topic areas will be discussed in terms of first pre- and then post-illness)

(1) Demographic information -- name, age, sex of each family member and other members of household, marital status, socioeconomic status (family income before taxes, employment history of parents.

(2) Family member personality profiles -- describe each child, spouse, self

(3) Family activities and relationships -- boundaries, coalitions

(4) Support systems -- friends, extended family, social network

(5) Religious background -- past and current beliefs, including views on death and afterlife

(6) Change history -- frequency of family moves, change of schools, family separations due to marital discord, work, hospitalization of any family member during child(ren)'s lifetime, famiy routines and roles

(7) Previous experiences with chronic illness and/or death -- circumstances, reactions of individual family members, involvement of children, coping behaviours

(8) Child(ren)'s school performance and peer relationships

(9) Sibling relationships -- supportive? typical

(10) Details of illness -- diagnosis, treatment history, current treatment protocol, relapses and remissions, prognosis, death

(11) Reactions to illness -- emotions which characterize reactions, fears, reactions to death where applicable

(12) Circumstances around diagnosis -- who told children? when? where? how? what were they told about prognosis? about cancer? how did they react?

(13) Children's involvement in illness -- hospital/clinic visits, cororespondence; involvement in care of ill parent, funeral attendance

(14) Impact of disease characteristics on children

(15) Changes in life, in general since diagnosis -- personal, family, children (positive? negative? financial difficulties?)

(16) Parents' understanding of cancer and its treatment

(17) Health of family members

(18) What would have helped you and/or your spouse to cope better? Your children

to cope better?

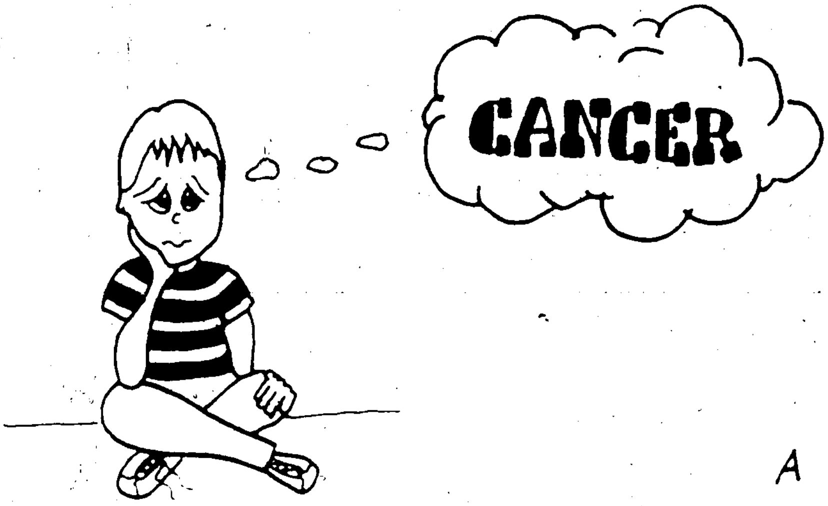
(19) What suggestions would you have for others in your situation?

(20) What materials would you like to see for your children?

(21) Would you be interested in having your children attend a discussion group with peers who are also children of cancer patients?

(22) What was most difficult for you to communicate to your children in the various stages of your husband's wife's illness?
What did you avoid or choose to avoid doing telling them

APPENDIX C: BOOKLET FOR CHILDREN OF CANCER PATIENTS



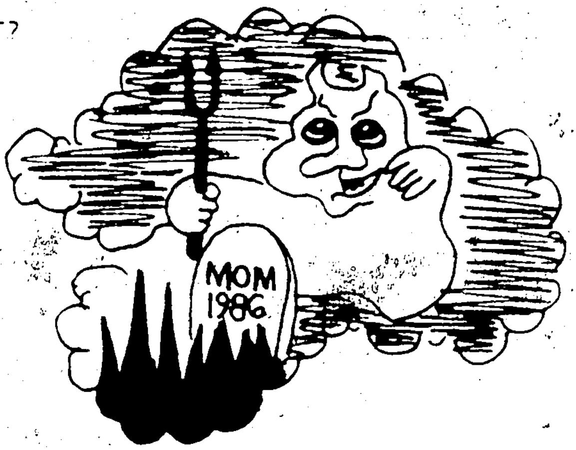
A Booklet for Children of Cancer Patients

By Michelle Goodman

You have just found out that your parent has cancer and you are not really sure what having cancer means. Don't panic. First of all you are not alone. There are people who work at the hospital that like to help children. They can answer any questions you have after you read this booklet. They can also find someone else who has a parent with cancer for you to speak with so you can share your feelings about what is happening.

In the beginning, your parents may be surprised that they have cancer and will probably need a few days to get used to the idea. After a week passes by, don't be afraid to ask them whatever you want. By asking them questions you can help them to understand what you are thinking and feeling. If your parent has given you this booklet, it means that they have read it first. They agree that asking questions, even very serious questions about death, is very important. Usually what happens is parents are afraid to upset their children by talking about what is happening to them and children are afraid to upset their parents. So both children and parents keep quiet about what is bothering them. Each of them is upset and might even cry by themselves in their bedrooms instead of together

(1) WILL MY MOM / DAD LIVE OR DIE OR WHAT?



This is usually the first question many children have when they find out that a parent has cancer. You might be wondering if the cancer your parent has is the same as Terry Fox's, if it is the kind of cancer that kills. Cancer is the name of hundreds of different cell diseases, some are more serious than others, some cause death, some don't. Many cancers, if they are found early enough, can be treated and cured. Even if they cannot be cured, death won't happen for a long time. So chances are that if your mom or dad has cancer, you have a lot of time to spend with them and to talk to them about your fears and worries.

(2) WHY DOES MEDICINE WHICH IS SUPPOSED TO MAKE YOU BETTER, MAKE MOM / DAD SO SICK?

You might be wondering about the kind of medicine the doctors are giving to your mom or dad to stop the cancer from spreading. The drugs are very strong and they might make your parent look even sicker than they were before they started having treatment. You might even wonder how something that makes them throw up, lose their hair or makes them feel tired all the time could be making them better. The drugs affect healthy cells, too, and they are so strong that they affect others parts of the body as well. After awhile the body recovers and your parent will not be so tired. They will have their appetite back again and their hair will grow in. Just remember no matter how different they look, they are still the same person inside and they will still love you the same. Moms and dads are our favourite people in the whole world and we will still love them even when they look and feel different.

(3) HOW WILL I FEEL AND ACT NOW THAT MY PARENT HAS CANCER?

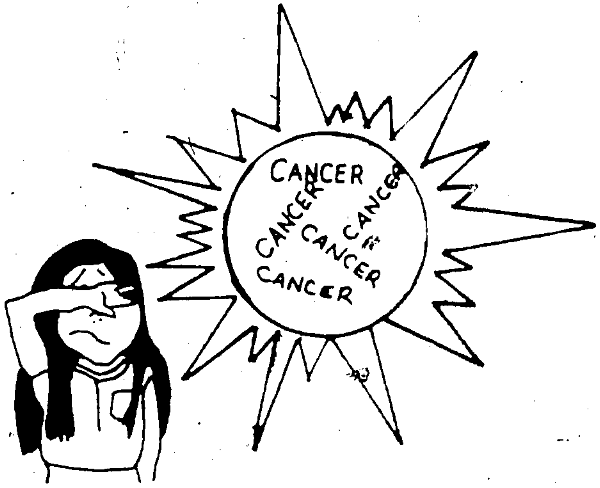
You may notice that you will start having trouble concentrating because you are worrying about your sick parent. Well this is normal and if it is causing you to have problems in school let your teacher know. Tell your teacher why you are having trouble paying attention or doing your homework. You might decide to tell your special friends about what is happening in your family and about how you are feeling. Sometimes other children are mean and make fun of things they don t understand. happening to them that they don t understand. They do this because they are afraid. If you explain to them that your parent is very sick with cancer, and that you are worried about them, these children will want to help instead of teasing you. They will probably want to know more about cancer and how it makes you feel.

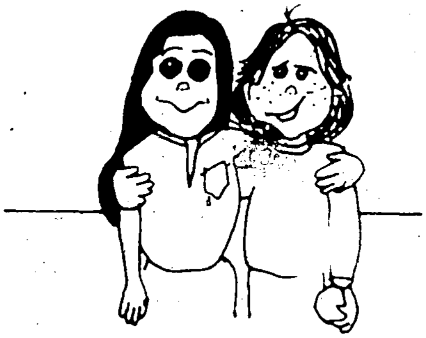
You will start to have all kinds of feelings while your parent is sick. Of course you feel very sad that this is happening and you are sad to watch your parent suffer. But most children start to feel angry, too. We all get angry when we can t have something that we want. You want cancer to go away, you wish that it never happened to your family. You wish that you could do things with your family like you used to. You wish that your sick parent would be home to make supper, to take you to hockey practice, or to go on holidays with you. After awhile, you will get very, very angry beacuse there are a lot of things you want that you can't have. You might start fighting with friends -- even with good friends! You might destroy some of your toys or yell at your brother or sister. You might feel like taking something that doesn't belong to you, from your parents or from a store. All of these are things kids do when they can't have something they really want. You might do these things when you are angry and are afraid to show your anger. So it builds up until you can't control how it comes out and then you explode! The pressure will get to a point where you can't stand it any more. There are things you can do to get rid of these angry feelings each time they come up. Here are some things other kids who have had these feelings do to help them.

(1) Go for a jog.
(2) Punch your pillow or teddy bear.
(3) Write a letter to a friend or to an imaginary friend telling them about how angry you are. You don't have to mail it, just writing it helps.
(4) Buy something special for youself.
(5) Talk about how you feel with a friend, coach, teacher or with your parent who isn't sick.
(6) Bake something or do something special for you and your family.
(7) Draw a picture about how you are feeling. Do you have any other ideas of what you can do? If you do write them down below.
(8) ______________________________
(9) ______________________________
(10) ______________________________
(11) ______________________________
(12) ______________________________

(4) WILL I EVER BE ABLE TO GET "CANCER" OFF MY MIND? WILL I BE ABLE TO HAVE FUN, AGAIN?

It is difficult to feel sad or angry all the time so you will probably try to forget about what is happening for awhile. This is a very good idea. Think about how hard it is to look at the sun for a long time. Your eyes start to hurt and you get a headache, so you turn away. It's kind of the same thing when you have a parent that is sick for a long time. When you worry about your parent all the time you might get a headache and you might start feeling sick to your stomach. When this happens try to take a break by playing with friends or by reading a book. By taking care of yourself you are also helping your parents. They, of course, don't want you to be sick. Don't feel badly that you are having fun while your parent is sick. It is important to have fun, especially when your parent's illness lasts for days and days and days.





(5) WHAT WILL HELP ME TO FEEL BETTER WHEN I AM SAD AND SCARED?

You can feel a little bit better if you and your family can all talk about your feelings together. Not everyone can do this. If you think that this is hard for you to talk about with your family, talk about it with other people that you like and trust. Talk about it with your teacher, with an older cousin or with a priest, rabbi, or minister. There are people at the hospital you can talk with, too. Remember, your mom or dad gave you this booklet to read to help you. They know that you might be interested in talking to someone at the hospital. So, just ask your parents and they will make an appointment for you.

(6) HOW DID MY PARENT GET CANCER? WILL I GET IT, TOO?

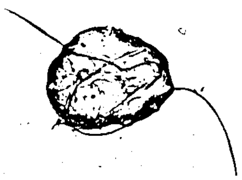
Do you ever think about how your parent got cancer? There are many things we still do not know about cancer but one thing we know for sure. It is impossible to give someone else cancer. You cannot give your parent cancer by making them mad at you or by hitting them by accident or by wishing bad things about them. Cancer happens because something triggers the cancer cells in the body and they keep multiplying until there are more and more. Soon they start to use up the space and the food of the healthy cells.

You know that smoking helps to cause some types of cancer. Some kinds of foods and some kinds of buildings have materials in them that may help to cause cancer. Cancer is not "catchy"! Some kinds of cancers happen to more than one person in a family. This is because sometimes, just sometimes, the same kinds of things go wrong in their bodies. This is something that only very few people have to worry about because not all cancers happen in families. But if your parent has breast cancer or another type of cancer that happens in families, this means that when you get older, you will have to go for regular medical check-ups to make sure that you find the cancer very early before it gets serious. If the doctor finds the cancer early, chances are it can be cured.

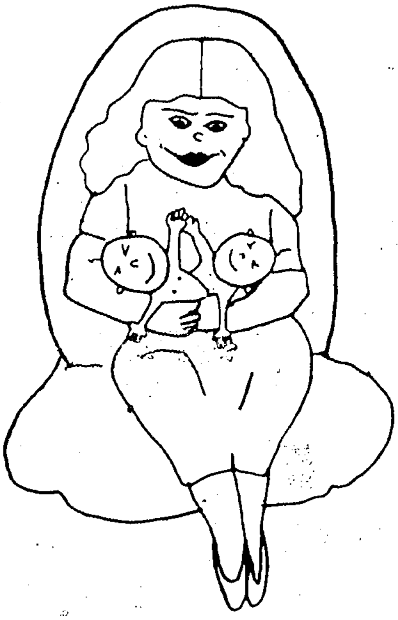
(7) IS IT NORMAL TO THINK ABOUT DEATH?

Even if your parent isn't going to die, serious illness still makes us worry about death. Most children worry about their parents dying even if their parents don't have cancer. If you are thinking a lot about death you might want to read about it. First go to the library and ask if they have books which can help children learn about death and about what might happen after death. One good book about death is called "The Fall of Freddie the Leaf" and it is written by a man named Leo Buscaglia. This is a story which helps us in understanding why we live and why we must die. At the end of this booklet is a list of other books that you might be interested in reading.

No one knows for sure what happens after we die. There is a make-believe story about twins who are in their mother's womb and they are talking to each other while they are waiting to be born. They know that they are going to be born soon and they are very sad. They are happy and comfortable in their mother's womb. They can eat and sleep whenever they like and the way they get their food is fun (through a long tube called an



umbilical cord). They know that once they leave they won't have the long tube anymore. They are frightened. They don't even know if they will have each other. They are very, very scared, because they don't know what will happen to them. Then they are born. They see bright, beautiful lights, nice colours, and they see their smiling mother. She s holding them and they feel cozy and warm. She is feeding them from something that is even more fun to drink from than a tube. And they are still together.



Birth is beautiful and for all we know, death might be beautiful, too. We are afraid of death because we are afraid of pain and suffering. But today there are drugs which can make people feel comfortable while they are dying. Mostly, we are afraid to die becaucse we just don t know what it will be like after. Some people believe there is life after death and we call this afterlife.' They believe in heaven and think that they will meet their families there. Nobody knows for sure. It might be even better than we imagine, but nobody knows for sure. The best thing to do is to ask other people what they think. You can ask your parents, your friends, and your teachers, too.

Everybody thinks about death. It is one of a few things that happens to absolutely everyone. It s something we all have in common. It s something we all worry about, too. The good thing about that fact that we must some day die is that it makes us do as much as we can, the best we can, while we are alive. So if your parent is dying, make the best of the time you have. Do things and tell your parent things that you have always wanted to tell him or her. Don't delay. Tell your parents that you love them, kiss them when you feel like it. Write them a letter telling them all the nice things they did for you that you liked, and all the times you had together that you enjoyed. Write about the funny things and the sad things. Death is a very sad, sad thing. You can t help but feel sad when someone you love is dying.

HERE IS A LIST OF BOOKS THAT YOU MIGHT BE INTERESTED IN READING:

MAMA'S GHOSTS by C. L. Lorenzo.

A dying grandmother helps a young girl understand that sometimes we must say goodbye to those we love even though it hurts.

THE FINAL MYSTERY by S. Klein.

This book has sections on death, ancient beliefs, death and religion, and medical progress.

A DAY NO PIGS WOULD DIE by R. N. Peck

This is about a boy's struggle to accept death and how his father influenced him.

SADAKO AND THE THOUSAND PAPER CRANES by E. Coerr.

In this book the author explains that we are placed on earth not to fear death but to make the most out of life. "To die a little later -- a little sooner -- does not matter. What matters is to live."

THE BOYS AND GIRLS BOOK ABOUT ONE-PARENT FAMILIES by R. A. Gardner.

This book has sections called "Some important things you should know about dying," "Thoughts and feelings you have about the death of a parent" and others.

A TAS[illegible] BLACKBERRIES by D. Smith

Littl[illegible] from a bee sting. His best friend is shocked by this. How he gets used to the [illegible] is described.

CHARLOTTE'S WEB by E. B. White

When Charlotte, the spider, dies at the fairgrounds, her friends manage to take her eggs back to the farm whre they could safely hatch. The friends understand that no one can ever replace Charlotte's special kind of friendship.

THE MOTHER TREE by R. Whitehead.

This is the story of a ten-year old girl whose mother dies suddenly. She now is required to help with the household chores as well as take care of her four-year old sister who asks "When will mother be home again?" The story is about the summer the girls spend with their grandmother.

WITH DAD ALONE by J. Beim.

A mother dies and her oldest boy takes over household duties and care of his younger brothers.

TELL ME ABOUT DEATH. TELL ME ABOUT FUNERALS by E. A. Corley.

A child learns firsthand about the details of what happens when his grandfather dies. What is a funeral home, an embalmer, casket, pallbearers, hearse, mausoleum? His parents comfort him: "You miss him very much, but you can still think about him and you can still love him."

LIFE AND [illegible] by H. S. Zim and S. Bleeker.

The authors discuss the physical facts, customs, and attitudes surrounding death. Funeral and burial procedures are compared with those of other cultures.

THANK YOU JACKIE ROBINSON by B. Cohen

Twelve-year old Sam and the elderly black cook, Davy, both share an interest in sports, especially in the late Jackie Robinson. When Davy dies from a heart attack, Jackie expresses his sadness and other feelings.

APPENDIX D: BOOKLET FOR CANCER PATIENTS

HELPING YOUR CHILDREN: A BOOKLET FOR CANCER PATIENTS

As a parent your main concern is the welfare of your children. However, when you or your spouse is diagnosed with cancer, your world changes into one in which much of your time and energy must be devoted to self-care and treatment. The time you do have with your children, therefore, is valuable. This booklet has been written with the understanding of how difficult it is to live with cancer and how hard it can be to share this experience with children. Your children rely on you for taking care of them physically, but just as important, they rely on you for their emotional health. A child's psychological adjustment is jeopardized when they are not treated with an open, honest approach to what is happening to their parent. You are not alone in fearing that by talking to your children about cancer, and especially about a fatal prognosis, that you will harm them. Many adults have this impression. Studies have shown, however, that children are harmed most when they are protected from serious crises in the family, when they are not given explanations, and when they are not allowed to ask questions.

Speaking about cancer to children is difficult and so the following guidelines have been prepared to help you with this enormous task. If, after reading these guidelines, you still feel uncomfortable about broaching the subject with your children, feel free to contact the hospital support services and a psychologist will help you.

1. **FIND OUT WHAT YOUR CHILDREN ALREADY KNOW.** What children understand about cancer and about death depends upon their age and upon their previous experiences. Children as young as three can sense when a parent is seriously ill, not only by what they see, but from what they overhear. Children will pick up bits and pieces of information from conversations they've overheard and put them together in ways that are confusing and frightening to them. Children and teenagers alike often make up their own imagined causes of cancer. Generally they have two mistaken impressions about cancer: one, they think that they in some way caused it; or two, they believe that it is contagious. They might think that they aggravated you so much that they made you sick. They may believe that while play-fighting with you, they caused the cancer to grow. Some children even believe that they brought germs home after being in a house where someone else had cancer. Very young

children are confused about an illness they cannot see and might start conjuring up their own symptoms.

There is so much still to be discovered about cancer though there are new discoveries all of the time. We as adults have many confusions about cancer how children, who have had so few experiences with life, can be confused.

To find out what children already know about cancer and its implications, try watching for themes that arise in their play, in their drawings, or in their conversations with friends, siblings, or with you. You might even suggest the subject directly or indirectly by introducing a doll or puppet that is "sick." Asking children to draw pictures of your family is also useful. After they have drawn a few pictures ask them to tell you about them or have them create stories about them. Doing this will lead into a conversation about cancer and will give you an idea of what your child is thinking and feeling about it. Understanding what your children already know about cancer will help you to know where you can start your explanation about what is happening to you.

WATCH YOUR CHILD'S PLAY OR PLAY WITH THEM, TO FIND OUT WHAT THEY KNOW, AND HOW THEY FEEL ABOUT CANCER.

(2) FIND OUT WHAT THEY WANT TO KNOW; CLARIFY WHAT THEY ARE CONFUSED ABOUT AND HOW THEY FEEL; GIVE THEM SOME IDEA OF WHAT WILL HAPPEN IN THE DAYS AHEAD.

It is important not to make assumptions about what your child might be asking you. For example, if a child asks "How did you get cancer?" you might assume that he or she is interested in the environmental factors which are involved (smoking, insulation in your home, certain foods) while further questioning uncovers that the child is trying to clear his/her own sense of guilt and responsibility for your illness. Or, underlying this question may be a fear of catching cancer. Ask your child what he/she thinks the answer is and this will reveal what the real concern is.

Clarify any confusions they have and stress that it is not their fault that you have cancer. Explain that cancer is caused by something that goes wrong with cells in the body and emphasize that they will not "catch" cancer. If your cancer is of a type that tends to occur more frequently in families, stress that it will be important for your children to have regular medical checkups when they get older so that the disease can be diagnosed and treated before it becomes serious. Assure them that they do not have to worry about this for many years.

Consider your child's age at all times when giving explanations. Very young children have vivid imaginations and require explicit, simple explanations of everything from chemotherapy to death and afterlife. Seven through eleven-year olds have a real fascination with how things work and will want to know about cell growth, the disease process (relapses and remissions), treatment procedures and side effects. Some common questions include:

- Will I get cancer?
- Do you have the same type of cancer that Terry Fox had?
- Why do you get sick, tired, and lose your hair after taking medicine that is supposed to make you better?
- Will you live, die, or what?
- Why did the cancer come back after you were feeling okay for so long?

If you know that your disease has a high cure rate it is important for you to stress to your children that you will be sick for awhile until your body gets used to the treatment and then you will be back to normal. If you are relapsing and you know that there is a possibility that you might die, share this with your children. They too have their ways of coping and will continue to hope for your restored health. If you are dying it is important for your children to hear this from you. Most children think about death immediately upon hearing the word 'cancer.' Recent studies have found that a parent's death is the number one worry for three-quarters of Canadian school children (Goldberg Collaborative Study, 1984). It is especially important to assure children tha[illegible]ways be someone there to take care of them. Share your beliefs in af[illegible]them and acknowledge any uncertainty you yourself have. When giving theolog[illegible]al explanations, make sure the children understand all of the concepts which are often too abstract for them. Children can detect when you are giving them explanations for the sake of pacifying them -- explanations which are inconsistent with your own beliefs.

Included at the back of this booklet are a list of books for you to read, and for your children to read which will help you with the difficult task of talking about death.

(3) **MODEL FREE EXPRESSION OF EMOTIONS AND GIVE THEM PERMISSION TO CRY AND TO BE ANGRY.** In our society, free expression of emotions is frowned upon so what very often happens is that while you are alone in hospital or at home crying, your children are doing the same. They might fear that their crying would further disturb you. Even adolescents have magical thoughts about needing to be strong in front of you to keep you healthy and alive. As parents it is important to show your children your humanness. A very important part of this is to show them your vulnerability as well as your strength. Sharing your emotions with your children will not burden them, but rather will unburden them. Seeing you cry gives them permission to cry. Boys need to be taught that crying can be a "macho" thing to do.

Open expression of anger is often discouraged so children will redirect the anger they have at you for leaving them, and their anger that "it had to be you" that got cancer. Their behavior might start to change and you will find that they are fighting with friends, throwing tantrums, and maybe even stealing. Some children will blame doctors or even your well spouse for not restoring your health. Assure your children that angry feelings are natural and share your own feelings of anger.

CHILDREN USUALLY KNOW THAT YOU ARE SERIOUSLY ILL, BUT KEEP THE INFORMATION TO THEMSELVES FOR FEAR OF DISTURBING YOU.

(4) [illegible]URAGE PARTICIPATION; ALLOW CHILDREN TO FEEL USEFUL.

[illegible]ve already begun to do this if you are openly and honestly communicating about your illness and related feelings. Children feel very alone when they are excluded from sharing thoughts and feelings with the family. Children are often isolated from their peers when a family member has cancer, and are ridiculed by schoolmates who have their own fears and misunderstandings about cancer. If you have an open attitude about cancer and explain illness-related facts and concerns with children, they will feel free to speak with friends about it. Instead of being excluded, they will become local cancer experts and will be offered support and encouragement from their comrades.

Including children in hospital visits is also important. Children three years of age and up are fascinated by the hospital experience, especially when they have never been to hospital themselves. They like bringing their drawings to you, making you smile when you are sick, riding in wheelchairs, eating off hospital trays, visiting the hospital cafeteria, and walking with canes. It is useful to explain the reasons for the machinery and intravenous tubing around you. Children are also interested in accompanying parents on clinic visits and staying for the chemotherapy treatments. Allow your children to miss a day of school to accompany or visit you. A hospital tour is also a good idea. If your physical appearance is drastically changing, it is important to let your children know "why." Explain that you are still the same person who loves them even though you look different. If, as parents, you decide that you are too ill for your children to visit, allow them to communicate by telephone, or through letters. Adolescents are old enough to make decisions about visiting, so let them or they will harbour resentment later. They are living through a period in which they are struggling for their independence and it is important to allow them their freedom. Some teenagers, and older children as well, may start taking over childcare and household responsibilities. This is okay as long as it does not interfere with their regular activities. At a time when routines in the family are changing and when so much is uncertain, it is extremely important that children have the structure of their usual after-school involvements. They can sacrifice some of their activities, but they must maintain some. When their caretaking assistance is no longer needed, they'll need something to return to. There is a tendency for adults to treat understanding, intelligent children as peers and confidantes when a spouse is ill. This places too much of a burden on them. It is important to find a friend or relative to fill this role.

Coping with your illness is stressful, coping with your children's reactions adds to this stress. Chances are that if yours is a family that typically communicates in an open and honest manner, you will continue to do this in times of sickness as you have in times of health. Living with cancer is not easy, nor is helping your family to live with it. But if you continue to be open, honest and caring, everything will be a lot easier. If you find that you are unable to speak to your children about your illness, but would like to do so, seek help from the psychologists at the hospital. Do not hesitate to reach out. Services are available.

HAVING AN HONEST, OPEN, AND CARING RELATIONSHIP IS THE BEST WAY TO HELP YOUR CHILDREN COPE WITH CANCER.

BOOKS FOR PARENTS:

Cook, S. S. ed., **Children and Dying**. New York Health Sciences Publishing Corp. 1974. The book is divided into two sections how children feel and react to death, and how adults react to the sick, dying, or bereaved child. "Children can misunderstand their mother's silence and think that their mother does not miss their father."

Fargues, M., **The Child and the Mystery of Death**. Glen Rock, New Jersey: Dews Books, 1966. Written under the auspices of the Paulists in France, Madame Fargues book is a blending of modern psychology and Catholic education concerning the child's understanding of the mystery of death. Included are discussion questions for teachers and clergy.

Grollman, E. A., ed., **Explaining Death to Children**. Boston: Beacon Press, 1967. A volume by outstanding writers from all of America's major religious faiths plus the fields of anthropology, biology, children's literature, psychiatry, psychology, and sociology. The authors stress that it is not harsh reality that undermines a child's emotional stability but [illegible] of love, understanding, and trust by those adults responsible for [illegible]'s spiritual, emotional, and physical well-being.

Jackson, E. [illegible]., **Telling Children About Death**. New York: Channel Press, 1965. Dr. Jackson writes with a rare combination of honesty, simplicity, and a profound respect for human dignity in telling a child about death. He covers such questions as when and how to talk about death and what to say to children of different ages.

Jewett, C. L., **Helping Children Cope With Separation and Loss**. Harvard, Mass.: The Harvard Common Press, 1982. Claudia Jewett, a family therapist provides a fine blend of explanations and strategies for aiding children who have experienced death, divorce, or some other change in family structure.

Mitchell, M. E., **The Child's Attitude to Death**. New York: Schocken Books, 1967. When a child becomes aware of death, his/her emotional reactions may be expressed in two simple sentences--"I don't want to die" and "I don't want you to die." The writer attempts to understand children's emotions from religious, scientific, and sociological points of view.

Wolf, A. M. **Helping Your Child to Understand Death**. New York: Child Study Press, 1973. A revised edition of this classic brings new material on the effects on the young of mass-media violence, televised war, and upheavals in traditional religious and moral values. As the former senior staff member of the Child Study Association of American, she writes with understanding and compassion.

BOOKS FOR CHILDREN:

Young children (ages seven and under, approximately)

Anderson, P. M., **Mr. Red Ears**. Philadelphia: United Church, 1960. The story of the death of a pet turtle.

Bartoli, J., **Nonna**. New York: Harvey House, 1975. After Nonna's funeral, family bakes cookies from one of her recipes. There are laughter and tears while they share memories of her.

Brown, M. **The Dead Bird**. Reading, Mass. Addison Wesley, 1958. Little children find a dead bird and bury it. Much later they bring it flowers and sing.

Buscaglia, L. **The Fall of Freddie the Leaf: A Story For All Ages**. New Jersey: Charles B. Slack Inc., 1982. This is indeed a story for all ages about the reflections of a leaf on life and its meaning and on death.

Carrick, C. **The Accident**. New York: Seabury, 1976. Christopher's dog is hit by a truck. His grief is quick and strong. Beautiful illustrations.

De Paoloa, T. A. **Nana Upstairs, Nana downstairs**. New York: Putnam, 1973. Parents share a loving experience with their little boy about his two grandmothers in their nineties. Beautiful and compelling illustrations.

Dobrin, A. **Scat!** New York: Scholastic Books, 1971. Scott, who lives in turn-of-the-century New Orleans, is a jazz musician. This angers his grandmothers. When she dies, Scott heeds her final advice to "...listen to what your heart says, not your head." So he chooses his own way to say goodbye. At her funeral he plays the blues on his harmonica.

Fassler, J. **My Grandpa Died Today**. New York: Human Services Press, 1971. Grandpa told David that he could not live forever, but he was not afraid to die. One day he did die. David's loss is great but this mother emphasizes the richness of the relationship, and that gives him happy memories of grandpa..

Harris, A. **Why Did He Die?** Minneapolis: Lerner Publications Co., 1965. A small child wrestles with the concept of his grandfather's death. Is he dead for good? Why can't he live forever? What is a cemetary? Finally he understands: "He won't forget his granddad, but now it's time to play."

"I and the Others" Writer's Collective. **It's Scary Sometimes**. New York: Human Science Press, 1978. Illustrated by children themselves. A delightful and insightful description of the how's and why's of children's fears. Helps young children recognize those situations in which it is perfectly reasonable or even useful to feel afraid and those where fears are really unnecessary.

Kantrowitz, M. **When Violet Died**. The death of a pet bird is softened with the realization that living things "last a long, long time" through the birth of new animals.

Mellonie, B., & Ingpen, R. **Lifetimes: A Beautiful Way to Explain Death to Children.** This beautifully illustrated book discusses the beginning and endings of all life--fish, birds, the tiniest insects, and people.

Miles, M. **Annie and the Old One.** Boston: Little Brown, 1971. An eleven-year old girl's experience with her grandmother. A beautiful story of an Indian girl who is given a weaving by her dying grandmother. To postpone her grandmother's death, the girl undoes the weaving. The Old One explains that one cannot change the order of nature. The story ends with grandchild taking her place at the loom. Death occurs and life goes on.

Viorst, J. **The Tenth Good Thing About Barney.** New York: Antheneum, 1975. When Barney the cat dies, his young owner tries to think about ten good things to say at the funeral. He can only think of nine. While helping his father in the garden, he discovers the tenth good thing--Barney will now help things grow.

Middle-Aged Children (seven through ten years, approximately)

Carlson, N. **The Half Sisters**. New York: Harper & Row, 1970. A girl copes with the death of her sister.

Coerr, E. **Sadako and the Thousand Paper Craners**. New York: Putnam, 1977. Japanese philosophy is explained: one is placed on earth not to fear death but to

make the most out of life. "To live in the presence of death makes us brave and strong. . .to die a little later--a little sooner--does not matter. What matters is to live."

Erdman, L. **A Bluebird Will Do**. New York: Dodd, Mead, 1973. About the death of a parent.

Gardner, R. **The Boys and Girls Book About One-Parent Families**. This book has excellent sections on "Some important things you should know about dying" and "Thoughts and feelings you have about the death of a parent."

Kennedy, R. **Oliver Hyde's Dishcloth Concert**. Boston: Little, 1977. When Oliver's wife died, he could only sit in a corner with a dishcloth over his head. Later he is able to play his fiddle at a wedding. The pictures clearly depict his loss and anger.

Klein, S. **The Final Mystery**. New York: Doubleday, 1974. Good sections on death, ancient beliefs, death and religion, and medical progress.

Lee, V. **The Magic Moth**. New York: Seabury, 1972. Maryanne is ill and dying from heart disease. A caring family share openly, the parents one way the siblings another.

Lichtman, W. **Blew and the Death of the Mag**. Berkeley: Greestone Publication Co., 1975. A sensitive and informative book about a young girl's experience with the death of an imaginative friend. Blew asks good qustions, and her feelings come up in a moving and inspiring way.

Paterson, K. **Bridge to Terabithia**, 1977. A fifth grade boy meets his new neighbor, a girl who becomes his close friend and opens up new worlds of imagination and learning to him. The thoughts they share during their time together help them to cope with her sudden death. Winner of the 1978 Newbury Medal.

Peck, R. N. **A Day No Pigs Would Die**. New York: Dell, 1974. Novel of a Shaker family in New England. Narrates a boy's struggle to accept death and how his father influenced him.

Smith, D. B. **A Taste of Blackberries**. New York: Thomas Y. Crowell, 1973. Jamie fooled around a lot. When he rolled on the ground after a bee sting, his friend thought that he was joking. But Jamie died and the friend felt guilty. In this Child Study Association Award-winning book, the friend finally accepts this terrible tragedy.

Stein, S. B. **About Dying: An Open Family Book for Parents and Children Together.** New York. Walker and Co., 1974. A children's book about the deaths of a bird and grandfather with a running commentary for parents.

Stevens, C. **Stories from a Snowy Meadow,** 1976. A gentle story with animal characters which centers on close friendships and the loss of a loved friend.

Watts, R. **Straight Talk About Death With Young People.** Philadelphia: Westminster, 1975.

White, E. B. **Charlotte's Web.** New York: Harper & Row, 1952. An animal fantasy. When Charlotte, the spider, dies at the fairgrounds, her friends manage to take her eggs back to the farm where they could safely hatch. The friends understand that no one can ever replace Charlotte's special quality of friendship. A warm, honest, sensitive approach to the death of a pet.

Whitehead, R. **The Mother Tree.** New York: The Seabury Press, 1971. The story of a ten-year old girl whose mother dies suddenly. She now is required to help with the household chores as well as take care of her clinging four-year old sister, who continually asks "When will Mother be home again?" A moving experience of how the girls spend their summer with grandmother.

York, C. G. **Remember Me When I'm Dead.** New York: Bantam Books, 1982. Two girls react to the sudden death of their mother.

Zim, H. S., & Bleeker, S. **Life and Death.** New York: William Morrow and Co., 1970. In a straightforward manner the writers discuss the physical facts, customs, and attitudes surrounding death. The various rites that constitute funeral and burial procedures are described and compared with those of other cultures.

Zolotow, C. **My Grandson Lew.** New York: Harper & Row, 1974. Lew, age six, shares his recollections of his grandfather with his mother. Wonderful illustrations. Grandpa whose "beard scratched" when he kissed and who would comfort Lew after a bad dream.

Adolescents

Agee, J. **A Death in the Family.** New York: Avon, 1959. The Pulitzer Prize winner describes death as an inseparable part of human experience. A novel of overwhelming sensitivity and compassion.

Armstrong, W. **Sour Land**. New York: Harper & Row, 1971. The boy in "Sounder", now old, helps three white children to understand death, injustice, and indignity.

Benchley, N. **Only Earth and Sky Last Forever**. New York: Harper and Row, 1972. A young Cherokee whose beloved dies loses hope for survival of the Indian nation.

Brown, J. M. **Morning Faces**. New York: McGraw-Hill, 1949. In the chapter "The Long Shadow" the author reveals the depth of understanding of an eleven year old boy who asserts "I don't like God anymore. . .Why should I? Now that he has done this to my father." The conclusion is that although death is final, memories have life of their own.

Crawford, C. **A Three-Legged Race**. New York: Harper & Row, 1974. Three children in a hospital become friends and become separated by both recovery and death.

Farley, C. **The Garden is Doing Fine**. New York: Atheneum, 1975. A high school girl makes an effort to lead a normal life while her father is dying of cancer. The living garden is the children of dead parents. The agony of slow sickness, guilt, and the happiness in between is presented.

Fine, J. **Afraid to Ask: A Book About Cancer**. Toronto: Kids Can Press, 1984. A book which explains the possible causes of cancer as well as the different types, treatment procedures, and side effects.

George, J. **Julia of the Wolves**. New York: Harper and Row, 1972. Eskimo girl's life is saved by a wolf pack. Her sadness at the death of the pack's leader makes her aware of the disintegration of her Eskimo heritage as well.

Hunter, M. **A Sound of Chariots**. New York: Harper & Row, 1972. A novel about a girl dealing with the death of her father, with a good interpretation of the sights and sounds of death.

Irish, J. **A Boy thirteen: Reflections on Death**. Philadelphia: Westminster Press, 1975.

Renaldo, C. I. **Dark Dreams**. New York: Harper & Row, 1974. The preadolescent search for self acceptance, viewed through a boy who is haunted by dreams of his dead mother.

APPENDIX E: EXPERIENTIAL ACCOUNT OF CLASSROOM VISIT

MY GAIN WAS THEIR LOSS

I must admit to being somewhat apprehensive when I was asked to speak to a grade six class in which one class member, eleven-year old Heather, had just lost her mom--her mom died of cancer. Two weeks prior to my visit, an oncology nurse spoke to the class about cancer; Heather was not back at school yet. I knew, however, that she would be there for my presentation.

I decided to universalize Heather's current experience by speaking not only about losing a parent through death but about "loss in general." I would further extend the discussion to include feelings and behaviours in general. First we would talk about "PICK ME UPS" and then we would talk about "BRING ME DOWNS." Then I would shift the tone by mentioning that some of the most difficult "BRING ME DOWNS" to handle are losses. I would read out an induction which would allow the children to think of "losses" that were pertinent to them. Included would be: losing a highly valued object; leaving a parent for kindergarden; being left with a babysitter; moving; changing schools (especially pertinent to a grade 6 class); having a family pet die; having a parent/grandparent leave on a long trip and maybe never returning. After the induction all the children had something to contribute--losing a necklace, moving four times, having a hamster die, an uncle die, and a grandfather die--little Annette began to cry as she spoke of her grandfather's death. I asked the class how many of them felt that it was okay to cry in front of others--they all raised their hands and Annette continued crying. She spoke of how her grandpa couldn't cry in front of others, but he assured her that he cried when alone. The other children squirmed in their desks, some giggled softly and we spoke about how very sad; hurtful feelings sometimes make us uncomfortable and we disguise them with laughter. Amanda, who had been physically fighting with others before class, continued to be disruptive during class; she was obviously uncomfortable. Her opposoiong force meant I had to try harder to capture the class, but that didn't take long. After awhile Amanda remarked flippantly: "My parents are getting a divorce and I think that's great!" Her classmates were surprised--her voice cut the melancholic air. I responded "That's fine" and went on to talk about how we may act one way but deep down inside we may have very painful feelings that we don't know what to do with. From that moment on Amanda sat still and joined the rest of us in our reflective, sombre moods.

Little Heather was fighting back her tears. Her eyes were watering and her face was bright red. Her classmates stole glances at her and then quickly back at me as though wondering if I knew what they knew about Heather. I treated Heather like the others--her stare told me that she did not want to be selected out--she wasn't ready. Every once in awhile, though, we exchanged glances, all-knowing glances, caring, loving glances and this seemed to comfort her. So much was happening on so many different levels[21] but I was too entranced with what was happening for me and these children to notice at the time.

I gave a metaphor for healing--I spoke of a wound which is really painful and raw to start with, but with time it begins to heal and once in awhile it gets disturbed, irritated when you brush it against an object, and again starts to bleed. But with more time it becomes tougher, stronger and soon it is just a little bit sensitive. It will never be as it was; there will always be a little scar, a reminder. The children interpreted this metaphor concretely, most of them anyway. They started talking about broken arms and legs. I said that breaking an arm or leg was a form of loss, too. One little boy, Greg, spoke of how his foot still hurt when he ran. The children generated so much information that I didn't need to. I could focus, instead, on the emotional reactions to what was being said in the classroom. The teacher, sitting at his desk in the corner unobtrusively, seemed very much affected by what was happening--he sat quietly, fighting back his own emotion.

We spoke about the unusual ways people might behave when someone they love dies--the guilt they feel, the fears they have. Heather and several others nodded their heads, they knew what I was talking about. I suggested that we can only feel the pain that accompanies loss when we have felt love for what we are losing.

I then went on to ask the children what they do to "pick themselves up" when they feel down. Their responses included: eating, listening to music, going to sleep, going for a long bike ride, talking to friends, and just going on with things as usual. We spoke about how we could recognize when others were down and what we could do for them when they were like that. The school principal had joined us by now. I didn't exchange any words with him but I found out later that he was interested in attending because his father recently died.

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[21] I found out just before class that the teacher was bereaved as a child. The principal, who joined the class later, was recently bereaved.

As we spoke of what we could do for others I mentioned hugs (as I squeezed Annette) and kisses--chocolate kisses, too. I handed out two chocolate kisses to each child (principal and teacher included). I asked them to keep one for themselves for after school and to give the other to someone they felt needed a "pick me up." Annette got up and approached Heather. She gave Heather a "kiss." The emotion peaked when Heather gave hers to Annette.

Later on that day I spoke to the teacher. He said he had overheard one of the kids say "You know, Annette got FOURTEEN kisses." She needed them. I think the chidlren will be able to give Heather what she needs, too.