"A CHILD IS STILL A CHILD": ADULT PERCEPTIONS OF CHILDREN WITH A PARENT WITH ADVANCED CANCER

by

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"A Child is Still a Child": Adult Perceptions of Children With a Parent With Advanced Cancer

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Abstract

This study investigated adult perceptions of children with a parent with advanced cancer. It was seen as a necessary first step in assessing the feasibility of designing effective counselling interventions for this population, who are growing and developing at the same time that their parent's health is deteriorating.

The case-studies of two boys are presented: one was six years old when his mother died, the other was nine when he lost his father. The children were located through hospice societies; both their families had used the services of a hospice volunteer. The experiences of these children in the final six months of their parent's life are reported as perceived by numerous adults who were in regular contact with them. Eleven interviews were held with a total of nine participants. The project was retrospective; all interviews were held within the first year and a half of the parents' deaths.

Interviews were tape-recorded, transcribed and systematically analyzed using qualitative methodology. Data were initially coded manually. In the second stage of the analysis the computer program HYPERRESEARCH was used to condense and further organize the codes. Major themes were extracted from computer-generated code reports. Once the results section was drafted, all participants engaged in the process of respondent validation.

The results indicate that both sets of parents gauged how much to tell their sons about the illness very carefully. Both boys were highly reactive and prone to sudden mood swings and unpredictable changes in behaviour. Their schools were an ongoing source of support and provided respite from the relentless difficulties of their home situations. Both children used art to express their understanding of and feelings about what was happening; both appreciated opportunities provided by various caregivers to engage in normal activities either with other children or with their parents.

Implications for other children with a parent with advanced cancer and for the adults who care for them are discussed. Avenues for future research include conducting prospective studies with both adults and the children themselves, investigating the experiences of children in single-parent or blended families, and implementing and evaluating counselling interventions designed specifically for these children.

Dedication

To the memory of my beloved aunt,
Minda Posen,
who taught me how to listen,
and how the stories would resonate
once I had heard.

And to the memory of my tenacious friends.
The gritty bedrock of their faith
transformed my world.

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To hospice personnel: the Hospice Coordinators, Coordinators of Volunteers and the volunteers themselves, who furnished the rooms from their fund of slow experience and the sweet certainty of their work at the very edge of our mortality.

To the participants who peopled the rooms with their memories, their reflections, their grief and the hard-won nuggets of knowledge they had mined from lived experience.

To the members of my thesis group - Brent, Carolyn, Lee, Mat, Sofia and Steve - for their long-term support and for their faith in me, particularly during the period when I wanted to lock the front door, drop the key back through the letter slot so that I could not retrieve it and simply walk away.

And to James Lindfield, who dwells at the heart of life itself, and whose enduring love has, yet again, seen me through.

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"You have to think of all the kids that still have to face that".

Jessie, Richard's teacher
(Case 1, interview 4)

CHAPTER 1

Introduction

Background to the Problem

This thesis had its impetus in questions that arose for me over the last six years as I watched two friends grapple with, and eventually die of cancer. Both were women in their mid-thirties; both had children. Throughout that lengthy period, I saw them struggle to continue parenting while concurrently dealing with an illness that made daily living progressively more difficult for them. As their illness advanced to the point where recovery no longer seemed possible, my friends were forced to abandon most of their responsibilities for their children. Other adult family members were required to take over the mother's parenting, at precisely the same time that they were attempting to provide additional care for the mother herself. The increased responsibilities they shouldered were accompanied by a wide range of intense emotional reactions that further impaired their ability to recognize the children's needs. Even when these needs were acknowledged, time and energy to meet them were often not available. The support services which would assist the family in providing appropriate care for the children were difficult to access. The two families I knew stumbled on services haphazardly, and only after their distress had become very great. For one family, a hospice volunteer provided information and emotional support to the children, who felt unable to discuss the impact of their mother's illness on them with their parents. In the other family, the church the mother joined in her final year of life provided a tightly-knit support network that continued to assist the family after her death.

This thesis addresses the question I formulated as I watched my friends' children struggle to understand and adapt to the altered circumstances of their families. What were the particular experiences of these children, as the death of one of their parents became imminent? Given that I had witnessed the rapport the hospice volunteer had developed with the children in one of the families, it seemed that hospice volunteers might prove a valuable source of information about the experiences of children with a parent with advanced cancer, and that interviewing hospice volunteers would be a worthwhile place to begin seeking an answer to this question.

Statement of the Problem

Each year in Canada, thousands of children, age 18 or under, lose a parent to cancer. The actual number of children affected is growing as the incidence and mortality rates for cancer, expressed as a percentage of the population, increases slightly each year. Between 1981 and 1988, the age-standardized incidence of all cancers combined increased an average of 0.8% per year in males, and 0.5% per year in females. Mortality rates between 1981 and 1990 increased 0.5% per year for males, and 0.4% for females (National Cancer Institute of Canada, 1993). Although publicly available statistics on the number of cancer deaths annually do not permit calculation of the exact numbers of children involved, it is possible to ascertain the number of adults between the ages of 25 and 54 who die. In 1990, the last year for which actual statistics divided according to age and sex are reported, 6,469 deaths from cancer were recorded for adults in that age group. The deaths were divided almost equally between the sexes: 3,106 were male and 3,363 were female (National Cancer Institute of Canada, 1993). It can be assumed that many of those dying were parents, who left behind one or more bereaved children. The perceptions and experiences of these children during their parent's final months are not clearly understood. This thesis takes an initial step towards increasing that understanding by exploring the perceptions held by adults of children with a parent with advanced cancer.

In this study, cancer has provided the context in which adult perspectives on children with a parent with advanced disease have been investigated. The progression of cancer is likely to be protracted, with the series of losses in functioning that the patient experiences, if and when the disease progresses, occurring gradually over months and years. Repeated adjustments to newly reduced levels of patient functioning and alterations in patient appearance are required of each family member at various stages of the illness (Hall & Kirschling, 1990; Rolland, 1987). The course of the disease is not unidirectional: periods of remission when the patient is relatively well and active may alternate with periods of recurrence and increasing debilitation.

These characteristics of cancer may in themselves have implications for the child's awareness of and preparation for the imminent death of their parent. The child may perceive the periods of remission as indications that their parent is getting better, rather than as temporary plateaus in an overall course that will most likely result in death (Christ et al., 1993). In this case, the response to each recurrence may be renewed fear of death, as has been reported for adolescents (Brown, 1992, 1995).

Even if the child is aware that his or her parent is extremely ill, the slowness with which the disease usually advances may bely any misgivings that the child has (Christ et al., 1993). In the words of a friend whose mother died of cancer when she was thirteen, after three years of illness. "It was a real shock to me when she died. She was sick for so long, I thought she would live sick forever."

Effects of cancer on the family

Research investigating the needs and concerns of healthy family members of the cancer patient has tended to focus either on the period immediately following diagnosis (Woods, Lewis & Ellison, 1989), or after bereavement (Berlinsky & Biller, 1982; Furman, 1974; Northouse, 1984; Parkes, 1987-88), rather than on the period of advanced cancer that precedes death. Both the period following the initial diagnosis and the one immediately following the death are sharply defined. Although the period of advanced cancer, which begins when aggressive medical treatment is terminated and palliative care commenced, may have a clear starting point for health care professionals, the family's experience of this period is one of confusion (Davies, Reimer & Martens, 1990; Davies, Reimer, Brown & Martens, 1995). Families move through a state of transition as they gradually begin to accept that their ill member is "fading away", and that they will be confronting a future without him or her (Davies et al., 1990, 1995).

The indistinctiveness with which the period of advanced cancer begins for the family does not, however, negate the alteration in the dynamics of the family system that are occuring; an alteration which profoundly affects each family member (Brown, 1992, 1995; Davies, et al. 1990, 1995). A family systems conceptual model that considers the effects of chronic illness on the family's life cycle has only recently been developed (Brown, 1989; Rolland, 1987, 1989). The model considers that serious illness and raising children both have a centripetal effect on the family; internal family life is emphasized and more time and energy are devoted to caring for those at home (Rolland, 1989). When the two occur at the same time the impact on the family can be devastating, with the escalating demands experienced by the healthy adult family members directly impinging on their abilities to care for the family's children (Brown, 1989; Feldstein & Rait 1992; Rolland, 1989).

The current position in health psychology and in the hospice literature that the family, rather than the individual patient, should be regarded as the fundamental unit of medical care provides an additional rationale for this study (Davies et al., 1990, 1995; Hall

& Kirschling 1990; Lewis, 1986; Lovejoy, 1986; Northouse, 1984; Schwenk & Hughes, 1983). If this position is to lead to a change in the delivery of health care services, the needs and concerns of all family members, including the family's children, must be more thoroughly understood. Adult family members possess valuable perspectives on the children, as do adults outside the family who are regularly involved with the children, like school teachers, family friends, or hospice volunteers (Doka, 1995, p. 8; Lewis, 1986; Siegel et al. 1992). Through interviews with both family members and adults external to the family, the current study contributes to an increased understanding of the children's experiences seen from multiple perspectives. It also examines some of the shifts in the functioning of the family system that directly affect the children.

The small body of research which has investigated family experiences during the period of advanced cancer has focussed almost exclusively on adult family members, including adult children (Davies et al.,1990, 1995; Hilton, 1993, 1994b; Lewis, 1986; Northouse, 1984). Research specifically investigating the experiences of adolescents (Brown, 1992, 1995) and younger children (Rosenfeld, Caplan, Yaroslavsky, Jacobowitz, Yuval & LeBow, 1983; Rosenheim & Ichilov, 1979; Rosenheim & Reicher, 1986; Siegel, Mesagno, Karus, Christ, Banks & Moynihan, 1992) with a parent with advanced cancer has only begun in the last decade. As the ill parent is increasingly incapacitated and in need of progressively more intensive care, profound effects are exerted on the family's children. The many tasks involved in caring for them are reallocated (Black, 1989; Hilton, 1994a), housekeeping duties are reorganized (Lewis et al., 1989), and the additional responsibilities for providing physical and emotional support for the ill family member are accomodated (Rosenheim & Reicher, 1986; Siegel et al., 1992). The affective, cognitive and behavioural reactions of individual children to these events are likely to be dependent on a host of factors (Corr,1995), including how much they are told about their ill parent's condition, their developmental stage, their cognitive conception of death, previous personal experience with death, their gender and that of the ill parent, and the religious and cultural attitudes held by the family.

Developmental issues

Children between the ages of 7 and 11, the age group on which this study focusses, are in the process of acquiring the ability to use the logical structures of concrete operational thought as they move beyond the Piagetian stage of pre-operations (Berger, 1988). A substantial body of research on healthy children with healthy parents has documented that advances in cognitive development are accompanied by changes in the child's concept of death (Corr, 1995; Kane, 1979; Koocher, 1973; Palombo, 1981; Stambrook & Parker, 1987). By the age of 7, the majority of children have acquired a cognitive conception of death that includes three major components: universality, irreversibility and nonfunctionality (Lonetto, 1980a, 1980b; Speece & Brent, 1984). Lazar and Torney-Purta (1991) added a fourth component, causality, defined as the ability to understand the objective causes of death, which has since been more widely incorporated (Corr, 1995). It can therefore be expected that the children in the current study possessed a cognitive understanding that death happens to everyone, that it cannot be reversed, that life-defining functions like sleeping and breathing cease when the person dies, and that the disease of cancer could cause death.

There is controversy in the literature over the exact age and the order in which children acquire the different components of a death concept, and indications that the methodology used directly influences the findings. Vianello and Marin (1989) found that when children between the ages of 2 and 5 were observed holding spontaneous discussions about death, they demonstrated the acquisition of some components earlier than had previously been reported. Lazar and Torney-Purta (1991) reported that the children in their sample understood the irreversibility and universality of death before grasping the concepts of nonfunctionality and causality. They stressed the importance of studying each component of a death concept separately as well as in relation to the others. Several researchers have reported that a young child's experience of death can stimulate earlier development of a more complete death concept (Corr, 1995; Kane, 1979; Lonetto, 1980b).

In contrast to children's cognitions about death, the nature of their affective responses has not been as thoroughly investigated (Hayes, 1993; Stambrook & Parker, 1987). Menig-Peterson and McCabe, in a 1978 study of spontaneous and eliciited narratives about death constructed by 96 children between the ages of 3 and 9, discuss the children's lack of emotional responses, especially apparent in the narratives of those aged five and under. The researchers attribute the lack of affect to the young child's denial of death, but fail to examine the influence of T.V., cultural attitudes to death and the influence of their own relationships with the children on their stories. The current study will focus on adult perceptions of the child's feelings as expressed in overt behaviour, as well as on the child's thoughts about their parent's illness and possible death.

In terms of psychosocial development, children in this age group turn increasingly to their peers for support, becoming both less dependent on their parents, and less egocentric (Berger, 1988). They show a growing ability to understand other people's points of view, and to adjust their behaviour in order to interact appropriately with others. Their increased awareness of events both within the family and in the larger community increases the likelihood that they will both be influenced by and respond to those events (Berger, 1988). When children in this age group are confronted with advanced cancer in a parent they can be expected to turn to their peers as well as their family for support, they will likely be very aware of and concerned about the parent's illness and they will be capable of modifying their behaviour in order to interact with the ill parent in acceptable ways.

Issues of gender and culture

The child's experience of advanced parental cancer is likely to be influenced by the child's emotional closeness to both the well and the ill parent and by alterations in the relationship between the ill parent and the child as a result of the illness (Brown, 1989). Aspects of the relationship would undoubtedly have a gender component; caregiving responsibilities being one example. In families where the care of the child was primarily the mother's responsibility, the child would experience greater changes if the mother rather than the father had cancer (Brown, 1989; Hilton, 1994a; Schwenk & Hughes, 1983). In families where the caregiving responsibilities had been more equally divided prior to parental illness, the child's experience of change once the cancer became advanced would be less marked. The family's eco-nomic circumstances would be adversely affected by the father contracting cancer if he had previously been the major earner (Rolland, 1989; Schwenk & Hughes, 1983). In this case, the changes experienced by the child would not be as disruptive of daily routines (Black, 1989). Evidence from the literature on childhood bereavement does indicate, however that a drop in financial circumstances following parental death is correlated with increased disturbances in the bereaved child's behaviour (Krantzler, Shaffer, Wasserman, & Davies 1990; Van Eerdewegh, Clayton & Van Eerdewegh, 1985).

A family's cultural background, race and religion have been considered important determinants of their beliefs concerning illness, dying and death and of their patterns of mourning an actual death (Feldstein & Rait, 1992; Parkes, 1987-88; Rolland, 1987). These beliefs and patterns can be expected to exert a profound effect on the child confronted with advanced parental cancer. Children's and families' previous experiences of illness and death would also be likely to affect the children's reactions to their parent's cancer (Corr, 1995; Rolland, 1989). In summary, the experience that children have of advanced parental cancer will undoubtedly be influenced by their developmental stage, their relationship to the ill and the well parent, their previous experience with death, and the family's beliefs about illness, dying and death (Brown, 1989).

Effects of childhood bereavement on children and adolescents

There is a distinction between childhood bereavement, which is the existential state of the child who sustains the death of a family member, usually a parent, and the grief experienced by the bereaved child, defined as the series of psychological and physiological responses to bereavement through which adaptation to the loss can occur (Pine, 1986). Grieving following childhood bereavement is a process which includes the following tasks: gaining an understanding of what has happened, accepting and working through the accompanying emotional pain, adjusting to an environment in which the deceased is missing, consolidating identity and resuming progress on age-appropriate developmental tasks (Baker, Sedney & Gross, 1992; Furman, 1983; Parkes, 1987-88; Worden, 1991).

A series of investigations have indicated that children bereaved of a parent possess increased vulnerability to mental health problems in the first few years after bereavement (Cheifetz, Stavrakis & Lester, 1989; Kaffman, Elizur & Gluckson, 1987; Van Eerdewegh et al., 1985). Only one of these studies, however, includes a control group that allows the researchers to conclude that the bereaved children's psychological difficulties were a result of the bereavement (Van Eerdewegh et al., 1985). Other reports indicate depressive symptoms in recently bereaved children between the ages of 5 and 12 (Weller, Weller, Fristad & Bowes 1991), social withdrawal and rebelliousness in boys between the ages of 9 and 14 (Silverman & Silverman, 1975), and delinquency in young people between the ages of 8 and 17 (Schoor & Speed, 1963). There is evidence for a connection between parental loss in childhood and the development of specific physical illnesses such as juvenile diabetes, thyrotoxicosis and juvenile rheumatoid arthritis (Parkes, 1987-88; Raphael, 1983). The child's experience of advanced parental cancer, which may radically alter how the family functions, may have certain effects that are similar to those of bereavement.

Effects of childhood bereavement on adults

The research on physical and mental health problems in adults who have lost a parent in childhood provides a further rationale for this investigation. It is apparent that childhood bereavement that is not adequately grieved may be a precipitating factor in compromising later mental health, although earlier studies claiming widespread pathology have been criticized on methodological grounds (Berlinsky & Biller, 1982).

Higher levels of loneliness in young adults between the ages of 18 and 25 have been correlated with participation in fewer mourning behaviours when these adults experienced parental death in childhood (Murphy, 1986). In university students who experienced the death of a parent before the age of 16, increased suicidal ideation and suicide attempts have been reported compared with a control group of adolescents from intact homes (Adam, Lohrenz, Harper & Streiner, 1982).

Two studies reviewed by Berlinsky and Biller (1981, p.116) indicated that men and women who had been parentally bereaved as children were overrepresented amongst suicidal psychiatric patients. The connection between the death of a parent in childhood and adult depression has been explored, but the results are inconclusive (Beck, Seti & Tuthill, 1963; Crook & Eliot, 1980; Saler & Skolnick,1991). Tennant, Bebbington and Hurry (1980) reported a significantly greater incidence of loss of a par-ent before age 16 in high-depressed versus non-depressed psychiatric patients. Num- erous studies have reported that maternal death results in adulthood depression more frequently than paternal death (Berlinsky & Biller, 1982; Tennant et al., 1980). Parkes (1987-88) has asserted that the effects of the loss itself need to be distinguished from the effects of any deprivation that might have followed.

In accordance with Parkes' argument, Harris, Brown and Bifulco (1986) reported that loss of the mother before the age of 17, either by death or by separation of over a year was correlated with clinical depression in adulthood only when the intervening variable of the quality of post-loss childcare was considered. Birtchnell (1980) found no evidence that death of a mother in childhood had a direct influence on the development of men-tal health problems in adulthood but reported a significant correlation between the mother's death and increased vulnerability to depression in adults as a response to stressful life events (Birtchnell & Kennard, 1981). Saler and Skolnick (1991) reported that the quality of parenting provided by the surviving parent to the bereaved child and the nature of the family environment following parental death were important factors mediating the development of depression in adulthood.

They found that emotional coldness or indifference in the surviving parent increased the risk of depression developing in adulthood.

Many researchers recommend some form of intervention directly after the bereavement in order to prevent or at least lessen the severity of difficulties with mental health in later life (Berlinsky & Biller, 1982). These recommendations raise an additional question: would the benefit to the child's future mental health be increased if a helping professional were to intervene sooner, before the bereavement occurs? Until the experiences of children with a parent with advanced cancer are more fully comprehended, the design, implementation and evaluation of proactive interventions that will be effective with this population cannot begin.

Research Question and Definition of Key Terms

The purpose of this study was to attempt to answer the following research question:

> What are the experiences of children aged 7 to 11 who have a parent with advanced cancer as perceived by adults both within and external to the family who have regular contact with them, beginning with the perceptions of the hospice volunteer?

Definitions are given below to clarify the specific meaning of each term used in the research question:

Perceive: To recognize or identify physical, emotional, and psychological qualities through a combination of direct observation, discernment, insight and intuition (Random House Dictionary, 1983).

Advanced Cancer: Cancer for which it is no longer possible or appropriate to provide medical treatment with the intent to either cure the patient (Brown, 1992) or to arrest the progress of the disease.

Hospice: An organization with a holistic approach to the delivery of health care services to patients and their families when cure is no longer a reasonable expectation and when death seems imminent. Physical, psychological, social and spiritual dimensions of patient and family functioning are addressed, with the goal of improving the quality of life. Hospice philosophy insists that the integration of the technical skill of health professionals with their presence as concerned and responsive human beings is essential to effective treatment (Corr & Corr, 1983, 1985).

Hospice volunteer: The hospice volunteer is committed to visiting a client and his or her family for approximately 4 hours each week for up to a year in order to provide companionship and emotional support, as well as respite for the primary caregiver. The hospice volunteers' responsibilities are primarily to the dying family member and his or her spouse, but they may also provide support to other family members as needed (Hospice Coordinators, 1993-5). Hospice volunteers are not paid for their services.

Method of Investigation

Given the current dearth of knowledge of the experiences of children with a parent with advanced cancer, this study was exploratory. Qualitative methodology, which is both emergent and inductive, was used in an attempt to uncover adult perceptions of the concerns of these children, which heretofore have not been documented (Kirk & Miller, 1986, p. 18; Merriam, 1988, p. 24). The data were collected using semi-structured open-ended interviews with adults who were in regular contact with the children. Rich, thick description (Hammersley & Atkinson, 1992, pp. 9-10; Merriam, 1988, p. 27) of adult perceptions of the experiences of children with a parent with advanced cancer was expected to result. This was considered to be a necessary first stage before a well-grounded research project investigating the perceptions and experiences of the child-ren themselves could be designed and implemented.

Limitations

Given that this investigation used qualitative methodology with a criterion-based selection procedure, the results are limited to the cases studied (Goetz & LeCompte, 1984, p. 71-74). A quantitative study with a narrower and more specific research question, employing a statistically random sampling procedure would be necessary in order for the results to be generalizable (Merriam, 1988, pp. 47-48 &173-174; Lincoln & Guba, 1985, pp. 110-128; Goetz & LeCompte, 1984, p.69).

The data sources of the current study presented other limitations. The perceptions of the adult participants, who were speaking about the children, were expected to differ from the experiences that the children themselves might have reported if they were speaking for themselves. The literature on childhood depression indicates a disparity between parental impressions of children's level of disturbance and the reports given by the children themselves: the children consistently report higher levels of depressive symptoms than their parents estimate (Siegel et al., 1992; Van Eerdewegh et al., 1985). In the case of parental terminal illness, Rosenheim and Reicher (1986) found that the ill parent did not think his or her children were experiencing a level of distress as high as that recorded by the children themselves.

Each adult who participated in this study reported perceptions that were at variance with those of the other participants because they had been made from a different location. Alcoff states: "where one speaks from affects the meaning and truth of what one says . . . one cannot assume an ability to transcend one's location" (1991, pp. 6-7). Given that direct interviews with the children themselves were not conducted, the current study could not examine the nature and extent of the differences between the varying perceptions of the adult participants and the children's reports. The lack of direct interviews with the children also meant that their stage of cognitive and emotional development, which was expected to affect their responses, could not be assessed.

The final limitation was imposed by the nature of the hospices through which the cases presented in this study were found. The hospice volunteers and other participants in this study were interviewed about their perceptions of the children of **clients**, people who had wanted and sought assistance from a hospice. Hospice clients are usually in their sixties or older; their children are themselves adults. Families with young children do not ordinarily seek the assistance of a hospice when confronted with advanced cancer (Hospice Coordinators, 1993-5). Unusual family circumstances, therefore, motivated the parents in the case-studies presented here to seek the services of a hospice volunteer. Adult perceptions of children whose parents neither desired nor sought psychosocial support from a hospice might have been quite different, and were not investigated.

Value of the Proposed Study

The current study takes a valuable first step towards increasing our understanding of the experiences of children with a parent with advanced cancer. An extensive search of the current literature located only one research project that investigated the parents' and teachers' perceptions of children with a parent with advanced cancer (Siegel et al., 1992). No studies were found in the hospice literature which examined the relationship between hospice volunteers and the family's children. In the cases presented here, a series of interviews with the surviving parent and with other adults who had regular contact with the child during his or her parent's final months, provide a polyphony of voices which augments the perceptions of the child provided by the hospice volunteer. No previous study focussing on the multiple perspectives afforded by a group of caregivers surrounding a particular child with a parent with advanced cancer has been reported in the literature reviewed for this study.

The results of this study may have implications for improvement in the delivery of health care services to the families of hospice clients. In addition, it is anticipated that the information provided by this study will form an important resource in the development of appropriate guidelines for direct interviews with the children themselves. The rich, thick description of the perceptions, concerns and experiences of the participants investigated here might uncover one or more underlying themes common to each child. Should this occur, the need for a more comprehensive study would be indicated. This, in turn, might inform the design, implementation, and evaluation of proactive interventions which could play a significant role in improving long-term mental health for older children, adolescents and adults who have been bereaved in childhood.

Organization of the Thesis

In the second chapter, I review the current literature on the impact of advanced cancer on the family, with particular emphasis on the experiences of children when the cancer patient is their parent. The third chapter presents a detailed description of the research methods used in this study. Background information on the nature of hospice work is provided in the fourth chapter, together with an overview of the characteristics and policies of the hospices that provided the two cases for this research project. The results of the analysis of the interviews with the participants for Case 1 is discussed in Chapter 5 and for Case 2 in Chapter 6. In the final chapter, I discuss the findings in relation to the existing literature, before concluding with an examination of the implications of the results for future research.

CHAPTER 2

Review of the Literature

This chapter addresses relevant theoretical issues and examines recent research in order to place this thesis in the context of the current literature. Given the paucity of research that specifically investigates the experiences of children with a parent with advanced cancer, a review is included of the broader literature that investigates the impact of cancer on the family system. This review includes research using both quantitative and qualitative methodologies that has been published in the last 15 years.

Building on what is now known about bereaved children, there has been a proliferation of research in the last two decades that reports and evaluates a wide variety of counselling interventions with this population. Nothing comparable however, currently exists for the child who is confronted with the likelihood of parental death, but who is not yet bereaved. A literature search in the fields of psychology and education revealed very few studies that were relevant. A search of the hospice literature was disappointing: the one article located that was devoted specifically to the needs of children did not report original research. The recent nursing and social work literature, however yielded numerous research reports and review articles, most of which called for further investigation. It is apparent that the need for clinicians to comprehend the perceptions and experiences of children with a parent with advanced cancer is only beginning to be recognized.

This review of the literature is organized into two sections. First, I examine research on the impact of cancer in adults on the family system. I then discuss recent investigations on the impact of parental cancer on the adolescent and younger child and examine preliminary studies on interventions with children.

The Impact of Cancer in Adults on the Family

Research on the impact of cancer in adults on the family is more extensive than the literature focussing on the impact of parental cancer on the child. It is a diverse literature, including all stages of the disease from diagnosis, through treatment and remission to advanced (or terminal) cancer and subsequent death. Two factors contribute to the complexity of research in this area. The first is that the impact on family members varies depending on the stage of the patient's cancer (Lewis, 1986; Northouse, 1984

#105; Woods et al., 1989). The second is that the impact is also affected by the family member's role and relationship to the patient (Germino, 1984; Woods et al., 1989).

The literature reviewed in the first part of this section deals specifically with the impact of cancer in an adult on healthy adult family members, who may be parents, spouses, adult children or other relatives of the cancer patient. Studies have tended to focus on the effects of cancer on one or two healthy family members; no studies were found that consistently included every member of the nuclear family. The stage of cancer is not always specified; three studies simply stated that they were conducted while the patient was hospitalized (Lovejoy, 1986; Welch, 1982; Wright & Dyck, 1984). In all three, data were taken from one self-selected family member and then aggregated with data from other families so that any differences that may have existed between spouse, parent, and adult children were lost (Lovejoy, 1986; Welch, 1982; Wright & Dyck, 1984). Two research projects were located that investigated the impact of cancer on at least three different family members: the patient, his or her spouse and at least one adult child (Davies et al., 1990, 1995; Germino, 1984). Only one of the two projects focussed specifically on the stage of advanced cancer (Davies et al. 1990, 1995).

The impact of cancer on adult family members

The literature search located four reviews of research on the impact of cancer in adults on healthy adult family members including adult children (Lewis, 1986; Northouse, 1984; Northouse & Peters-Golden, 1993; Woods et al., 1989). Two are comprehensive reviews that include formal tables detailing the sample size, phase of illness, method and outcome of each study reviewed (Lewis, 1986; Northouse, 1984). A third article, less comprehensive in approach, presents a brief overview of the literature on the concerns of healthy adult family members and investigates how those concerns and coping patterns vary as the status of the disease changes (Woods et al., 1989). The fourth article summarizes the relevant literature before recommending strategies specifically designed to assist the spouses of cancer patients (Northouse & Peters-Golden, 1993).

The first review article examined 24 studies on the impact of cancer in adults on the family. Of these, 14 investigated families where the patient's stage of cancer was classified as either terminal or advanced (Northouse, 1984). The second review summarized 15 studies, of which 5 dealt with advanced cancer (Lewis, 1986). Three of these 5 studies also appeared in the first review; there are a total of 16 different studies on advanced cancer in the 2 reviews. Both articles stressed that a family functions as an interdependent system and that illness in one family member affects the equilibrium of the entire system (Lewis, 1986; Northouse, 1984). The relevance of family systems theory is illustrated by the finding that adjustment of the cancer patient is profoundly affected by the responses of other family members (Northouse & Peters-Golden, 1993; Woods et al., 1989). Given that family members are taking an increasingly active role in providing psychosocial support for the cancer patient, the need for professionals to identify and address the specific difficulties faced by healthy family members is acute (Northouse, 1984).

Reports on the impact of cancer on family members can be divided into three distinct areas: communication, physical and emotional needs, and roles and responsibilities. In all areas, cancer in the family is a major stressor; the impact of the disease on family members is likely to be extensive (Hilton, 1994b). In the first area, family members expressed their desire for better communication with health care professionals and their dissatisfaction with both the amount of information they had received and the way it had been delivered (Northouse, 1984; Wright & Dyck, 1984). They also reported either having difficulty discussing impending death with the patient, or avoiding the subject altogether (Northouse, 1984). Hilton (1994b) reported three different patterns of communication between couples confronted with early stage breast cancer: selective open disclosure, talking openly with others rather than each other, and divergent views where one partner wanted to talk and the other didn't. The first was perceived as the most satisfactory for both partners. Communication between different family members in the same family might vary considerably. Germino (1984) found that at the time of diagnosis adult children consistently disclosed their concerns to their mothers and other family members, but rarely disclosed to their fathers.

A series of findings related to physical and emotional needs. For the patient, family members were the primary caregivers for both their physical and emotional needs (Northouse, 1984). The most desirable nursing behaviours perceived by healthy family members were focussed on controlling the patients' symptoms and caring effectively for their physical needs (Wright & Dyck, 1984). Family members were also concerned to learn more about meeting those needs themselves (Lewis, 1986; Northouse, 1984). In the area of emotional concerns, one researcher has focussed on the uncertainty experienced by women with nonmetastatic breast cancer, the stress it creates both for them and their families and the various strategies they use to cope (Hilton, 1988, 1994b).

Transition to the advanced stage of cancer has been established as a particularly emotionally vulnerable time for family members (Lovejoy, 1986). Davies et al. (1990, 1995) used interviews with three adult members in each of 8 different family units in order to conceptualize this stage as a complex process of "fading away". Specific tasks for family members during this process included redefining the family unit, dealing with increased burdens, struggling with the paradox inherent in living while dying, contending with change, and preparing for the death and the time after death. Emotional reactions during the process of "fading away" included confusion, uncertainty about the future and a sense of disconnection; fear and grief at the impending loss; anxiety and helplessness at the patient's suffering; and existential concerns about the meaning of life and death (Lewis, 1986; Northouse, 1984; Welch, 1982; Wright & Dyck, 1984). Sleeping and eating patterns were often disrupted and might contribute to an overall profile of depression (Lewis, 1986; Lewis, Woods Hough & Bensley, 1989; Northouse & Peters-Golden, 1993).

The third area relates to shifting roles and escalating responsibilities. Family members reported experiencing considerable role strain, often over a lengthy period, as they attempted to maintain the household at the same time they were caring for the cancer patient (Northouse, 1984). Disruption of daily routines might manifest itself in alterations in employment, changes in child care plans, increased household duties and decreased social activities (Northouse & Peters-Golden, 1993). Role strain was particularly acute for young families with school-age children (Lewis, 1986). Family members were often unaware of the support services that were available to assist them (Lewis, 1986).

Family members' experience of cancer and the nature of their coping responses varies depending on their position in the family and their relationship to the patient (Woods et al., 1989). As a result, their concerns may differ or they may give the same concerns different priorities (Germino, 1984; Woods et al., 1989). Germino (1984) investigated patterns of concern in 224 members of 90 families within 4 months of diagnosis. Both spouses and adult children were concerned about the illness and existential issues, but the children were more concerned with social dependency while the spouse focussed on personal issues. In addition, individual family members differed in the amount they disclosed to other family members (Germino, 1984).

Studies which focus on the impact of cancer in an adult on the family need to include as many healthy family members as possible, in addition to the patient, if they are to accurately reflect the experience of the family unit. Past experience with loss and death, which appears to influence how family members deal with the transition of "fading away" (Davies et al., 1990, 1995) needs to be established for each participating family member. Lewis (1986) has indicated the need to include individuals external to the family in future research in order to address recognized shortcomings in relying solely on self-report. Longitudinal research could allow researchers to investigate the changing impact of the disease on family members through time. If the research includes the period both before and after the family member's death, then both prospective and retrospective aspects of a family's experience can be examined. The need for longitudinal studies has been advocated for over a decade (Lewis, 1986; Northouse, 1984).

Helping adult family members

Research on intervention strategies for families dealing with cancer is fairly recent. An assessment of the needs of family members must precede the implementation of psychosocial support services (Davies et al., 1995, p. 87; Feldstein & Rait, 1992; Welch, 1982; Wright & Dyck, 1984). Several authors have advocated a family life-cycle framework for the collection of family systems data by medical personnel. They have stressed that consideration of the family's developmental stage and level of organization could increase the effectiveness of nursing care in either a hospital or home-care setting (Feldstein & Rait, 1992; Hall & Kirschling, 1990). Clinicians need to be aware that cancer can seriously tax family members rearing young children by amplifying the centripetal or inward-turning effect of this developmental stage of the family life cycle (Feldstein & Rait, 1992). Once assessment is completed, additional intervention strategies fall into the basic categories of providing information and social support (Northouse, 1984; Northouse & Peters-Golden, 1993).

Depending on the setting, either oncology nurses or the health care professionals employed by hospices may provide family members with appropriate information about the patient's treatment (Hall & Kirschling, 1990; Wright & Dyck, 1984). Health care professionals need to examine what kind of information is relevant to the advanced stage, when and how it should be given, and who would be in the best position to provide it (Northouse & Peters-Golden, 1993). Reassurance can be provided by preparing family members for expected physical and emotional reactions as the patient enters the advanced stage, and by normalizing these reactions as they occur (Davies et al., 1990, 1995; Northouse & Peters-Golden, 1993).

The oncology nurse is ideally situated to provide informal and ongoing social support to family members while the patient is hospitalized (Lovejoy, 1986; Wright & Dyck, 1984); hospice personnel are in a position to provide support to those receiving hospice services (Hall & Kirschling, 1990). Ensuring that family members have adequate support for themselves can enhance their ability to sustain a supportive role with the patient (Northouse & Peters-Golden, 1993; Yancey & Greger, 1990) as well as with other family members (Godkin, Krant, & Doster, 1983-84).

Many cancer patients and their families prefer to care for the patient at home during their final months. The palliative care and hospice literature have documented the trend away from hospitalization of the dying and towards community and family-centred care (Buckingham, 1982-83). Health care costs are reduced and psychological well-being for families and patients are often increased when families choose home rather than hospital care (Buckingham, 1982-83). A qualitative prospective study of 24 adult family members (patient, spouse and adult child) from 8 families, (Brown et al., 1990) divided the advantages of home care the participants discussed into 5 interrelated concepts. These were: *being there,* the sense that home is the centre of meaningful activity; *normalcy,* the maintenance of normal routines in the home environment; *sustaining relationships,* the relative ease with which connectedness could be maintained; *self-determination,* which described how patient and family could set their own routines; and *reciprocity,* in which family members could demonstrate their connectedness to the patient through caregiving.

The findings reported by Brown et al. (1990) and Davies et al. (1995) indicate that a supportive environment that actively encourages family involvement in patient care can ameliorate emotional and behavioural difficulties for family members dealing with advanced cancer. Prospective studies with larger samples which use appropriate control groups are required, however, if the efficacy of providing information and social support to family members of the patient with advanced cancer, either at home or in a hospital setting, is to be firmly established (Brown et al., 1990; Buckingham, 1982-83; Davies et al., 1995; Lewis, Ellison & Woods, 1985; Lewis, 1990).

The Child with a Parent with Advanced Cancer

> ... children's mental health in the period immediately before parental death from chronic illness typically has been overlooked by clinicians, research investigators, and perhaps even by parents. This may be attributed, at least in part, to the focus of professionals and family members on the patient's survival,

> as well as to the persistent belief that children should not be confronted with, and in fact should be sheltered from, issues surrounding serious illness and death. However, children may already be exhibiting high levels of distress in response to the significant life changes accompanying parental terminal illness.
>
> (Siegel et al. 1992)

Since the early 1980's, the Memorial Sloan-Kettering Cancer Centre in New York has produced a series of articles investigating the effects of parental cancer on the child, and documenting the design and efficacy of their interventions with children who are about to be bereaved (Adams-Greenly & Moynihan, 1983; Christ & Siegel, 1991a; Christ, Siegel, Mesagno & Langosch, 1991b; Christ et al., 1993; Siegel et al., 1990, 1992). Israeli researchers have also focussed on the adaptation of children with a parent with cancer, and on the need for psychotherapy with this population to prevent long-term deleterious effects (Rosenfeld et al., 1983; Rosenheim & Ichilov, 1979; Rosenheim & Reicher, 1986). A rigorous longitudinal study of families with school-aged children whose mothers have non-metastatic cancer has made an important contribution to research in this area (Lewis 1990; Lewis et al., 1985, 1989). An extensive study of family adjustment and coping during early stage breast cancer has also included some relevant data on families with younger children (Hilton, 1993, 1994a).

Additional articles from various sources can be divided into the same two groups: those that examine the effects of parental cancer on children and adolescents (Brown, 1992, 1995; Issel et al., 1990; Nelson, Sloper, Charlton & White, 1994; Wellisch, 1979), and those that document and evaluate counselling groups implemented specifically for these children (Call, 1990; Greening, 1992). The literature on chronic illness and critical care nursing has produced a few articles on the needs of children with an ill parent that are relevant to the current study (Lewandowski, 1992 #184; Peters & Esses, 1985; Titler et al., 1991). The above research tends to be exploratory, and the results, many of which are based on pilot projects, tentative. I will examine the literature on the impact of parental illness on adolescents and younger children before discussing recent research on counselling services for children with a parent with advanced cancer.

The impact of parental illness on adolescents

Five studies are discussed in this section: the first deals with the impact of parental chronic illness on the adolescent (Peters & Esses, 1985) while the succeeding four examine the experiences of adolescents when their parent has cancer (Brown, 1992, 1995; Nelson et al., 1994; Rosenfeld et al., 1983; Wellisch, 1979). Only one research project dealt exclusively with advanced parental cancer (Brown, 1992, 1995); two are retrospective and focus on the adolescents' reactions at the time of diagnosis (Nelson et al., 1994; Rosenfeld et al., 1983). The final study deals with children whose ages on parental diagnosis ranged from 6 to 16 (Nelson et al., 1994). It is included in this section because the only statistically significant findings it reports are for adolescent boys.

The first study used a family systems perspective to examine the impact of a parent chronically ill with multiple sclerosis on the family environment as perceived by a non-clinical population of 33 adolescents aged 12 to 18 (Peters & Esses, 1985). The ill parents had been diagnosed for at least a year. Experimental design included the use of a control group matched for age, sex, number of siblings and socioeconomic status, selected from a parochial high school, and the administration of a standardized questionnaire to assess family functioning. This study is one of the few in which the influence of the child's or chronically ill parent's sex on subscale scores was tested, and found not to be statistically significant. Significant differences between the experimental and the control groups were found on half the subscales: the experimental group reported less family cohesion and organization, more conflict, and had lower scores for intellectual-cultural orientation and moral-religious emphasis. The authors discussed reduced cohesion as the product of two factors: a reduction in the number of family activities, combined with physical and emotional withdrawal of individual family members. They suggested that task overload experienced by healthy members may have contributed to both the lack of cohesion and the increased conflict experienced by the participants. The experimental group's lower score on intellectual-cultural orientation was also related to task overload: faced with escalating demands, healthy family members had little time or energy for intellectual and cultural pursuits. Differences between the two groups in moral-religious emphasis were considered an anomaly resulting from the control group's religious affiliation. This study underscored the need for investigation of the family's support system, which the authors felt had the potential to moderate some of the adverse effects of parental chronic illness.

The first of four articles on the impact of parental cancer on adolescents, Wellisch (1979) presented six brief case-studies of families referred for therapy when adolescent members began to act out after their mother or stepmother contracted cancer. Two case-studies focussed on the period immediately preceding death, two dealt with the period when death seemed likely but was not imminent, and two concentrated on fami-lies where the long-term prognosis was good. The adolescents' behaviours included being sexually active with multiple partners, failing to observe curfews, using drugs, drinking, driving while intoxicated and refusing to attend school, help out at home, or visit the ill parent in hospital. The findings support Wellisch's argument that the central conflict for adolescents with a parent with cancer is between the intensification of family relationships resulting from the illness and the natural developmental course of adolescence towards emotional separation from the family. A serious limitation of this report, however, is that a clear distinction is not made between observation of the adolescent's behaviour and the author's interpretation of that behaviour.

The second article presented the results of a preliminary, retrospective study on the adaptation to parental cancer of 8 women between the ages of 12 and 20 whose mothers had had a mastectomy 2 to 3 years earlier (Rosenfeld et al., 1983). The wide age range unfortunately includes both children and young adults. Whether or not the mothers were currently in remission was not recorded. The researchers used a standardized interview to obtain information which was then recorded on a questionnaire, neither of which are presented. Most of the participants saw their mother's cancer as a serious threat whose outcome was uncertain; 5 worried that their mother would die and the 2 youngest expressed concern that they would get sick themselves. The majority continued to perform well academically although 3 experienced a transient decline in the months directly following their mothers' mastectomies. All reported experiencing either psychosomatic problems such as headaches, dizziness, 'flu and weight loss, or mood disturbances including depression, sadness, crying spells and loss of sleep. Their symptoms were strongest during their mother's hospitalization. Two-thirds of the participants felt they were given insufficient information and support from their families about their mother's cancer; only 5 explained their situation to friends. The level of participation in the study was high: the researchers concluded that unmet needs for support and high stress levels had motivated the daughters to participate.

Brown (1992, 1995) used grounded theory (Glaser & Strauss, 1967) to analyse interviews with 11 adolescents aged 15-19 with a parent with advanced cancer and to compare the results with the conceptualization of "fading away" developed by Davies et al. (1990, 1995) for the process of adjustment undergone by adult children. The age range is narrow and the results more meaningful than if the experiences of younger adolescents had been included. Although interviews with both the healthy and the ill parent were also conducted, only the results of the interviews with the adolescents were reported. The analysis is thus restricted to a single data source. Brown's results (1992, 1995) supported the argument advanced by Wellisch (1979). They revealed fundamental differences between the experiences of teenagers and adult children which were directly related to the different developmental stages of the two groups. The teenagers coped with trying to achieve physical and emotional separation from their parents while at the same time encountering increased demands to spend time at home, by shielding themselves from thoughts of their parent's illness and the likelihood of their death. The act of shielding meant that the teenagers were poorly prepared for parental death in comparison with the adult children, who had accepted that death was imminent (Brown 1992, 1995; Davies, et al., 1990, 1995).

This section concludes with a British pilot study which used semi-structured interviews and self-report questionnaires with 24 young people between the ages of 11 and 21 whose parents had been diagnosed with cancer 2 to 6 years earlier (Nelson et al., 1994). The parents were currently in good health. The study assessed retrospectively the participants' difficulties on parental diagnosis when they were between the ages of 6 and 16. The results are therefore based on an awkward age span which includes both younger children and adolescents; no breakdown of the sample by age is presented. The study needs to be replicated with a sample matched for gender, a smaller age range and a more finite time since diagnosis.

Problems with schoolwork and attendance were more likely to be reported by sons than by daughters. All daughters reported that their relationships with the ill and well parent either improved or stayed the same following parental diagnosis; 2 sons reported deterioration in their relationship with the ill parent and 4 in their relationship with the well parent. Overall, there was a tendency for parents to tell older children more about the nature of their parent's illness; younger children were often given no information at all. More than half the children stated that no-one at school had known about their parents' cancer. Approximately half recalled giving up some of their leisure activities and spending less time with friends. The five adolescent boys with elevated anxiety scores were significantly more likely to report inability to discuss parental illness with either parent, deterioration in schoolwork and reduction in the amount of time they spent playing sports or being with friends than participants whose anxiety scores were not elevated.

The results of this pilot study indicate that adolescent boys may be particularly at risk for developing high anxiety after a parent is diagnosed with cancer, especially if they are unable to discuss the illness with their parents and the time they can spend away from home is curtailed. The authors conclude that maintaining a normal home, school and social life may enable children to cope more effectively with parental cancer.

The centripetal effect of parental illness on the family life of adolescents is in conflict with their developmental task of separating from their families (Brown, 1992, 1995; Furman, 1985; Wellisch, 1979). In this respect, it differs from the impact of parental illness on younger children. The findings that specific effects on adolescents may include physical symptoms and changes in behaviour as well as emotional disturbances, and that developmental factors need to be carefully considered may also be relevant to younger children. There are indications that adolescent boys may be especially at risk. The suggestion has been advanced that the family's support system might be able to modify the reduced family cohesiveness and increased conflict that result from parental illness; recommendations have been made for research in this area. The literature search did not locate any reports documenting indivdual or group counselling interventions designed specifically for adolescents with a parent with advanced cancer.

The impact of parental illness on children

The first two articles examined in this section are drawn from the critical care literature and focus on the needs of children and other family members when a parent is in critical care (Lewandowski, 1992; Titler et al., 1991). There are major differences between critical care hospitalization, which is sudden, acute and gives family members no time to adjust, and advanced cancer. The cancer patient may have taken years to decline to their current state, and the family will have had time to make a series of adjustments as they became necessary. Nevertheless, the critical care nursing literature, which has begun to investigate the needs of healthy family members including the family's children, has reported findings that may prove relevant for children with a parent with advanced cancer. The succeeding articles investigate the experiences of children when their parent has cancer: the first examines children's reactions at the time of diagnosis (Issel et al., 1990); a second focusses on parents' concerns for their children (Hymovich, 1993). A series of articles on a longitudinal research project conducted by Lewis' group at the University of Washington documents patterns of family interaction in families with breast cancer in the mother and at least one school-aged child during the period following early treatment (Lewis 1990; Lewis et al.,1985,1989). Another series of reports devoted to family communication patterns and challenges for families with early stage breast cancer included families with children between the ages of 2 and 23 who were living at home (Hilton, 1993, 1994a). Succeeding articles concentrate on the period after the parent's cancer has been classified as advanced (Christ et al., 1993; Rosenheim & Reicher, 1986; Siegel et al., 1992). The studies span a broad age range from infants to adolescents and young adults. Differences between adolescents and younger children are not consistently reported.

The first study from the critical care literature used grounded theory (Glaser & Strauss, 1967) to extract thematic content from semi-structured interviews with 12 spouses and 11 sons between the ages of 7 and 18 of patients who had been hospitalized in a critical care unit (Titler et al., 1991). The nursing staff and the patients themselves were also interviewed. The interview guidelines were included in the article. Children and adolescents are at different developmental stages and have very different needs. The wide age range of the children in this study therefore presents a major drawback.

Some of the six themes that emerged were particularly relevant to the children's situation. One was lack of communication between different family members about feelings. Another was the parents' protective attitude towards their children: they tried to shield them from information and experiences they thought could provoke anxiety and were reluctant to allow hospital visits. Although both parents indicated that they did not think their children knew what was happening, the children were able to give vivid descriptions of their ill parent's situation. Feelings of vulnerability, uncertainty, and intense emotions such as fear, anger, guilt, frustration and despair were common. The 5 children under the age of 13 were physically ill with 'flu, headaches or stomach-aches at the time of their interviews. These children had had less contact with their ill parent than the older boys, were given less information, and had fewer opportunities to express their feelings to either parent. Spouses discussed their regrets that they had so little time to spend with their children; nurses tended to concentrate their attention on caring for the patient and were generally unaware of the children's experiences. The authors concluded that the family's children had specific needs during critical care hospitalization that were not being addressed.

The second was a review article which focussed on the needs of healthy children during the critical illness of either a parent or a sibling. Lewandowski (1992) integrated the existing literature on children whose family member had critical or chronic illness with developmental research in order to compile an extensive table of developmentally appropriate interventions for infants, toddlers, preschoolers, school-age children and adolescents. The author stressed that the individual child's resources and vulnerabilities must be considered and that it was essential to provide an environment in which the child could safely express his or her feelings. As a compilation of practical advice for professionals dealing with families in critical care, this article is extremely sensitive, but its recommendations are limited by the exploratory state of the literature on which they are based.

In the first of a series of studies devoted specifically to cancer, young people's ability to cope with their mother's breast cancer was investigated (Issel et l., 1990). All mothers had been diagnosed within the previous 2 1/2 years. Semi-structured interviews were conducted with 81 children, divided into two age groups: 6-12 and 13-20 years. The interviews were content analyzed, coded, and checked for interrrater reliability. The study has several limitations for younger children: the interview questions were not phrased in developmentally appropriate language and the reliability of the children's reports was not established by comparing them with data from parent interviews. The interview schedule is presented, and an example given of the condensation of verbatim categories into second-level categories and hence into four domains. The second-level categories, however, are more revealing of the variety of strategies the children used to cope.

The younger age group thought the family helped them to cope by spending time together, talking about their mother's illness, and by being nicer to each other. One-quarter of them, however, stated that the family did nothing to help them. Things that the younger children described doing by themselves to cope included regular activities, playing alone or with friends, helping their mother and not thinking about her illness. Although the children stated that parents, other family members, adult friends of the family and the children's peers all provided support, they mentioned family members more frequently. The four domains or strategies for coping are summarized as: acting as though the children were *in their mother's shoes,* carrying on *business as usual* (i.e. acting normal), tapping into *group energy* for support, and putting their mother's illness *on the table* (i.e. being open about it).

A more recent study focussed on the parenting concerns of cancer patients and their spouses rather than directly on the children (Hymovich, 1993). Grounded theory (Glaser & Strauss, 1967) was used to analyze semi-structured interviews with 13 parents: 10 cancer patients and 3 of their spouses. Their children were between the ages of 9 weeks and 18 years, a vast age span for such a small sample. The time since diagnosis ranged from 4 weeks to 7 years; the stage of cancer was not specified. The results indicated that child-rearing stressors experienced by parents included the lack of concrete information about the illness to give the children, the need to maintain composure in front of them and con-cern for the future. The parents carefully considered the age of the child, and were concerned to maintain a trusting relationship with the ill parent both at home and during hospital visits. Communication issues included deciding which approach to use and judging what content would be appropriate. The parents identified the following stressors on their children: changes in family life-style, embarrassment over the ill parent's appearance, hospital visiting and obtaining information. They reported their children asking questions about the cancer, expressing concerns about the future and behaving differently. For younger children, this included crying more often and clinging to their parents. This study is severely limited by the vast age range of the children, the omission of the stage of parental cancer, and the lack of interviews with the children themselves. It does, however provide an exploratory overview of the parenting concerns of younger cancer patients.

A longitudinal study of 126 families with non-metastatic cancer in the mother of school-aged children by Lewis' research group at the University of Washington has generated a series of articles (Lewis, 1990; Lewis et al., 1985, 1989). The large sample size is exceptional for research in this area, as is the focus on interviewing all family members. Children were divided into three age groups: 7-10, 10-13 and 14-19 years. A preliminary report discussed the results of initial open-ended interviews with the mother, father and their school-aged children (Lewis et al., 1985). The interview schedules and details of a systematic analysis of the data were not given. Interviews with the healthy father and the ill mother revealed nearly 50 different demands experienced as a direct result of the cancer. Responses from the youngest group of children included concern about what would happen next, loneliness and anger. Fear for the integrity of the family unit expressed by this group came at a time of developmental transition away from the family and towards peers, and was considered a potential source of difficulty for these children. Children aged 10 to 13 had a different orientation. They tended to view their mother's illness in terms of the amount of disruption they experienced as a result, and spoke of having to take on more responsibility and perform more household tasks. They were also more concerned than the younger group with the need for information about their mothers' treatments and prognosis.

Lewis' research group also examined the impact of the father's relationship with his 6-12 year old child on the child's psychosocial functioning in a subset of 48 families in which the mother had either diabetes, fibrocystic breast disease or non-metastatic breast cancer (Lewis et al., 1989). A family systems approach informed the research design. Standardized scales used the father's self-report to measure marital adjustment, family coping, adult psychological functioning and child psychosocial functioning. For all three forms of illness, the family's use of introspective coping behaviours characterized by frequent feedback, reflection and adjustment increased as the demands experienced by the father escalated. The family's use of introspective coping behaviours positively affected the father-child relationship and thus increased the child's level of psychosocial functioning, as did a better marital adjustment between father and mother. The findings reflect the complex nature of the interactions occurring between healthy parent and child when a family confronts illness in the mother.

A more recent article from Lewis's research group recommended nine different types of support services for the family experiencing cancer based on a review of the literature and the above research. The three particularly relevant to children are: interpretation of the illness specifically for them, interpretation of the patient's emotions, and referral services for exceptionally distresed families (Lewis, 1990).

Hilton used grounded theory (Glaser and Strauss, 1967) to analyze group interviews with 55 families held at 5 different points in the first year after the diagnosis of breast cancer in one member (Hilton, 1993, 1994a). The interviews focussed on the issues, problems and challenges confronting the families and on the patterns of communication they used. Uncertainty about the future and the stress uncertainty caused were major issues. This study did not focus specifically on families with young children, but it did include 13 families with children between the ages of 2 and 23 who were living at home. Although the parents' concerns about their children or comments made by the children themselves were neither consistently sought nor reported, this study does indicate some of the effects the mother's early stage breast cancer was having on children. The parents of young children discussed their concerns about how much information to give their children and when to give it, their own increased irritability and childcare concerns. They reported the following changes in their children: shorter attention span, reduced school performance, minor difficulties in behaviour and more physical illness. The children's emotional responses varied from being able to express their concerns to being unemotional and blocking the cancer out. Interestingly, some participants also reported positive changes in their children such as increased confidence and independence, increased displays of affection and less moodiness.

The child's experience during the period when their parent has advanced cancer has been the focus of several studies (Christ et al., 1993; Rosenheim & Reicher, 1979; Siegel et al., 1992). Two included both parents' and child's perceptions of the child's feelings and behaviour (Rosenheim & Reicher, 1986; Siegel et al, 1992). Rosenheim and Reicher (1986) compared the maladaptive behaviour reactions reported by 24 children between the ages of 6 and 16 with an assessment of the child's behaviour by both the ill and healthy parents prior to the commencement of a family counselling group designed specifically for families dealing with cancer. A positive correlation was found between the healthy parent's assessment of the child's behaviour and that of the child, while the correlation between the ill parent's assessment and the child's report was negative. Neither of the two correlations was statistically significant, but the difference between them was, while the difference between the two correlations for a control group of families with cancer who had refused counselling was not significant. A serious drawback of this study is that the original scores on the instruments used are not presented; this makes it impossible to verify the correlations reported. The results indicated a lack of concordance between the child's perceptions of his or her behaviours and the perception held by the ill parent in families that had agreed to attend counselling. The authors concluded that lack of parental awareness of the children's emotional difficulties contributed to the loneliness, apprehension and helplessness the children reported. Their findings in fact warrant a more cautious conclusion: lack of awareness on the part of the ill, but not the healthy parent may have exacerbated the child's predicament.

The following articles from the research group at Memorial Sloan Kettering Cancer Centre are based on data drawn from families who participated in a preventive psychoeducational parent-guidance intervention (Christ et al., 1993; Siegel et al., 1992). The intervention itself is discussed in the following section. The first article presents a thorough statistical analysis of the levels of depression, anxiety and self-esteem reported by a large sample of 62 children aged 7-16 who had a parent with advanced cancer who died within 6 months of the investigation (Siegel, et al. 1992). The study used two data sources: the children's self-reports on standardized inventories for depression, anxiety and self-esteem and the parents' reports of their children's behaviour. Results were compared to a control group of children with healthy parents, matched for age, sex, and number of children in the household. Siegel et al. (1992) found significantly higher levels of depressive symptomatology and anxiety, and lower levels of self-esteem in the experimental group. Their parents scored these children significantly higher than the control group on total behaviour problems and lower on social competence and school performance. Parents were aware of their children's maladaptive behaviours, but did not conceptualize those behaviours as distress. The authors concluded that children with a parent with advanced cancer experience problems in multiple domains at a time when fewer family resources are available to assist them. They did not, however, investigate the child's support system.

Another article generated by the parent-guidance program presented preliminary findings from assessment interviews with 87 children between the ages of 7 and 11 (Christ et al., 1993). The researchers' claims were illustrated by quotes from individual interviews but a systematic qualitative analysis that would lend conviction to their claims had not yet been completed. The researchers reported that virtually all children evidenced distress during the interview in the form of sadness, anxiety or anger. The children also expressed guilt that their behaviour may have been responsible for their parent's cancer, or had contributed to their parent's current anger, withdrawal or lack of affection. The majority were afraid of the disease's symptoms and the side effects of treatment they were witnessing. The parent's previous asymptomatic periods and the length of the illness made some children disbelieve that the chances of remission were poor; others worried that their parent would die. Patterns of pre-operational thinking in some of the younger children contributed to their misconceptions of the cancer process. The children were fearful that the irritability, fatigue, sadness and depression they observed in the well parent indicated that that parent might also get sick and die. At the behavioural level, sleep disorders, somatic complaints, inability to concentrate at school, and increased conflict or withdrawal from parents, siblings and peers were common. The authors concluded that the high levels of distress that children exhibit in their parent's final months of life warrant psychosocial intervention.

The dependence of younger children on their parents makes the impact of parental illness far more serious and threatening for them than it is for adult children. The literature on the impact of parental illness on children is small; only three articles were located that dealt specifically with the stage of advanced parental cancer to which the current research project is devoted. The literature suggests that the child's feelings, thoughts, and behaviour may all be affected. Several researchers discussed the intensity of children's emotional responses to parental cancer. These included fear, anger, guilt, frustration as well as loneliness and despair (Christ et al., 1993; Lewis et al., 1985, 1989; Hymovich, 1993; Rosenfeld, et al., 1983; Rosenheim & Reicher, 1986; Siegel et al.,1992). Depression and lowered self-esteem were two consequences (Siegel et al., 1992). Psychosomatic complaints (Christ et al., 1993; Hilton 1993, 1994a; Rosenfeld et al, 1983) and sleep disorders (Christ et al., 1993; Rosenfeld et al., 1983) seemed to be common. The current study focusses closely on the child's feelings, thoughts and behaviour as perceived by the adult participants.

Impairments in academic achievement have been reported by a series of investigators (Hilton 1993, 1994a; Nelson et al., 1994; Siegel et al., 1992) as has increased conflict or withdrawal from family members and peers (Wellisch, 1979; Siegel et al., 1992). The interview with the child's teacher included in this research project affords the opportunity to assess the child's school performance and to examine his or her social interactions with peers. The interview with the surviving parent permits discussion of any changes in the child's relationships with other family members.

The studies in this review have also indicated that how much information to give to the child about his or her parent's cancer, and how much information the child wants are ongoing issues for both parents and child (Hymovich, 1993; Hilton 1993, 1994a; Lewis 1990; Nelson et al., 1994; Rosenfeld et al. 1983). The current study examines the kind of information about cancer given to the child, when that information is given and how it is phrased.

The research reviewed here has identified various factors that assisted children to cope with parental illness. They included: allowing children to engage in normal, everyday activities (Issel et al., 1990; Nelson et al., 1994; Peter & Esses, 1985), being open about the illness and inviting children to express their thoughts and feelings (Issel et al., 1990), and ensuring that family members and the family's support system addressed the children's needs and concerns (Issel et al., 1990; Siegel et al., 1992). The current study considers the frequency of the child's participation in ordinary, everyday activities with family members and friends, and examines the nature of the child's support system.

Helping children with a parent with advanced cancer

This section is comprised of eight articles, four of which come from the Department of Social Work at the Memorial Sloan-Kettering Cancer Centre in New York. The first report comes from Israel; all others originated in the United States. Assistance for children can be divided into five categories: assisting individual parents to help their children, working with parents in groups, working with parents and children together, working with children individually, and working with children in groups. The first article falls into the fourth category. The next advocates working with both parent and child. The three that follow discuss a single parent-guidance program that focussed primarily on educating the parent, although the child was also interviewed. The last two articles focus on group counselling; one with the children alone, and one with parents and children in separate groups that were run concurrently.

Rosenheim and Ichilov (1979) reported the results of short-term individual therapy designed to enhance the emotional and behavioural adjustment of 12 children between the ages of 10 and 14 whose mother or father had advanced cancer. Advantages of this study include the small age range, the use of a control group of children with a parent with advanced cancer who did not receive therapy and the fact that none of the children in either group had had previous psychological treatment. The small sample size presents a major drawback. Therapy consisted of 10-12 weekly individual sessions which focused on the children's home situation and their feelings about their parents and themselves. The children, their teachers and their parents were all involved in pre and post treatment measures. The children were administered a scale for anxiety; their teachers filled in a standardized questionnaire on their scholastic and social adaptation; and their parents were interviewed about the children's functioning at home, at school and with their peers. The anxiety level of children in the experimental group was significantly lowered post treatment on 3 of 5 subscales: "worries and fears", "cognitive difficulties" and "dysphoric mood" and their adaptation to school improved when compared with the control group. The parents of children who had received therapy reported significant improvements in their functioning at home, school and with their peers. The results indicated the efficacy of short-term individual therapy in decreasing anxiety and improving adaptation at home and school for children with a parent with advanced cancer. The authors discussed the possibility of assisting more children through the use of group counselling and consultation with parents on how to communicate more effectively with their children about the illness.

An early article from the Memorial Sloan-Kettering Cancer Centre summarized the literature on the development of a death concept and on mourning behaviours in children before suggesting psychosocial interventions that the authors have found helpful for children with a parent with advanced cancer (Adams-Greenly & Moynihan, 1983). This paper is characteristic of the state of the literature 15 years ago: no re-search was conducted to support the authors' claims, but anecdotal information based on specific cases was presented. Five basic needs of children with a fatally ill parent were identifed: the need for information they can understand, the need to feel involved and important, the need for reassurance about the grief of adult family members, the need to express their own thoughts and feelings, and the need to maintain their own age-appropriate interests and activities. The importance of working with parents as well as the children is stresed.

More recent reports from the same department have documented the implementation of a psychoeducational parent-guidance intervention with the goal of preventing or lessening the deleterious effects on children of advanced parental cancer and the parent's subsequent death (Christ & Siegel, 1991a; Christ et al., 1991b; Siegel et al., 1990). The rationale for this form of intervention was based on both the existing literature and on the extensive clinical experience of the authors. The research drew on an exceptionally large sample of 200 families confronted with advanced cancer and used an appropriate control group: 100 families received the parent-guidance intervention and 100 received standard social work services. The study design was extremely thorough, combining extensive pre-treatment investigation of the children with post-bereavement follow-up over a number of years to evaluate the long-term effects of the intervention. Multiple data sources were to include the parent, child, and the child's teacher. Both semi-structured interviews that could be qualitatively analyzed and standardized scales that required quantitative analysis were incorporated into the research design.

The intervention was offered to intact families with children between the ages of 7 and 16, beginning approximately 6 months before the death and continuing for 6 months afterwards. This period was chosen as the one in which parents and children experience the greatest distress and family disorganization. The intermittent grieving patterns of children over a lengthy period were instrumental in the decision to target them primarily through their parents, who would be available to them throughout that time. The researchers were also concerned to address parental distress so that the barrier it might present to optimal parenting could be removed.

The intervention before the death consisted of six individual sessions with the well parent, one or two sessions with the child and one session with the well parent and child together. The ill parent was included in some of the sessions if appropriate. A similar pattern of sessions was repeated after the death. The format for each session is described: a collaborative approach was taken, with the professional building on the parent's existing strengths and abilities. The pre-death sessions focussed on assessing the family's and child's adaptation, providing support to parent and child, increasing parenting competence, discussing with the parent how the child's stage of development would affect their ability to understand illness and death, facilitating open communication about the illness and fostering stability in the child's daily environment. Details of the initial assessment interview with the child are given in the previous section. The preliminary findings indicated that most children welcomed the opportunity to talk about their experiences and found the intervention helpful. Younger children who were angry at their parents were, however initially reluctant to participate. Parents reported that the normalization of their children's reactions had alleviated some of the children's anxiety. Details of the effects of the intervention on the parent-child relationship and on the child's functioning after the death are not yet available.

Two reports were located on the use of group counselling with children with a parent with cancer. The first included children confronted with any life-threatening illness in a family member (Call, 1990), the second accepted children whose parent had had a recurrence of cancer and was currently receiving treatment (Greening, 1992). In the first article, a succession of 26 school-based groups were conducted for children between grades 6 and 12. Some of the groups, however, were exclusively for children who had recently been bereaved. Although the groups were divided according to age, no breakdown is presented; the age span must have included children as young as 10 and as old as 18. The school-based groups were set up by a cancer agency and co-led by an agency professional and a school counsellor. The groups met once a week for 10 weeks during regular school hours. Interventions focussed on providing education about the illness, normalizing the children's responses and building on existing strengths. Holding the groups on the school premises had several advantages. Transportation difficulties were eliminated and the support system formed between group members remained intact after the group ended, as they all attended the same school. Group members could also continue to derive support from the school counsellor, who was now familiar to them.

As with most other studies in this section, this report lacked systematic outcome evaluation. The authors presented quotations from individual children to illustrate their findings. The children expressed loss of the sense of being carefree, and both hurt and anger at the remarks of friends who did not understand their difficulties. They displayed an intense desire for a return to normal life, as well as emotions of fear, sadness, anger, guilt, and anxiety. They also reported experiencing similar behavioural changes and somatic complaints to those discussed by Adams-Greenly & Moynihan, (1983), Hymovich (1993) Nelson et al. (1994) and Siegel et al. (1992). In verbal and written feedback, participants emphasized that the group experience had been positive. Their parents noted that their children were less angry and worried, more able to concentrate, shared their feelings more readily and were calmer. The authors concluded that group counselling can be a powerful adjunct to other forms of psychosocial intervention, and is particularly effective in normalizing childrens' feelings and behaviours and in reducing their sense of isolation.

A pilot group counselling project led by a social worker, chaplain and nurses was designed to address the needs of younger children as itemized by Adams-Greenly & Moynihan (1983): 21 parents and 30 children between the ages of 4 and 8 participated (Greening, 1992). The groups for children and their parents, which met once a month, were held in separate rooms but shared a common theme. Facilitators of the parents' group encouraged parents to exchange solutions to difficulties in parenting, invited them to recognize their parenting strengths and to provide support to each other, discussed how their children's stage of development might affect their ability to understand and cope with the cancer, and stressed the importance of giving age-appropriate information. The children's group was carefully structured, and included appropriate activities built on 7 specific topics, details of which are presented. Informal feedback from parents indicated that the groups had been helpful for both them and their children and should be continued. The facilitators felt that the normalization of feelings for both parents and children resulting from the group experience had been particularly beneficial. The program has since been expanded and a formal evaluation kit for parents and children developed.

The results of the studies reviewed in this section indicate that children with a parent with cancer derive benefits from professional intervention whether the form of that intervention is to educate the parents, work conjointly with parent and child, or work with the child individually or in a group setting. Each form of intervention is in need of more thorough research that will systematically evaluate both short-term and long-term effects. Although the current study does not focus exclusively on forms of intervention, it examines the professional services and sources of support available to assist either the child or the surviving parent. The age range of the children studied needs to be substantially reduced and more clearly defined in order to consider the very different needs children have of their parents at different stages of their development. The ages of the children considered eligible for the current study were restricted to 6 to 11 years. Attention needs to be paid to the gender of the child and the ill parent, to the child's culture, religion and socio-economic status and to his or her previous experiences with death. In the research project presented here, these factors are investigated and reported.

In the future, comparative studies will be necessary in order to assess whether one form of intervention is more effective than another, or if several different approaches with the same family may enhance individual effects. The studies discussed do not consistently report their participation rates, nor the characteristics of those who refused. Families who would not have benefitted from a particular approach may simply have decided not to participate. As reports from the Memorial Sloan-Kettering Cancer Centre demonstrate, large cancer agencies are ideally placed to conduct extensive and long-term research projects to measure the efficacy of specific interventions. The rationale for equipping the healthy parent to interact more effectively with his or her children beginning well before the death is sound and would seem to promise long-term benefits for both child and surviving parent. Of the numerous programs discussed above, group counselling with children appears to make a unique contribution to the normalization of their responses to advanced parental cancer.

Conclusion

Researchers studying children with a parent with advanced cancer or any other life-threatening illness, work within a limited time frame whose end-point cannot be known in advance. Even the month when death may occur is uncertain; oncologists are rightly becoming more reluctant to predict when their patients will die. In a paper devoted to the problems of implemention of the parent-guidance intervention described in the preceding section, Christ et al. (1991b) discussed the difficulties of identifying the population from which a large research sample could be drawn. The screening criteria for physicians were carefully phrased: they were asked to identify patients who had a poor prognosis but an expected survival time of at least 16 weeks. The researchers gave assurances that families would simply be invited to participate in a program to help children cope with the stresses of having a seriously ill parent; death would not be mentioned unless the participant brought it up. Although the parent-guidance study was not retrospective, it did have a retrospective component. The data collected from families whose member with advanced cancer had not died within 6 months were excluded from the research findings.

The literature on the experiences of children with a parent with advanced cancer is sparse and for the most part, exploratory. A consideration of the broader literature on the impact of advanced cancer on the family raises a host of considerations pertinent to research on the experiences of children with a parent with advanced cancer. The most urgent is the need for more studies, like the current one and those reviewed in this chapter, which draw on non-clinical populations of children. Results based on samples of children who had exhibited behaviour disturbances prior to their parents' illness may not be applicable to children who had not previously needed counselling.

Although prospective studies with children who have a parent with advanced cancer are difficult to implement, they may uncover factors not apparent in retrospective studies. The latter occur after the enormous stresses and uncertainties of the final months of illness have passed; participants can be invited to look back and reflect on their experiences before the death but they are no longer living inside that time. Prospective studies involve children who exhibit high levels of distress (Siegel et al., 1992) and are therefore more difficult to conduct. For ethical reasons, it is incumbent upon the researcher working with children with a parent with advanced cancer to ensure that prospective studies possess a proactive component that extends beyond the collection of data.

An additional consideration which has arisen from this review of the literature is the need for longitudinal studies which commence before the parent's death and continue afterwards. The research team at Memorial Sloan-Kettering Cancer Centre in New York (Christ & Siegel, 1991; Christ et al., 1993; Siegel et al., 1990, 1992) has designed a longitudinal research project that also has a proactive component. Data on children confronting advanced parental cancer are collected in conjunction with the implementation of an appropriate psychosocial intervention with the family unit. Evaluation of the effects of the intervention in the year following the death has been built into the research design. Another issue involves the dearth of studies that compare the impact of advanced parental cancer on adult children, adolescents and younger children. The diversity of the current literature makes a meaningful comparison across existing studies virtually impossible. The research of Brown (1992, 1995) on the experiences of teenagers living with a parent with advanced cancer, which builds on the previous findings of Davies et al. (1990, 1995) provides one notable exception.

Research data need to be collected in age ranges that accurately reflect children's different stages of development and their changing understanding of death. When data from preschoolers are aggregated with data from children nearing puberty, the the effects common to both age groups will be distinguished but the effects specific to a narrower age range may not be isolated. In accordance with these considerations, this research project focusses on children of a limited age range. The wide variety of factors that have been found to influence a child's response to bereavement will likely also be affecting the child confronted with advanced parental cancer. Research designs that include multifactorial analyses of the different factors need to be conducted. The sex of the ill parent and the child needs to be reported in all future studies, as it is in this one. Socioeconomic status is a factor that has been given insufficient attention. The longitudinal research project at the University of Washington is based on a sample drawn from the upper middle class (Lewis et al., 1985; Lewis et al., 1989; Lewis, 1990). Although the project design is rigorous, its results may not be applicable to families drawn from the working classes or the lower middle class.

Lewis (1986) has recommended including participants external to the family who are involved with the child on a regular basis. Children can be expected to behave differently in different situations. In the current study, interviews with the hospice volunteers, alternate caregivers and school personnel provide multiple perspectives on the many different aspects of the child's daily functioning which augment the perspective provided by the surviving parent. Both Siegel et al (1992) and Lewis (1986) have discussed the importance of including the teacher's assessment of the child in their research. If the child's experience is to be approached through the perceptions of adults with whom he or she is in regular contact, then the quality of the relationship between the child and those adults needs to be ascertained, whether they are family members or individuals external to the family. In the current study, the amount of time the child and adult spent together, the kinds of things they did and the nature of the adult's understanding of the child that resulted have been examined and recorded.

Chapter 3

Method of Investigation

Theoretical Issues

Qualitative methodology, with its discovery-based and inductive capabilities, was eminently suited to the exploratory nature of this study (Hammersley, 1990, p.8), given the lack of research investigating either adult perceptions of children with a parent with advanced cancer, or the experiences of the children themselves. Although both positivist and post-positivist paradigms employ qualitative methodology (Lather, 1986; Miles, 1984 p.19-21) this research project is firmly situated within post-positivist forms of inquiry.

Positivism asserts that reality is an independent entity that operates through immutable causal laws (Guba, 1990). The noninteractive position that positivist inquirers adopt is considered to result in the acquisition of knowledge that is objective and value-free. Positivist scientific investigation uses the hypothetico-deductive method; the results provide either support for or refutation of the theory being tested (Guba, 1990; Hammersley & Atkinson, 1992, p.4-5). Emphasis is placed on the use of random sampling procedures which allow the results to be generalized to a larger population (Hammersley & Atkinson, 1992, p.4).

Post-postivism represents a proliferation of many different forms of inquiry, rather than a single paradigm (Lather, 1991, p.12). Post-positivists are divided in their beliefs about the existence of an independent reality. They agree however, that it is not possible for human beings to perceive the real world in a singular way with their limited sensory and intellectual apparatus (Guba, 1990). Scientific findings emerge from the interaction between the researcher and the researched; the human qualities the researcher brings to his or her work are essential aspects of the research instrument (Guba, 1990). The process of discovery by which new theories may emerge is considered one important aspect of the kind of science that post-positivist paradigms encompass (Merriam, 1988, p.3). In this research project, I have drawn on the post-positivist forms of inquiry advocated by naturalism, critical theory and the social construction of reality. The aspects of each that are relevant are discussed below.

Naturalism and the social construction of reality

This research project was conducted within the ethnographic tradition of naturalism, with specific regard for the concept of reflexivity, which indicates that the researcher is part of, and exerts influence upon, the world he or she is studying (Hammersley & Atkinson, 1992, p. 14). My emphasis on describing and understanding the context within which the events perceived by each participant occurred is derived from naturalism (Hammersley, 1990, p.7-9). Although the interviews used for data collection were set up specifically for the purposes of the research, and were in that sense not "natural", the concern that they be as natural as possible was addressed through their semi-structured format (Hammersley, 1990, p.7).

I have adopted the position that human knowledge is composed of the mutual interaction of multiple, socially constructed realities (Berger & Luckmann, 1966, p.1; Lincoln & Guba, 1985, p.37-8). As human beings we are incapable of discovering the nature of an "objective" reality that may or may not actually exist. What we take for granted as the "reality of everyday life" (Berger & Luckmann, 1966, p.19) is in fact a series of pluralities, negotiated on the basis of the numerous and varied understandings of many individuals and maintained by those understandings. Once the position is adopted that what we know of reality is socially constructed, scientific research can no longer be regarded as value-neutral, scientifically "objective" and devoid of political interests (Lather, 1991, p.51-52; Popkewitz, 1990). Popkewitz (1990) states that "to probe the character of a critical science in education is to bring the theme of the socially constructed character of knowledge into questions about methodology".

Critical theory

Critical theory forms a basis for post-positivist inquiry (Lather, 1991, p.12), derived from the work of Jurgen Habermas and the Frankfurt School of Marxism. Habermas argues that the natural sciences are motivated by a cognitive interest in establishing instrumental control, which is neither a legitimate nor an ethical goal for the study of human behaviour. He regards interpretive research as more appropriate to the social sciences (Hammersley, 1990, p.12).

Critical theory addresses the issue of the purposes for which knowledge might be used and argues the importance of making explicit the social values and political relations that may be operating implicitly within scientific research (Hammersley, 1990, p.12; Popkewitz, 1990). Lather (1991, p. 52) discusses the role of emancipatory knowledge in increasing awareness "of the contradictions distorted or hidden by everyday understandings", and in directing "attention to the possibilities for social transformation inherent in the present configuration of social processes". Critical theorists criticise ethnography for simply describing the social world as it is, rather than making a commitment to the development of a more just social order by conducting openly ideological research (Guba, 1990; Hammersley, 1990, p.15; Lather, 1991, p.50).

Goal of research

Postpositivists argue that research in the social sciences cannot uncover a single, objective "truth". Instead, the goal of research is to explore and attempt to make sense of the complexities of human existence in light of the postpositivist recognition that the 'facts' research purports to uncover are not independent of the values held by the researcher who uncovers them (Lather, 1991, pp.51-52). Naturalism considers that the purpose of conducting research is to establish an increased understanding of individual cases, which can in turn contribute to more useful and productive interactions between people (Lincoln & Guba, 1985, pp. 37-8). Postpositivist forms of inquiry are characterized by " research designs that are interactive, contextualized and humanly compelling because they invite joint participation in the exploration of research issues" (Lather, 1991, p.52) rather than place sole responsibility and power in the hands of the researcher.

Methodological implications

Lather (1991, pp. 55-56) advocates interactive, dialogic research designs in which a reciprocal relationship is developed between the a priori theory held by the researcher and the grass-roots knowledge and lived experiences of the participants. The developing theory encourages participants to reflect on their experiences within the context of the larger social order and empowers them to apply the knowledge they acquire as a result . The contribution of the participants in turn illuminates and modifies the theory. The researcher's attitude that he or she is prepared to learn from what the participants say conveys an attitude of profound respect that shifts the focus of the research. The use of reciprocity in fieldwork establishes conditions that will generate particularly rich data (Lather, 1991, p.57). Two of the numerous approaches Lather suggests for building reciprocity have been used in this study. Firstly, I conducted the interviews in an interactive, dialogic manner that used self-disclosure (telling the participants about my experiences with my two friends who died of cancer, and how those experiences had motivated me to do this research). Secondly, through the process of respondent validation I gave each participant the opportunity to modify the description and emerging analysis so that they were actively involved in validating the interpretation that I had placed on their words (Lather, 1991, p.61).

Validity

A postpositivist reconceptualization of validity appropriate to qualitative research has been used in this study to ensure the rigour of the research and to provide empirical accountability to the participants. As advocated by Lather, this reconceptualization has four components: systematized reflexivity, triangulation of data sources, methods, and/or theories, face and catalytic validity (Lather, 1986; Lather, 1991, pp. 52-3). Each component is discussed separately below.

Construct validity or systematized reflexivity

Construct validity in qualitative research asks whether the participants' constructions of reality have been adequately observed and represented by the researcher (Merriam, 1988, pp. 167-168). The systematized reflexivity recommended by Lather focusses on the responsiveness of the researcher to the participants' constructions and "seems essential in establishing construct validity in ways that will contribute to the growth of illuminating and change-enhancing social theory" (Lather, 1991, p.67). It requires an ongoing critical appraisal of how one's preconceptions have been modified by the "logic that the data itself presents" and necessitates an interactive, dialogic encounter with the participants (Lather, 1991, pp. 64-67). A less rigorous version of this process is discussed by Hammersley (1990, p.8), who states that the foreshadowed problems which provide the initial focus for a research project will be "narrowed and sharpened and perhaps even changed substantially" as the research proceeds. Systematized reflexivity in a research design guards against the imposition of a priori theory by requiring that the researcher continually seek alternative explanations of the data.

In this study, a systematized reflexivity revealed how the biases and assumptions with which I commenced were being continually modified by what I was told by the participants. Fieldnotes maintained throughout the course of the investigation documented this process of modification. Keeping fieldnotes was also essential to an alternative concept of reflexivity proposed by Hammersley: my recognition and acknowledgement of the specific circumstances in which the participants seemed to be reacting directly to my presence (Hammersley & Atkinson, 1992, p. 15).

Triangulation or the use of multiple perspectives

Triangulation is not essential to establishing the validity of qualitative research but can act as a useful adjunct. The process commonly refers to the triangulation of multiple data sources (Hammersley & Atkinson, 1992, pp. 198-200; Kirk & Miller, 1986 p. 30), which allows the researcher to check the accuracy of conclusions drawn from a single data source against those drawn from other sources (Goetz & LeCompte, 1984, p.11). Lather expands the concept of triangulation to include methods and theoretical approaches as well as data sources (Lather, 1991, p. 67). The use of triangulation in one or more of its forms increases the trustworthiness of the research by requiring the researcher to consciously seek counter patterns as well as convergence in the data (Lather, 1991, p. 67).

The opportunity for data triangulation in the two cases presented in this study was afforded by the use of one method of investigation, the semi-structured interview, across multiple data sources (Denzin, 1989, p.237). Multiple perspectives on the same child were provided by the numerous adults interviewed who were in regular contact with him or her. The use of respondent validation could be interpreted as another form of triangulation, in which the same participants provided additional data at a much later point in time (Hammersley & Atkinson, 1992, pp.198). It was not expected that data triangulation would result in a coherent, consistent picture (in which all participants would report the same event in the same way) but would contribute to the rigour and richness of the research (Denzin, 1989, p.239). It was also expected that triangulation of data sources would permit a deeper and clearer understanding of the child's situation (Taylor, 1984, p.69): different participants might have perceived the same event in very different ways; each might also have been present on different occasions from the others.

Face validity or respondent validation

Face validity in qualitative research involves the "submission of a preliminary description of the data to the scrutiny of the researched" (Lather, 1991, p. 53) and seeks congruency between what the researcher has reported and the experiences of the participants. Lather's position is backed by Lincoln and Guba's claim that validity in qualitative research is dependent on the demonstration "that the reconstructions ... that have been arrived at via the inquiry are credible to the constructors of the original multiple realities" (1985, p. 296). They assert that a fitting alternative in qualitative research to the positivist notion of internal (or face) validity is the concept of credibility defined as the presentation of "such faithful descriptions or interpretations of human experience or interpretations of a human condition that the people having the experience would immediately recognize it from those descriptions as their own" (Guba and Lincoln,1981, cited in Sandelowski, 1986, p. 30).

Respondent validation, which is the process of giving the participants the opportunity to check through and modify the description, emerging analysis and conclusions, plays an important part in democratizing the research process (Lather, 1991, pp.58-67). Social meaning continues to be negotiated at this stage in a dialogic enterprise between the participants and the researcher (Lather, 1991, p.59). The extension of the process of negotiation begun during the interviews may increase the participants' sense of their own agency and motivate them in ways that cannot be foreseen until the research project is nearing completion.

Face validity or respondent validation was established in this study by taking the emerging findings back to all participants, giving them the opportunity to check through a draft section of the thesis dealing with their interview, and making the modifications they judged necessary. Participants were not permitted to alter the statements of other participants in the study, but their responses to those statements have been included in the results section.

Catalytic validity

Research conducted by critical theorists "sets out to explain the nature of a social order in such a way that it serves as a catalyst for the transformation of that order" (Hammersley, 1990, p.66). "Catalytic validity" is how Lather terms this radical component of the four-part reconceptualization of validity she proposes. It represents the extent to which participants may be motivated by the increased understanding of their reality gained through involvement in the research process to transform that reality (Lather, 1991, p. 68). This component directly contradicts the positivist requirement that the researcher take a neutral position. It also differs from the conventional ethnographer's concern with description and explanation (Hammersley, 1990, p.66).

The use of catalytic validity encourages the researcher to consciously channel the research's ongoing impact so that respondents gain "a deeper understanding of their particular situations" (Lather, 1991, p.56). It requires that the researcher investigate the impact of the research on the participants, and include those findings in the research report. The use of research in the social sciences as a catalyst for social change is not a simple task, and it does not have a single endpoint. Hammersley states that the use of research as praxis:

> . . . may be seen to involve making decisions in the light of multiple, schematic (and possible conflicting) values that have to be interpreted in relation to concrete and changing situations about which we have limited information. It is *not* the pursuit of some fixed end state, but the preservation or improvement of a situation in the light of a set of values whose validity one accepts for the moment . . .
>
> (Hammersley, 1990, p. 68)

The application of catalytic validity needs to be tempered by a grasp of the fluidity of a particular situation and by recognition that the values applied to it will undoubtedly need to be revised at a later date as understanding of the situation changes.

My intentions for the catalytic validity of this study were modest. Like the hospice volunteers interviewed, I was concerned that there be "something in it for the children" (Case 4, interview 1) and also for the participants. I had not anticipated the high level of involvement of the participants, and their continuing interest in the research findings a year later when I requested respondent validation. Specific indications that some form of catalytic validity was starting to occur during the process of conducting the research are described in Chapter 7.

I anticipated that having the participants read the emerging findings and ensuring that they had access to the final document would increase their awareness and understanding of the perceptions held by the other adult participants of the experiences of the child during the period when that child's parent had advanced cancer. In addition, I thought that the participants might find similarities as well as differences between the child with whom they had been involved and the other child whose case-study is also presented in this report. The forms of action that might be taken as a result of this increased understanding remain unknown at the time of writing.

My Background

> . . . what I am uncovering . . . is the child's experiences seen from the outside - an adult perspective on the thing rather than the thing itself.
>
> (Fieldnotes - Case 2, interview 4)

The fieldnote cited above illustrates my awareness that there were limitations to my understanding of the children's experiences as gleaned from interviews with adult participants. It wasn't until the following month however, that I grasped the importance of my own role at the level of felt experience, rather than at the previous level of knowledge acquired from books and lectures. I realized that the perceptions that I reported here had been transmitted through a second, highly significant filter: that afforded by my understanding of what the adult participants reported to me. The results of this study are thus twice removed from the experiences of the children themselves. My realization dovetailed with Alcoff's claim that "a speaker's location has an epistemically significant impact on that speaker's claims" (Alcoff, 1991). As my previous experiences exerted a profound influence on the research and writing of this thesis, both in the wider sense of the kind of education I have had and the work I have done, and in the narrower sense of my involvement with my dying friends and their families, a brief description of those experiences is included here.

My introduction to positivist science came in the early 1970's when I studied for my undergraduate degree in honours psychology at McGill University. Psychology, as the department interpreted it at that point in time, was the study of the science of human behaviour, an objective discipline modelled on research in the hard sciences, and firmly situated within the positivist paradigm. Once a sound research design had been established to counteract the effects of researcher bias, any "residual" effects that the researcher's presence might be having on the research were considered inconsequential and were not discussed. I did not know that postpositivist forms of inquiry using qualitative methodology existed.

The research that I performed for my degree was narrowly focussed on the neurophysiology and behaviour of the white rat, and seemed to me to have only limited applicability to human beings. Large segments of what was important to me about human experience were not being admitted into psychology at that point as valid areas for study. Frustrated and disillusioned, I left the discipline and moved to Great Britain where I attended art school. I returned to this country a decade later as a teacher of art to children. In the last seven years, I have also taught courses in art education to preschool and elementary school teachers.

Given that my earlier experiences with psychology were disappointing, I returned to university for my current degree with trepidation. I thought that the discipline of counselling psychology, which had made important advances in the intervening decades, might allow scope for my current concerns. I was returning for practical reasons: having taught art in a classroom setting that included children who were either emotionally or physically challenged, I wanted to qualify as a counsellor equipped to use expressive therapies in individual sessions designed specifically for these children.

This is my first piece of qualitative research. It has not been easy to contradict the conditioning to write "scientifically" and to efface any traces of myself that I experienced as an undergraduate. Yet I am convinced that "objectivity" in the social sciences is a chimera, and that the researcher has a profound impact on what the participants say, how they say it and how the researcher then understands and interprets their words. Who I am is in fact part of the instrument with which I have conducted this research (Hammersley & Atkinson, 1992, p. 18).

Biases and Assumptions

My experiences with the two families mentioned in the introduction had a definite influence on the results I expected to find. The two adolescent girls in the first family were reluctant to discuss their feelings with either their ill mother or their well father, and were unresponsive when their mother tried to provide information about her illness or attempted to discuss her feelings with them. The hospice volunteer, on the other hand, who was contacted in the year following the initial diagnosis, found that the girls eagerly absorbed any information that she provided and were willing to discuss their thoughts and feelings with her. Both girls had difficulty applying themselves to their schoolwork, and found that very few of their teachers attempted to understand their situation and to provide support. Their grades were poor, and both had quit attending altogether in the months immediately preceding their mother's death.

The child from the second family, who was six months old when her mother was diagnosed and had just turned four when her mother died, lacked consistent caregivers throughout those years. In the final year of her mother's life, she expressed very little affect, and attempted to do what she could to take care of her mother. It seemed to me that she understood that something was very wrong, yet her parents assumed that it was better not to distress her by telling her what was happening. They were convinced that she was "all right" because she was not "acting up" and did not ask questions or express thoughts or feelings about her mother's illness that she might well have had. The pre-school teacher at the church my friend joined in her final year was very supportive of the child, although I do not know whether she and the child were able to discuss the topic of death.

Both families then, experienced difficulties in gauging how much information to give the child or children - neither too much nor too little; in phrasing that information so that it was developmentally appropriate; and in deciding who would give it so that the child would be likely to accept it. Neither family sought outside assistance specifically for their child or children until the likelihood that the parent would survive was poor, the family was in great distress, and time and energy were limited. These families had difficulty locating services that would provide appropriate support for their children.

My experiences with my two friends and their families led me to expect that other families with a parent with advanced cancer would also face the dilemma of deciding how much and what kind of information to give their children, and who should give it. I assumed that additional support services would be required for the children, and that these services might be difficult to access. My belief that the support these children would need would take the form of counselling formed yet another bias. In the light of these biases, I speculated that one of the study's findings might be that outside support for the child would have been unnecessary because the families concerned had themselves provided adequate support. An alternative finding might be that the nature of the support that had been needed, as perceived by the participants, would be quite different from what I had anticipated. The interview guidelines reproduced in Appendix III provide additional documentation of the biases and assumptions with which I commenced this research project.

Issues in Changing the Topic

My initial intention was to conduct a series of interviews with children who had a parent with advanced cancer in a playroom, as the use of play materials is well-documented as being more effective than direct questioning in eliciting thoughts and feelings with this age group (Garbarino, 1992, pp. 154-169; Landreth, 1978). However, two issues made the implementation of this plan problematic. The first was the difficulty of obtaining access to these children, given the protectiveness of the various agencies contacted, and their reluctance to provide access to an outsider in circumstances that were emo-tionally fraught for the entire family. I considered that this difficulty might have been surmounted, however, given sufficient sensitivity, patience and time.

The second issue was an ethical dilemma that involved the discrepancy between being a researcher gathering data and being a clinician providing ongoing support and treatment. It was clear that in my capacity as a researcher, I would be restricted to using active listening skills for a few sessions with each child, with the goal of elucidating the child's experience. I would be unable to provide intensive and ongoing support for the child, if it was required. Under the influence of my assumption that these children would need some form of longer-term support, I felt strongly that it would be unethical not to provide that for them. I was concerned that severing contact after a few sessions might interrupt the child's delicate process of developing trust in me, and that this experience might harm a child already dealing with an extremely difficult family situation. Under the circumstances, I decided that it would not be ethical to provide merely a few sessions, and given the current state of the literature, I considered that it would be premature to implement any interventions designed to provide treatment. The needs and concerns of these children could not be addressed until there was adequate documentation of what these needs and concerns actually are.

I then asked: who is already providing support to the family, including the children; will continue to do so until the death has occurred; and is likely to maintain contact with the surviving family members after the death? There were several answers, but the hospice volunteer was the person most readily accessible to me, given that I was not involved with a cancer agency. I therefore decided to interview hospice volunteers who had regular contact with the child or children as part of their ongoing work with the family. This would allow me to gather information without intruding directly on the family myself. The hospice volunteer's perceptions of children during the period when the family is abandoning hope of recovery, but before the parent has died, represented a potentially valuable resource, which had not been previously investigated.

I excluded single-parent families from this study because I anticipated that the needs of children whose parent with advanced cancer was the sole parent with whom they lived might be quite different from the needs of children who lived with both parents. In the initial stages of designing the research project, I had not intended that the study be retrospective, but no active cases were available through hospices at the time. Accordingly, I considered all cases that had occurred within the previous two years eligible.

Issues of Ethical Approval and Access

Ethical approval for this study was obtained from Simon Fraser University Ethics Review Committee and from participating hospices. Six hospices in the province of B.C. were formally approached about the possibility of providing access to eligible hospice volunteers. One Hospice Coordinator sought and obtained approval for the research project from the hospice's Board of Directors, subject to the Coordinator's right to edit any material that I might collect from that hospice's volunteers. Another Hospice Coordinator provided approval subject to restrictions put in place by the district's Research Director, to whom I was referred. Four other hospices granted access with very little formality once their Coordinators knew that access to the first two hospices had been obtained. The following fieldnote records my thoughts on this process:

> . . . the access I now have to two hospices is acting as a lever - the other hospices have just opened their doors.
>
> (Fieldnotes - Feb, 24, 1994)

Three of the six hospices contacted each located a single eligible hospice volunteer who indicated to their respective Hospice Coordinators their willingness for me to contact them in order to explain the research project. The case suggested by a fourth hospice was included, although the child was younger than the selection criteria indicated, and it was the nanny rather than the hospice volunteer who had had regular contact with the child (see "Selection of Participants", page 57 for details).

Following an initial phone conversation with the prospective participant, I mailed or delivered an information letter that clearly outlined the nature and purpose of the study and the extent of the participant's involvement. The information letter also stated that the hospice volunteer's decision whether or not to participate would not affect their position at the hospice nor their relationship to hospice staff. A consent form describing how the information acquired from each participant was to be used in order to respect confidentiality, and how the anonymity of the participant and the family they discussed would be protected was read and signed by each participant before the interview commenced. The family that the hospice volunteer intended to discuss was also contacted by the volunteer prior to the interview, and the surviving parent's permission requested for the release of information concerning the family's situation. Letters of information, consent forms and the form authorizing the release of information by the surviving parent are reproduced in Appendix II. Obtaining ethical approval, and access to the hospices and the hospice volunteers took approximately four months.

Although four volunteers from four different hospices originally participated in the study, only two of the four cases are presented in the results section of this thesis. In these two cases it became possible to interview other adults who had had regular contact with the child after the family's authorization for release of information by the hospice volunteer had been obtained.

The hospices in Cases 3 and 4 would not permit contact with the family in question in order to request their authorization for release of information. The hospice volunteer from one of these cases was concerned that the request would "drag up old wounds" (Fieldnotes, Mar. 22, 1994) that she thought unwise to reopen. The Coordinator of the hospice involved with the other case stated that it was a foundation of hospice work that "you do not ask for anything in return" (Fieldnotes, Mar. 8, 1994). Her position was that if authorization was requested by the hospice, the family's freedom to decide might be compromised by the indebtedness they might feel to the hospice volunteer.

Although approval was granted by the University's Ethics Review Committee to conduct interviews in Cases 3 and 4 without requesting authorization from the families, I have decided not to present the results of these interviews. The hospice volunteers in these two cases, although extremely perceptive, provided the sole source of information about the child in question. Their comments are included in the section of Chapter 4 devoted to the motivation of the hospice volunteer. By comparison, the interviews conducted in Cases 1 and 2 with numerous participants afforded the opportunity for triangulation of data sources: they provided multiple perspectives on the experiences of two children with a parent with advanced cancer. Some of the participants were external to the family and had interacted with the child in quite different settings from family members (Lewis, 1986). It is the analysis of the interviews from the first two cases that is presented in the results section (Chapters 5 and 6).

The surviving parents in Cases 1 and 2 not only granted authorization for release of information by the hospice volunteer but expressed their willingness to be interviewed themselves. In turn, they suggested approaching other adults who had known or worked with the child during the months preceding the ill parent's death. These were unexpected and welcome developments. Approval for interviews with the surviving parent in Cases 1 and 2 and the nanny in Case 2 was obtained from the Ethics Review Committee in a second submission. At this point, the Committee stated that similar minor deviations would not require additional submissions as long as similar procedures were followed. The title of the research project was changed from "The Hospice Volunteer's Perceptions of Children with a Parent with Advanced Cancer" to "Adult Perceptions of Children with a Parent with Advanced Cancer" to reflect the inclusion of other participants.

Details of the other adults interviewed are as follows. In Case 1, contact was made with the teacher and school counsellor, and in Case 2, with the school teacher. I was particularly interested in contacting school personnel as one group of researchers had discussed the importance of obtaining a more complete picture of the child's school performance and peer relationships (Siegel et al, 1992), and another had suggested that these two factors might indicate children's overall level of adjustment (Rosenheim & Reicher, 1979). The hospice volunteer in Case 2 suggested contacting the mother of a friend of the child's.

These four contacts were handled differently because they had been obtained directly from a participant. A research package was sent to each containing a copy of the form giving consent to participate, and a personalized letter of information about the research project explaining why their contribution would be valuable. The letter made clear that although the surviving parent had given his or her approval for the interview to occur, the person contacted was under no obligation to participate. A period of two weeks was allowed to elapse before I phoned these four contacts. All four indicated their willingness to participate, even though it was near the end of the academic year, and an extremely busy time for the two teachers and the school counsellor.

I then made formal submissions to two school boards requesting permission to conduct a single interview with each of the two school teachers and with the school counsellor. Given that the school year was nearly over (it was early June), I was fortunate that both school boards rapidly processed my requests and granted me access. Written authorization from the respective surviving parent for release of information by the additional participants was then obtained. One of these participants was concerned that some of the comments she had made in her interview might be inappropriate. After she received an initial transcript of the interview to edit, however, she decided that nothing needed to be altered.

The following fieldnote was written after access had been granted by the second school board:

> I have been thinking of the number of access problems I have had. The research has involved nothing as simple as getting clearance from a single school board to go into a single classroom - or clearance from a single hospice, for that matter . . . Getting through those school boards wouldn't have, in itself, meant a thing. There were also principals, teachers and a counsellor, and behind it all, the surviving parent of the child. Step by step by slow step. All the individually customized forms that I have prepared . . . all the permutations and combinations of consent. Well I've got the knowledge now, and the experience, and most precious of all, a kind of calmness about the whole business. . . Part of what has carried me through . . . is this doggedness and grit of determination

> - nothing glamorous and nothing brilliant. And part of it is an accrual of knowledge in which I am beginning to take substantial satisfaction.
>
> (Fieldnotes - June 9, 1994)

In Cases 1 and 2, the numerous additional interviews conducted with adults other than the hospice volunteers had not been anticipated when the research project was originally designed, but the flexibility and responsiveness of qualitative methodology accomodated their inclusion. A fieldnote entry comments on the level of participation:

> . . . It is an extraordinary fact . . . that after . . . I have been able . . . to talk with the prospective participants - I have not had a single refusal. Not one. Everyone I have been permitted to speak to has . . . been interviewed by me. Every single person.
>
> (Fieldnotes - June 9, 1994)

The level of participation in this study is similar to that encountered by Kuntz (1991) who had only one refusal out of 27 possible participants, and Rosenfeld et al. (1983), who reported that of nine women with breast cancer approached for permission to interview their daughters, only one refused.

The possibility that participants might become distressed during the course of the interview, and that referral to a health care professional might be required was considered. Many participants did become upset and cried, sometimes at length, but none wished to terminate the interview when this occurred. In one case the surviving parent and child were referred to a local agency for family counselling once the interview was completed.

Selection of Participants

> Although some phenomena can be identified and characterized as salient prior to entering the field, many others emerge only as the fieldwork proceeds. Consequently, selection in ethnographic research is a developmental, ad hoc procedure rather than an a priori parameter of research design.
>
> (Goetz & LeCompte, 1984,p.69)

Initial participants for this study were selected using a nonprobability sampling strategy called purposive or criterion-based sampling (Goetz & LeCompte, 1984, p. 73; Merriam, 1988, pp. 47-9), which requires the establishment of selection criteria prior to the commencement of the research. In this study, hospice volunteers were selected who had had contact with children of a specific age-range. Succeeding participants were selected on the basis of the amount of regular contact they had had with the child and the depth of information they might thereby provide.

Hospice volunteers contacted through six hospices in the province of B.C. had to meet the following criteria to be eligible:

The hospice volunteer:

1) had in the last two years, worked for at least three months with a family in which the adult member with advanced cancer was parent to at least one child between the ages of 7 and 11. Single-parent households were excluded.
2) had had direct contact with the child concerned.
3) lived in a location accessible to the researcher.
4) was able to communicate in English.

Formal overtures to six hospices yielded three hospice volunteers who met these criteria. All three were willing to participate in the research project. As I was concerned that three cases might not provide sufficient data, a fourth case was accepted in which the child was younger - he turned six during the period when his mother had advanced cancer. The hospice volunteer in this case had had almost no direct contact with the child, but the hospice was able to refer me to the family's nanny, who was willing to participate, once authorization from the surviving parent had been obtained.

In the two cases this thesis presents, a variant of criterion-based selection called network selection became possible once access to the surviving parent had been obtained. In this variant, successive participants are contacted through referral by a preceding participant (Goetz & LeCompte, 1984, pp.79-80). In the first case, the mother suggested contacting her son's teacher from the previous year and the school counsellor, for further information. In the second case, it was the nanny rather than the hospice volunteer who obtained access to the surviving parent. The father in turn mentioned that his son's teacher had been extremely supportive and gave permission to contact her. The hospice volunteer for this case, who herself had had almost no contact with the child, suggested contacting the mother of a friend of the child's, who had spent considerable time with him both before and after his mother had died.

Data Collection

The two case-studies presented in Chapters 5 and 6 involve two boys - one aged 9 when his father died and the other aged 6 when he lost his mother. Each boy had a younger brother and no other siblings. Prior to being interviewed, the hospice volunteers filled out a questionnaire that gave background information on the family, and on the nature and extent of their involvement (reproduced in Appendix III). In total, eleven individual, semi-structured interviews lasting between forty-five minutes and two hours were conducted with nine different participants in the two cases. With two participants it was apparent that the initial interview had not provided sufficient time. An additional interview was scheduled for a week or two later. The interviews took place over a three-month period between March and June, 1994.

Each participant is listed below, followed in parentheses by the pseudonym they chose for themselves:

Case 1 - Hospice volunteer (Anna), mother (Elizabeth) , school teacher (Jessie), school counsellor (Jane).
Case 2 - Hospice volunteer (Sue), nanny (Ashley), father (Paul), mother of a friend of the child (Jan), school teacher (Sarah)
Case 3 - Hospice volunteer (Peter)
Case 4 - Hospice volunteer (Kerry)

For my own voice as researcher, the abbreviation (R) is used throughout. Abbreviations for other people discussed in the interviews are as follows:

Case 1 - Child (Richard), child's younger brother (Robin), father (Ralph), friend of the child (Dean)
Case 2 - Child (Graham), child's younger brother (Lawren), mother (Christine), friend of the child (Ross).
Case 4 - Mother (Sheryl)

I conducted all interviews myself, utilizing my qualifications as a Master's candidate in counselling psychology with experience interviewing in a therapeutic setting, and my experience of the previous decade as a teacher of art education to adults and art to children. I found conducting the research interviews similar to the counselling interviews in their emphasis on reflective listening, clarifying and probing. Research interviewing differed from counselling in being less directed and more open-ended. I continually had to remind myself that my goal in the research interviews was to understand the participant's experiences rather than to assist the participant to move towards change.

All interviews were audiotaped for later transcription. At the end of each interview, the tape recorder was disconnected. The participant was then debriefed by discussing what it had been like to participate in the interview. The recorded interviews were augmented by descriptive and reflective field notes which were either tape-recorded or hand-written as soon as possible after each interview was completed. Of the nine participants, five chose to be interviewed in their own homes. The hospice volunteer in Case 1 chose to be interviewed in my office; the two teachers and school counsellor were interviewed in their respective schools.

The semi-structured interview format provided the flexibility to respond appropriately to each participant's perspective, while permitting the acquisition of specific information desired of all participants (Merriam, 1988, p.74). Formal interview guidelines were developed for the hospice volunteers and for school personnel (reproduced in Appendix III). Interviews with the two surviving spouses, the nanny, and the mother of a friend of the child used interview guidelines similar to the one prepared for the hospice volunteer. In constructing profiles of each child, I listened closely for indications of developmental stage. I also paid particular attention to changes in the division of childcare responsibilities as a result of the illness, to the cultural and religious background of the family, and to the family's and child's previous experiences of death.

In the first few interviews I found that certain questions were not useful to pursue and others needed to be rephrased using language that the participant understood. The questions asked were not restricted to those presented in the guidelines. Where appropriate, I encouraged each participant to describe in detail experiences he or she mentioned that I had not anticipated when devising the interview guidelines.

A letter of thanks was sent to each participant within five days of his or her interview. The letter was specifically composed to be appropriate to the person for whom it was written. Details of the participant's relationship to the family, certain aspects of the interview, or specific qualities that the participant had brought to it might be included. A copy of a generic letter is given in Appendix IV.

Interviewing and use of the interview guidelines

Reflective listening was fundamental to my role as interviewer. I would probe and ask for clarification as needed. When the participants were discussing the child's feelings, I would ask them to give specific examples of situations when the child behaved in ways indicative of those feelings; I wanted to go beyond generalities. As the interview proceeded and the participants became more comfortable, I found it possible to ask highly emotive questions that would have been inappropriate at the start. On the rare occasions when participants said something mildly judgemental of a family member, or indicated an area of conflict, they immediately retracted their words when I repeated what they had said. No-one wanted to say anything that might be construed as "speaking ill of the dead" or of the dead person's family. Points of difference that had occurred earlier seemed to have been subdued and transmuted by the fact of death. At the same time, the participants strove to be honest about their own difficulties and those of the child. They negotiated these uneasy moments with tact and diplomacy.

Participants took seriously the statement from the consent form that they could refuse to answer specific questions and were free to terminate the interview at any time. Although all of them completed their interviews, I was asked on several occasions to turn the tape recorder off while they explained a point or answered a particular question. A few times I was specifically told that what was said could not be included in the thesis.

The interview guidelines were continually modified as the interviews proceeded. The first interview I conducted, with the hospice volunteer from Case 1, gives an example of the need to alter a question as a result of the volunteer's response. The comment I made that the family situation she described was "abnormal" revealed to her my fundamental misunderstanding of the kind of family that sought assistance from a hospice. Her response was calculated to dispel that misunderstanding:

> **R:** So, what I'm seeing is you bring to it a lot of experience and your kind of assessment that this is a really abnormal situation. First of all you tell me - now, I know, from our talk - how abnormal it - untypical it is . .
>
> **Anna**: You say that, you know - but when you work with hospice - the main reason that a hospice worker - most of the time - will visit either with the patient or with a caregiver, is because there's a void somewhere in the family - because in a supposedly good, united family, the **family** is there. . . . They don't **need** anybody else. They don't **want** anybody else - it's a very precious time. They don't want a stranger coming in, on their territory, at this time of life [when a loved one is dying]. They really don't. So you'll find that where there's a **very** united family there's no hospice worker.
>
> **R**: There's no room - and no need.
>
> **Anna**: But - there's no room. But when there is a **void,** or there is a **problem** - then - you need this outsider. So in most of the time that you're saying that this is unusual - like the -
>
> **R**: Most cases are unusual.
>
> **Anna**: Exactly.
>
> (Case 1, interview 1)

As a result of this interchange, in succeeding interviews with hospice volunteers, I jettisoned the question from the interview guidelines:

> "Given your experiences as a hospice worker over *(# of)* years, were the experiences of this family typical? Atypical? In what ways?"

Instead I asked questions that would increase my understanding of the nature of the family's support system, from which their need for a hospice worker had arisen.

The following passage, from the interview with the school teacher in Case 1, gives an example of a question that was not part of the original interview guidelines, but was asked to clarify a comment made by the teacher. Many of the questions I asked were of this type.

> **Jessie**: Once in a while the girls would be scrapping among themselves a bit, and I'd say, "Look, girls, you've got to stick together. There's only *(gives number)* of you!" So, they basically did. But the girls were quite tolerant of him, too. Yeah, you know, and quite understanding. So I tried to be -
> **R**: How did they show that tolerance? Is it just that they didn't take offence if he -
> **Jessie**: They didn't take offence if he wasn't very polite that day or, you know - if he showed anger about something, they just sort of shrugged their shoulders and walked off or brushed it off. . . . They didn't sort of rise to the bait, so to speak. They were pretty good. I was trying to remember if there was anything else.
> **R:** Yeah. It's exactly what I was going to ask - is there anything else about -?
> **Jessie:** Just offhand, I can't think of anything else.
>
> (Case 1, interview 4)

This example also gives a little of the flavour of the interviews, which, while covering the topics given in the interview guidelines, developed with the easy flow of a conversation. In all interviews, it was the participant who did the bulk of the talking, and much of the information they gave was simply volunteered.

Influence of the interview setting

Conducting interviews either in the participant's home or at school had both advantages and disadvantages. The advantages centred around the participant's sense of being comfortable and of having control. My role as a researcher, which was somewhat intimidating to the participants, was ameliorated by my position as a guest who had been invited in, and who could, if need be, be asked to leave. I think the feeling of ease this gave the participant was very important, given the difficult and highly emotive nature of the material discussed. In the one interview held in my office the hospice volunteer was visibly ill at ease, avoided looking at me and talked to the carpet or her hands. As this was the first interview I conducted, I was very nervous myself, and neglected to ask her how she was feeling and why. It was only after she had gone, and I relaxed that I realized the unfamiliar and rather formal environment had probably contributed to her discomfort.

The disadvantages of conducting the interview in the participant's home or at the school centred around **my** increased discomfort. I would arrive in one strange location after another with tape recording equipment to set up and consent forms to be signed, before proceeding to interview a total stranger. I was always nervous at the start, and uncertain precisely how to begin, given that each participant was different and the questions I intended to ask were highly charged. I could not control sound quality as carefully as I could in my office. In two of the interviews conducted in the participants' homes, the microphone was too far away to pick up comments that were spoken very quietly. In the interview with one teacher, the roar of a vacuum cleaner outside the classroom door drowned out several of her comments. In the other two interviews held in schools, periodic interruptions were caused by the odd child coming and going from the room, or large groups bustling down the corridor between classes.

An unexpected event occurred in the home of one participant. During the initial interview with the mother in Case 1 (Elizabeth), the younger son (Robin) was present and needed to be entertained. He looked at pictures in a book, watched television, and then played with a group of playdough people that I made for him. When he had tired of these activities and was in need of something else to do, his mother placed his pet guinea pig on the table at which we were all seated, and gave him lettuce leaves to feed it. Robin was delighted, and chattered away to the guinea pig as it ate. After a while, the guinea pig scuttled to the back of the table and crept behind a vase of flowers. Both the mother and I assumed that it had gone to sleep. What it was actually doing was quietly chewing through the microphone cord! The guinea pig survived the experience, but I lost the second half of the interview.

It was extremely unfortunate that this was the part in which Elizabeth had described the actual moment of her husband's death, what she had done immediately afterwards, how her sons had reacted when she had told them, and how her older son, Richard, had behaved at the funeral. She had cried throughout the telling. Although she agreed without hesitation to a second interview, she was understandably reluctant to repeat the section of our conversation that dealt with her husband's final hours. In the second interview, Elizabeth said, "I don't want to get into that because I'll get all choked up, but I'll get into aspects of it." (Fieldnotes - Case 1, interview 3).

Use of the tape recorder

The use of the tape recorder definitely affected the participants. This was particularly marked during the debriefing conducted at the end of the interview, after the tape recorder had been turned off. Most of the participants visibly relaxed at that point and spoke more openly. During the interview, some participants were more nervous than others - one seemed to be affected by the presence of the tape recorder throughout. Others were inhibited at first, but seemed to forget their words were being recorded after a while. The following excerpt from my fieldnotes was written after I had conducted my second interview, with the nanny in Case 2:

> At the end, Ashley told me that she had really gotten uptight when the tape recorder was turned on. I think that one of the things I need to do is to take time at the start to acknowledge the participants' possible feelings about this, and not just railroad ahead as if they don't have them, just because they're not expressing them. . . Ashley said that she felt quite nervous at the start, but then just relaxed . . .
>
> (Fieldnotes - Case 2, interview 1)

The following excerpt from the beginning of one of the last interviews I conducted shows how I incorporated an acknowledgement of the tape recorder's presence into my first comments:

> **R:** I really appreciate you being willing to do this interview. I need to say that again.
> **Jessie:** Okay.
> **R:** And hopefully in a few minutes we'll forget about this machine, you know, and -
> **Jessie:** Yeah, right.
> **R:** It helps me a great deal.
> **Jessie:** Well I'm sure, because then you don't have to take notes.
> **R:** Yeah. So I understand from Elizabeth that you were Richard's teacher last year?
>
> (Case 1, interview 4)

Participants would often relate information during the debriefing, after the tape recorder had been turned off, that was highly relevant to the research. This was a frustrating experience for me as I scrabbled to listen and take notes at the same time. In later interviews, I sometimes asked for permission to turn the tape recorder on again. I found there was a delicate balance to maintain between allowing the participants to talk freely at the end of the interview and keeping an accurate record of what they were saying. The following fieldnote excerpt illustrates this:

> Anna gave me a lot more [information] towards the end and unfortunately I had turned the tape off, because it was the debriefing part when I asked her what it

> had been like for her to do this interview.
>
> (Fieldnotes - Case 1, interview 1)

As the research continued, I became increasingly aware of the profound effect that the tape recorder's presence was having on the data. This fieldnote entry was written after I had conducted the first five interviews:

> *(From a dream the previous night)* I am trying to explain . . . the level of my understanding of what it actually means to have a tape recorder in the room when I am talking with the participants . . . the tape recorder's presence changes not only what is said, but the ways in which the things that are said get said.
>
> (Fieldnotes - April 16, 1994)

As a direct extension of my understanding of the tape recorder's effect, I began to realize the unique quality of each interview, as is illustrated by the following passage from the same fieldnote entry:

> I am also grasping that no-one else could have quite the same conversation that I am having with the participant - that together we are the co-creators of a conversation that is not repeatable, not replaceable. I know that when I go back to talk to Elizabeth again . . . that the conversation will be quite different from the one we had last time.
>
> (Fieldnotes - April 16, 1994)

On participating: feedback from the participants

The use of catalytic validity required that I consider the reactions of the participants to the research as an integral part of the research project (Lather, 1991, p. 56). One important reaction came from Paul, the father in Case 2, when, a month and a half after I had interviewed him, I returned in order to obtain his authorization for release of information by the teacher (Sarah) and the mother of a friend of his son (Jan). We talked about recent developments in his life, and then discussed my research, particularly my recent realization that I had not had a single refusal from prospective participants. My fieldnotes record Paul's comment:

> . . . He said that . . . I am pioneering ways of doing the work that allow people to be comfortable [discussing difficult material], and that that is extremely important. He was adamant that that needs to go in my methodology chapter! I was so surprised! After all the talk about him and his situation, it was an astonishing experience to have his powerful intellect [Paul himself has a graduate degree] turned away from . . . his current difficulties, and directly onto my research. I felt . . . he was giving out something to me that . . . goes beyond his own experiences as a participant.
>
> (Fieldnotes - Case 2, interview 2)

Earlier the same day, I had written the following passage on the issue of participation:

> . . . I am coming along with my request 6 months or more after the death, when people are wanting to reflect . . . They are over the initial stages of being awash with grief and are starting to ask: "Well, what did it mean?", "How has it changed me?", "How have I resolved it?", "What did I learn?". . . The other reason that people let me in is that I'm open right from the start about my own experiences [with my two friends] . . . [which they recognize have] similarities with what they have lived through. . . I think that the work that I do . . . by being attentive and supportive - is very important for the participants. That the experience of the interview itself is actually valuable for them - and that, for all my fears of being a taker, that is not what is actually happening. These people want to talk about their experiences. My presence and interest provide the opportunity . . .
>
> (Fieldnotes - June 9, 1994)

In the light of this realization, I understood that if the study had not been retrospective, the response rate might not have been as high. When the parent was still alive, the participants were actively involved with him or her and might not have had the time or energy, let alone the inclination to discuss their ongoing experiences with a researcher. I also realized that although the participants I was contacting after the death still needed to talk about their experiences, they often felt that it was no longer appropriate to do so with family or friends. Fieldnotes made after a preliminary phone conversation with one participant illustrate this:

> Had a phone call from Jan . . . confirming our interview for tomorrow. . . She said that she really did want to talk about [her experiences] - that it's been a year and a half since Christine died, and that she realizes certain things she just put on a shelf . . . She said "I don't want you to think I'll be using you as a counsellor". I did, however, get from her very clearly that the need for her to talk, now that I've come forward and asked, is palpable.
>
> (Fieldnotes - Case 2, interview 4)

At the end of her interview, the nanny in Case 2 said that she felt participating had been helpful to her. This is how she phrased it:

> **R:** Ashley, I really thank you.
> **Ashley:** You're welcome.
> **R:** I feel like you've opened your heart to me. I really do.
> **Ashley:** Do you? *(Laughs - a few sentences are unintelligible as both talk together).* Ohh - maybe I needed to, you know. It's not often I can talk about it just because there's not many people that can relate and after I read your thing about losing friends and I thought, "Oh, you **know**".
>
> (Case 2, interview 1)

The following passage also underscores the highly interactive nature of the research project. One of the reasons that the participants were able to be so open was because of the reciprocity on which the study had been built: I had been open about my experiences with my own friends from the start.

> **Jan:** . . . I've talked about this so little with people who have any comprehension of it, whatsoever.
> **R:** Well - it's wonderful for me. And I will say to you that part of what happens for me when you talk and I'm sitting and listening. I'm thinking - yeah - about my friends, too, you know, and I haven't talked about it very much in a long long time. But I just recognize certain things that you're saying, you know, that this is quite, kind of aside from that I have a thesis to write. [And for] that I thank you.
> **Jan:** Well, no I recognize that.
>
> (Case 2, interview 4)

The teacher in Case 1 stated that her primary motivation for participating was her appreciation of the importance of the research. She said:

> **Jessie:** . . . it's pretty hard to refuse - on those terms because you know, I remember when I read your letter thinking "well this is obviously an area that needs to be dealt with, too."
> **R:** Yeah, oh yeah. For more than just yourself - because these children -
> **Jessie:** Yeah. You have to think of all the kids that still have to face that.
>
> (Case 1, interview 4)

In an initial phone call, Sarah, the teacher in Case 2 stated that her willingness to participate was the result of two factors: the consideration with which I had initially approached her, and her understanding of the importance of research.

Hospice Coordinators, Coordinators of Volunteers and hospice volunteers also recognized the importance of the research, as this excerpt from the interview with the hospice volunteer in Case 2 indicates:

> *(Towards the end Sue explained that she had taken the afternoon off work)*
> **R:** Did you do this for me?
> **Sue:** Well, no, for me, too.
> **R:** Oh, really.
> **Sue:** I need it for myself because I can just be *(unintelligible).*
> **R:** Well, Sue, I really thank you.
> **Sue:** No, it's important.
>
> (Case 2, interview 3)

At the end of each interview, I debriefed participants by asking them what the interview had been like for them. Responses ranged from it having been "all right" to it having been "helpful". None of the participants felt that the interview had been a negative experience, even though five of the nine had cried at some point, often at length. The following passages from fieldnotes detail what some of them said:

> Ashley cried a lot towards the end. When I was doing the debriefing . . . she said it had been really good to do [the interview], and that the environment had been really important - she was glad that she could do it in her own home. The empathy that she got from me, she said, had also been helpful - she didn't think for a minute that she would have been able to say all the things she had if I had come in looking like some ivory tower researcher from the university. So I joked about being in a white lab coat.
>
> (Fieldnotes -Case 2, Interview 1)

> [Although it's been a year and a half, Paul] still has times now when he really misses her and. . . feels jolted all over again . . . He thinks, "Oh, I lost my wife", and . . . [is] incredulous that this could have happened. He said that that didn't happen to him in the interview with me, at all . . . the interview . . . was very comfortable. He said, "It was nothing" - in the sense that it was not traumatic or emotional for him. Paul told me these are things that he thinks about all the time, and in fact he thinks it's helpful for him to talk them out.
>
> (Fieldnotes - Case 2, interview 2)

> Sue said that she found doing the interview good - that it didn't upset her in any way.
>
> (Fieldnotes - Case 2, interview 3)

> . . . at the point where I turned the tape recorder off, Kerry was crying. Tears just spilling over for a while . . . I didn't probe - I let her have her grief . . . She [then] said that she had had real reservations about doing the interview with me. She felt that there really had to be something in it for the children or she wasn't prepared to divulge all she did . . . she felt that I would use the information in ways that would be beneficial for the children and for other hospice volunteers - and so it was all right. . . .
>
> (Fieldnotes - Case 4, interview 1)

> Elizabeth said at the end, after I had turned the tape off, that it was good to cry - it was good to get this out of her system, to talk about it. She was thankful that she had done the interview.
>
> (Fieldnotes - Case1, interview 2)

As the interviews progressed, I became aware that the participants were far more open with me about their experiences than I had originally anticipated. My experiences as a researcher have convinced me that it is possible to conduct research in a highly sensitive and emotional area respectfully and humanely, with two significant effects: the quality of the data collected will be richer and the experience for the participants more worthwhile.

My own process

I found that as the research project progressed, periods when I felt enthusiastic alternated with periods when I was either confused or discouraged. My fieldnotes documented the various shifts in my attitudes and feelings.

> Some of the stories that I heard tonight [at a support group meeting for hospice workers] make me very sorry that I'm not interviewing actual children, all over again. I want to help make a difference in people's lives as they confront death . . . Am I capable of doing this work? Could I stand it? If I get some of those answers for myself out of this piece of research, that will be enough.
>
> (Fieldnotes - Feb. 1, 1994)

One low period came in the months of January and February, when I was struggling to prepare the original submission to the Ethics Review Committee.

> I told Celia that I had just gotten through Ethics today and that the prospect of starting the research was wonderful. She agreed, "It's exciting" - exactly what Janie [member of thesis committee] had said in her message. I also told Celia how disheartened I got, through that last stretch in January - I thought I was never going to get over that hurdle - and then I did. She nodded, and said it was important to keep a record - that this kind of research definitely has its ups and downs . . .
>
> (Fieldnotes - Feb. 24, 1994)

Another difficult period came a month later, after two hospices had refused permission to request authorization from the families, and I decided to re-submit the altered circumstances those two cases presented to the Ethics Review Committee.

> It's been a hard day - have been wound up like a cork. However, I'm getting somewhere. My second potential participant has her package and is seeing the father [to ask for authorization] this week. I got the letter to Ethics to go with the resubmission written. . . . signed and into the Ethics Review Committee straightaway.
>
> (Fieldnotes - very early April, 1994)

I discovered that the process of interviewing, which took place between late March and the end of June, could be both exhilarating and heart-wrenching. I learned to respect that my reactions to what the participants told me would take time to process and that I needed to pace myself by conducting no more than two interviews a week. The fieldnotes made through this period documented my enthusiasm as well as my doubts:

> I am so thankful that I am doing this research . . . for my own growth and development. It is a . . . moving experience to be in the room with these people and listen to their stories . . . this conversation that has the hard edge of mortality that transforms words [into] acts of understanding that pass between us. I want more than I have - I've gone from wanting to get through this ruddy thesis, to being so engaged that I don't really care how long it takes to get

> finished. Well, I do care, but it's more important to me that I get done the other things that I can see now to do, than that I am finished by a specific date.
>
> (Fieldnotes - Apr. 16, 1994)

> Celia said to me today "It looks like you're nearly finished [the research]". This really astonished me. I certainly don't feel as if I'm nearly finished. Indelible - these experiences - the way these people have opened their hearts to me, the way they hope that their participation may be of benefit to others. It has been a very humbling experience . . . I think in the end that what this study does is to tap what the hospice volunteer knows - and to make that knowledge accessible to a wider audience of professionals. Emergent and inductive indeed. It is so messy! So undefined and nascent! I really don't know what I have [yet] - except that a lot of it is really solid . . . I know that from how I felt during the interviews . . . [I] don't know if I should cut [the research] off here or try for more. . . Part of me is still wondering - yeah, but is this enough?"
>
> (Fieldnotes - April 28, 1994)

> How am I going to analyze this? How am I going to write it up? It feels as if I'm blundering around in the dark, with a daunting task ahead of me. There is no help for it but to go forward, stumbling. If I stay here I shall never get finished. . . I need to push my way through this last round [of interviews] so that I can close [the data collection] off . . .
>
> (Fieldnotes - May 12, 1994)

In late May, it became apparent that I needed to submit additional research packages to two school boards in order to formally request their permission to interview the two teachers and the school counsellor, who had already received their packages and expressed their willingness to participate. The following excerpt records my reactions:

> Last week, I was extremely disheartened. All I could see was that another barrier had formed, one that I hadn't anticipated - and that it meant more work at a time when I felt so sick and tired that all I wanted to do was sleep. . . . I've started to understand in the last few days that this thesis is not just an ordeal to be gotten through - although a part is certainly that. I'm growing in knowledge and understanding . . . and what I read now about the research of others will be tempered by my own experiences. It's a kind of grass-roots understanding; one that I'm only beginning to articulate. One of the signs of it was that when [the Director of Research at the School Board] pointed out that I had neglected to include my research instrument in the package, I was able to fire off the series of questions that I intend to ask . . . faster than he was able to write them down. . .
>
> (Fieldnotes - June 9, 1994)

In July I was stunned by the extremely picky and time-consuming task it was to transcribe and check the tape recordings of the interviews.

> I look at the date and I can't believe it's taken me these three weeks of incredibly hard slog just to get the data entered into the computer. All those interviews to be transcribed - all the fieldnotes to put in. Me and my fancy ideas. . . if I in-

> tended to analyse the data by computer, then the stuff has to be **in** the computer . . . It felt like I was pushing a boulder up an endless slope, that the ground would never ever level off. But to my great surprise and gratitude, it finally has. And next month I'll be able to get on with what I planned to do in July.
>
> (Fieldnotes - July 25, 1994)

Throughout the research process, what sustained me was the astonishing warmth and generosity of the participants and their belief that my work (and their part in it) has a significant contribution to make to our understanding of children with a parent with advanced cancer. Similar thoughts have also been expressed by Raudonis (1992), a clinical nurse conducting qualitative research with hospice patients.

> I have loved doing the interviews. I have learned so much from the people with whom I've talked. . . now I feel it is incumbent upon me to write the thesis so that it honours and does justice to [their] experiences . . . my allegiance to them is becoming as, if not more important than my responsibilities to the university.
>
> (Fieldnotes - June 24, 1994)

But what am I doing here?

In late April, after I had completed interviews with the first three participants in Case 2, I had formed an impression of the deceased mother Christine as a very private person. I began to feel like a peeping tom, as I became increasingly concerned that by learning about her, I was invading her privacy in ways that she would not have approved, had she been alive. From that point, my concern broadened; a period ensued when I questioned the ethics and significance of the entire research project. My work took on a sinister and despicable cast as I grappled with these issues. The following passage from my fieldnotes documents my concerns:

> Talked . . . about the eerie feeling I am getting by impinging on Christine's privacy - when it is becoming more and more apparent what a very private person she was. Big questions are forming in my mind around, "Why am I here?" and "What the hell am I doing?" . . . ethical issues [come from this] - around me getting my thesis out of the terrible heart-rending experiences these families have lived through. At some level, I'm getting my degree out of Christine's pain, out of the tragedy of her death. And part of me is just revolted by this, and thinks that it absolutely stinks. And doesn't want any part of what I'm up to here.
>
> (Fieldnotes - April 28th, 1994)

I managed to attain an uneasy truce with my conscience in two ways. The first was that I reaffirmed that the thesis would focus on the participants' perceptions of the child Graham and that I would not divulge information about his mother unless it pertained directly to him. The second, which at the time was far less convincing, was to remind myself that I would make available to other health professionals the understanding I was gaining from the interviews, as my fieldnotes show:

> In the end . . . it is the researcher who benefits from the research - the thesis will be my journey into understanding. My participants will be educating me - which is certainly what I'm finding.
>
> (Fieldnotes - April 28th, 1994)

Although I attempted to deal with these concerns, I think that at some level they were (and are) unanswerable. Acknowledged, they remained with me as I continued to interview participants.

Commitment to qualitative methodology

My fieldnotes also documented my growing conviction that qualitative methodology was the right choice for this research project. As the research progressed, I grew more appreciative of the flexibility it allowed to pursue suggestions made by the participants to contact other people who had been involved with the child. I also found that the semi-structured interview format allowed the participants to volunteer unexpected pieces of information that I might have lost if the interview format had been more highly structured. The semi-structured interview format also permitted me to be responsive to what the participants told me and enabled me to convey respect. I could let them "take the lead", which I think was crucial given that some of the experiences they related were extremely painful. The excerpts from the fieldnotes cited below illustrate the shift in my commitment to the methodology I was using:

> Part of me is screaming for the possibility of replication I find it so hard to let go of that.
>
> (Fieldnotes - Jan. 6, 1994)
>
> I am very excited about doing qualitative research because of what it admits. The idea of emergent theory - building theory from the ground up - is beginning to come alive for me.
>
> (Fieldnotes - Feb. 26, 1994)
>
> I am thankful that I chose the methodology that I did - that allows me this surface that can expand or contract as needed - that does not tie me in to premature hypotheses that would likely have fallen apart in the first interview, leaving me with . . . nothing to build on.
>
> (Fieldnotes - April 16, 1994)
>
> . . . if I had gone in [to the interview] with a set of questions in the form of a fully structured interview, . . . they would almost certainly have been the wrong questions, because I knew and understood so little . . . The truth is, that when I started, I didn't know what to ask. I have really liked the interactive nature of this

> kind of research and the fundamental respect it entails for the participant's world. It fits with the notion of reality as a social construction. It also fits with the position that I use in counselling - that I am not an expert, and that the most important thing I have to offer is the quality of my listening and the responsiveness of my questions.
>
> (Fieldnotes - June 24, 1994)

Data Analysis

Data collection and data analysis proceeded simultaneously, with emerging insights arising from earlier interviews recursively influencing succeeding ones (Merriam, 1988, pp. 119 & 123). The assumptions with which I commenced this study gradually altered as data collection continued and conceptual categories began to emerge from the data already collected. Extensive fieldnotes began once initial overtures to the hospices were made documented this process of systematized reflexivity in which my viewpoint shifted as a result of what I was learning from the Hospice Coordinators and the participants (Lather, 1991, p.67).

The bulk of the interviews were completed before data transcription commenced. All interviews were transcribed in their entirety. Names, dates, locations and other identifying information were either omitted or altered to protect the family's anonymity. In six of the eleven interviews, the participant had either cried, become audibly upset, or had used names that I could not allow an outsider to hear. I transcribed these interviews myself. The other five interviews were professionally transcribed. All transcripts were checked against the original tape recording - several times for passages where the sound quality was poor.

After the transcripts were completed, an initial examination was done manually, using the margins of the printed transcripts to make comments and to note salient passages and recurring themes. I attempted to read each interview dissasociated from what I had already learned about the case. A specific colour was used to highlight passages of the transcript that dealt with a specific person. If aspects of a relationship were being referred to, alternating dashes of the colours representing the two people involved were used. Once the first stage of the analysis was completed, it was possible to see at a glance when the child was being discussed. Summary sheets were then made of the tentative codes as they had started to emerge. In the second stage, the computer program HYPERRESEARCH was used to further organise and condense these codes, and to cross-reference them to the original transcripts. All codes referring to one person were re-encoded so that they began with that person's name. Periodic computer print-outs of the code lists generated by HYPERRESEARCH were used to check the codes and to condense those that in fact referred to the same phenomenon into more abstract conceptual categories or themes (Merriam, 1988, pp. 126 & 131).

An abbreviation was used for each person during this stage of the coding. It made clear the person's relationship to the child and thus provided more information than the pseudonyms used to write the results chapter. The codes indicate first, which person is acting, and second, the person their action is directed towards, before describing the nature of that action. For example, in Case 1 instances when the mother encouraged her son to express his feelings are encoded "M1 OB1 encourages son to feel". In this way the nature of the relationship to which a respective code refers was embedded directly in each code.

The abbreviations, relevant codes, and frequency count for the number of times across all interviews in a case that that code was used, are given in Appendix V. The frequency with which a code appeared across all interviews begins to quantify the data and provides an indication of how pervasive the appearance of that code was. For example, in Case 1 the code "M1 demands on self" which refers to the demands experienced by Elizabeth, occurs 43 times across the five interviews. This outnumbers any other code in this case. The number of times participants discussed Richard's anger, taken from the frequency count for the code "OB1 shows anger", is 23.

The HYPERRESEARCH program increased the rate at which data analysis proceeded, but also necessitated decisions made specifically to suit the program's requirements. A record was kept of the points at which this occurred. One instance was encountered in the initial stages of data entry. The (text only) format required by HYPERRESEARCH meant that the bold type used to indicate emphatic speech and the italic type which marked an explanatory note were lost.

Another drawback became apparent once the second stage of analysis had commenced. HYPERRESEARCH does not leave any marks on the original document to indicate how specific passages have been coded. As data analysis proceeded it became increasingly difficult to grasp the overall picture that the manual analysis with hard copy had readily allowed. This drawback was addressed by checking the HYPERRESEARCH coding for continuity once coding was completed. Codes were sorted according to reference and the character count for each code checked to ensure it followed consecutively from the previous one. The inclusion of the code "uncoded" for all material irrelevant to the analysis meant that every word of transcript should be included in the final list. Where gaps in character count existed between successive codes, the coded material was checked against the relevant passage of transcript.

Once the coding process using HYPERRESEARCH was complete, comprehensive reports displaying every transcript passage using a particular code across all interviews in a case were printed for each relevant code. The two results chapters were written using a constant interplay between the reports generated by HYPERRESEARCH and the original transcripts. It was at this stage that individual codes were condensed into more meaningful and comprehensive categories or themes. After an initial draft of the results section had been completed, a final check through each report ensured that no relevant codes or salient passages had been omitted.

Issues in transcription

The initial transcript of the first interview reproduced the "umms" and "errs" of the participant, and the "um hmms' and yeahs" that formed the background murmur of my reflections. Although this transcript was linguistically accurate, I found that the continual interjection of these non-words interrupted the flow of the conversation, and made it more difficult to understand what the participant was saying. As my concern was with general meaning rather than the specifics of discourse analysis, I decided to drop the non-words from the transcripts. I found they read more smoothly as a result, although I was also aware that certain information was lost.

As transcription proceeded, I realized that additional information was also being deleted. The gesture of a hand or downward movement of the eyes were not recorded. Inflections of the voice and modulation in tone that were vivid forms of expression on the tape could only be crudely indicated in transcription. The transcript began to appear as limited as the script for a play which needs an actress's or actor's art to make it come alive. It seemed to me there was a considerable risk that the participants' words might be misconstrued when segments from the transcripts were removed from their context in order to be quoted in the thesis. Passages from my fieldnotes record these concerns:

> I'm . . . struck by the gap between what was actually said and understood, in the room, and what it looks like written down. The live conversation is so much richer, by comparison. The transcript is open to misinterpretation by readers that would not be possible if they had actually been there . . .
>
> (Fieldnotes - May 12, 1994)

> The good thing in all the slog of doing the transcripts myself is that I have gotten very close to those interviews and have some ideas of what to start with when I begin analyzing. I have noticed how differently I feel about the interview[s] that [were professionally] transcribed . . . voice and intonation don't come back as vividly when I read [the participants'] words on the page.
>
> (Fieldnotes - July 25, 1994)
>
> My comments in italics are quite crude - as is the boldface type I use to indicate emphasis. Neither admit the great variety of expression of which we are capable. What the participants said to me resounds in my head because I was in the room with them and because I have spent so much time listening to the tapes. . . So there are three layers : the actual conversation . . . the tape recording of it, supplemented by fieldnotes, and the transcript. Each stage is . . . less alive than the preceding one. [When I come to write] if I don't flesh out the participant's words with the fieldnotes, [which record] atmosphere and nuance, then I will have reproduced absolutely nothing of the richness of the conversation . . .
>
> (Fieldnotes - late August, 1994)

I also found that the transcripts provided an excellent opportunity to reflect on what I had and had not accomplished as an interviewer:

> Doing the transcripts . . . I get an excellent sense of the slow wanderings of the conversation . . . and the way I go with it, wait for the pauses and then probe for what it is I want to hear about next. I'm also finding that most of my reflections are accurate - Peter picks up on them and repeats them verbatim. . . . That's for the most part. There are places where I squirm as I transcribe - places where I think - "Now why the hell am I getting into that?" - and "Enough, already - why don't I stop?" - but mercifully, there aren't many of them.
>
> (Fieldnotes - June 9, 1994)

As I prepared them, the transcripts entailed a deliberate compromise between being faithful to the conversation as it occurred and omitting the non-words that interrupted the flow of the participant's thoughts. The transcripts alone were in fact a poor facsimile of the original conversation. They were fleshed out by my memory of specific moments in the interview and by the fieldnotes I had recorded as soon as possible after each interview was finished.

Respondent validation

Approximately one year after the interviews were held, data analysis was completed and a draft of the two results chapters had been prepared. At this point, the participants were contacted by phone and given the opportunity to check through the sections that dealt specifically with their interview. They were also offered an unmarked copy of the transcript of their interview. All participants expressed their interest and took part in the process of respondent validation which assured that this project possessed face validity. The following two passages record my initial thoughts about this process:

> . . . respondent validation is becoming more and more important to me - because it will help ensure that I am interpreting [the participants'] stories in the way that they were meant - that they will actually have a hand in the writing process - so that it too becomes interactive.
>
> (Fieldnotes - June 9, 1994)
>
> [The participants] can only edit their own words and no-one else's . . . that needs to be made very clear or I cannot contain what happens. I guess my fear is that nothing will be left of my research afterwards. On the other hand, if each participant agrees wholeheartedly with all that I have said about them, then what is the point of going back to them? . . . I won't [know what they think] until I ask. Maybe I can stack the deck in favour of modification by stressing that I really am open to what they have to say. . . . I must remember . . . [that] I am increasing my validity just by asking. And leave my ego at home.
>
> (Fieldnotes - June 24, 1994)

I found respondent validation an unexpectedly time-consuming endeavour: participants took anywhere from forty minutes to four hours to read through the relevant material. Some participants were comfortable with the excerpts I had used, felt that my analytical comments were accurate, and did not request any changes. Others wanted explanatory notes added at certain points: they were concerned that the context in which their words were said was either unclear or might be misconstrued. Several participants, motivated by their consideration for ongoing relationships and their regard for the deceased parent, wanted certain passages deleted completely. The meaning they had intended continued to be negotiated in the interactive manner advocated by Lather (1991, pp. 59-67). I was also aware that by using respondent validation I was asking the participants for their permission to speak about them as I had (Alcoff, 1991).

Once I fully understood the participants' concerns, I respected their requests for either the addition of explanatory comments or the deletion of their words. In the process of reading, they sometimes responded to another participant's description of a particular incident. These responses were added to the relevant passage. After a participant had gone through the results section, the alterations they had asked for were made before the new draft was presented to succeeding participants.

Respondent validation had three different effects, two of which were positive: my analysis was either judged credible or sharpened and the description of specific incidents was enriched. The third effect, a minimization of specific difficulties or points of conflict, especially if they related to the deceased parent, was more problematic. The following fieldnote records my concerns:

> I sit in the room with the participants as they read. Sometimes I hold my breath - but it's usually in the wrong places. I don't often anticipate the points where they want changes or deletions. There have been a few moments when I worried that my whole thesis might disappear in a welter made of their concerns. But that hasn't happened. The meaning that emerged through my analysis still stands, although it has been considerably softened at a few points. I think the process of time has had something to do with that too. The participants don't feel now the way they did a year ago when I interviewed them; they didn't feel then the way they did when the ill parent was alive.
>
> (Fieldnotes, early June, 1995)

Chapter 4, which focusses on the nature of hospice services, was read by two Hospice Coordinators and one Coordinator of Volunteers. The additions and modifications they suggested increased the accuracy and validity of the chapter. All three felt that the fictional hospice I had described did not follow quite the same procedures that they used with their own hospice volunteers, but accepted that my writing presented an amalgamation of procedures from several different hospices.

The process of respondent validation held another surprise for me. I had not anticipated that all participants would still be interested in the research a year later, and that senior hospice personnel would also find time to check through what I had written. Once they had finished with the draft, many of the participants expressed their interest in reading the entire thesis once it became available. When I thanked Paul, the father in Case 2, for the time and care with which he had read, he patted his copy of the transcript and said that he wanted to thank me, too. "I see it as a two-way street," he told me. "You've given me a record of a piece of my life that I wouldn't otherwise have had - and that means a lot to me" (Fieldnotes, early June, 1995).

Conclusion

This chapter gives a detailed discussion of the interactive, dialogic process used in data collection for this qualitative research project. In summary, 11 interviews with 9 different participants contributed data to two separate case-studies, each of which focussed on the experiences of a child with a parent with advanced cancer. The impression this chapter might give that the research process was straightforward is deceptive; it was anything but that at the time. I hope excerpts from my fieldnotes convey some of the difficulties I encountered and provide glimpses of my periods of in-decision. My fieldnotes also provide evidence for the systematized reflexivity (Lather, 1991, p. 67) with which the biases and assumptions I held when I commenced this study shifted as the research proceeded. I have also paid close attention to the effects of the research process on the participants required by catalytic validity. Content is inextricably related to process: the quality of the data collected was profoundly affected by the interactive nature of the research. The following chapter presents background information on the hospices which played a central role in the initial stages of this research project. The results of data analysis for the two case-studies are discussed in Chapters 5 and 6.

CHAPTER 4

Hospice

Introduction

This chapter sets the context for the two case-studies that follow. It provides background information on the nature of hospice services before discussing a fictional hospice society that incorporates the characteristics and policies of the four hospices involved in this project. The chapter concludes with an examination of the particular qualities possessed by the hospice volunteers who participated in this study and the motivation behind their ongoing commitment to a succession of hospice clients.

The Nature of Hospice Services

> "... dying, like birthing, is a process requiring assistance. It is an event that asks us to be present for one another with heart and mind, bringing not only practical help as necessary, but also attentive awareness, and appreciation of the individual involved."
>
> (Stoddard, 1991, p.10).

The hospice movement, which took hold in Britain in the 1960's, and in North America a decade later, has been characterized by its determination to extend the conventional hospital's concern with clients' physical needs to include psychological, social and spiritual aspects of the clients' and their families' functioning in the final months of life (Corr & Corr, 1985). Today, hospice and palliative care refer to the same process: the provision of compassionate care to the terminally ill and to their families when the disease is no longer responsive to treatment with the intent to either cure or prolong life (Hospice Coordinators, 1993-5). The difference between the two terms is simply a matter of location: hospice units are closely allied with community health care services, while palliative care units are located in hospitals (Hospice Coordinators, 1993-5).

Hospice care entails first of all a philosophy of naturalizing and humanizing the processes of dying, death and bereavement, and may or may not include an actual physical site (Corr & Corr, 1985; Hospice Co-ordinators, 1993-5). Many hospice organizations in Western Canada are not free-standing facilities; their clients may receive hospice care while at home, in hospital or in long term care. Hospice organizations may either be integrated with or augment the services provided by the palliative care units currently being established in many hospitals.

The hospice team is multidisciplinary; it may be composed of physicians, nurses, social workers, physiotherapists, occupational therapists, nutritionists, art or music therapists, chaplains and volunteers. A Hospice Coordinator oversees the work of the entire team; in larger hospices there is also a Coordinator of Volunteers. Pain and symptom management are addressed by the physicians and nurses; occupational and physiotherapists help the client maintain mobility. Psychological, emotional, social and financial concerns of client and family are addressed by social workers; spiritual concerns are addressed by the chaplains. Hospice volunteers provide emotional support which augments the services provided by paid team members and enhances the care of client and family. The nature of the volunteer's services depends on the needs of individual hospice programs, the client's and family's requirements, and the skills and imagination of the volunteers (Corr & Corr, 1983, pp. 215 & 216). Hospice volunteers are carefully selected and trained, operate within strict guidelines, and receive regular support and supervision from either the Hospice Coordinator or the Coordinator of Volunteers (Hospice Coordinators, 1993-5).

Hospice volunteers are of all ages and backgrounds and have many different occupations. Retired health care professionals may well become hospice volunteers, but local hospices also have in their volunteer pool teachers, computer analysts, travel agents, homemakers, bank tellers, medical students and businessmen, to name a few. The hospice volunteer's motivation might include the personal experience of nursing a dying member of his or her own family, the desire to contribute time and energy to the community in a meaningful way, or the discovery that regular contact with the very ill helps the volunteer maintain perspective on his or her own life (Hospice Coordinators, 1993-5).

The Hospices in this Study

As only four eligible cases were located through the hospices originally contacted, I am concerned that describing the specific details of each hospice might lead to inadvertent identification of the families involved. In order to protect their anonymity, a composite picture of the six hospices initially approached is presented here in the form of a single fictional hospice, Open Hand Hospice Society. Characteristics common to these hospices are emphasized while identifying details are either altered or omitted.

Open Hand Hospice is housed in a tiny office crammed with files and references, located in an official municipal building. The Hospice Coordinator holds the only paid position, which is part-time; there is no Coordinator of Volunteers. The hospice has approximately 60 hospice volunteers on its books, although all of them are not actively involved with hospice clients at any one time. Hospice volunteers are carefully selected. The Hospice Coordinator conducts an initial screening interview before prospective volunteers commence the training program, which lasts several days. Those who pass the screening demonstrate the ability to communicate effectively and to evaluate the results of their actions. They are open to different beliefs and customs, able to deal with personal loss, live full lives and demonstrate a sincere desire to be of service. The training program is regarded as an integral part of the screening process. Prospective volunteers may decide after completing the training that the work is not for them after all. Once screening and training are completed, hospice volunteers make a commitment to visit a client for 4 hours a week for up to one year.

In 1993, Open Hand Hospice Society received over 100 referrals for a hospice volunteer. The majority of the referrals came from the home care nurses with whom the clients were in regular (often daily) contact. Referrals were also made by other members of the health care team. Occasionally, clients made the initial call to Open Hand Hospice themselves, after hospice services had been suggested by family members, friends, or community service organizations. Potential clients were visited first by the Hospice Coordinator who explained the services available and discussed the client's needs and concerns. The medical prognosis was also considered, given that the hospice mandate is to take clients that have weeks and months rather than years to live. Open Hand Hospice is fully prepared, however, to continue to provide services to clients who outlive their prognosis. Approximately two-thirds of the 100 referrals received in the past year became hospice clients and were placed with a hospice volunteer.

The average age of a client at Open Hand Hospice is over 60. The children these clients may have are themselves adults who often have children of their own. The cases eligible for this study, in which the hospice client with advanced cancer was parent to one or more young children, were rare.

Different hospices have different philosophies about who the hospice client is. The Coordinator at Open Hand Hospice Society regards the entire family as the unit of care. The hospice volunteer is trained to provide support to whoever is in need of it: this customarily includes the dying family member. There are numerous cases, however, when the hospice volunteer will be more actively involved with the healthy spouse or other family members than with the one who is ill. Very few hospice volunteers at Open Hand Hospice are prepared to work specifically with the family's children, however and there is no specialized training available for them at the hospice. Current hospice literature is also starting to acknowledge the need for hospice personnel to be better equipped to work with children. One hospice worker was recently quoted as stating:

> We deal with children and grandchildren all the time, yet we are trained to deal primarily with the elderly and terminally ill. Children may not be patients in our hospice program but they are certainly part of our responsibility. As we support them, we really do serve our patients as well.
>
> (Doka, 1995, p. viii)

The hospice volunteer and the client may engage in a variety of activities, depending on the hospice volunteer's initiative and the client's preferences and degree of mobility. They may go out for tea or coffee together, visit the local library or attend a medical appointment. If the client is confined to bed, the worker may sit and chat, read aloud or, if the client is asleep or unconscious, maintain a quietly supportive presence. With other family members, the hospice volunteer may listen attentively to their concerns and assist them in finding answers to their questions. The volunteer will also relieve family members from their care-giving responsibilities for short periods. The Hospice Coordinator contacts each active volunteer two or three times a month to check on how they are doing and also maintains regular contact with the client/family unit.

In the period immediately preceding the death, the hospice volunteer might spend more than four hours a week with the dying family member and his or her family. During this time the need to provide support to other family members often increases. After the client has died, the volunteer provides bereavement follow-up to surviving family members for a brief period. The hospice telephone team then takes over this task.

Open Hand Hospice pays close attention to the needs of the hospice volunteer in the first few weeks following the death. The Coordinator debriefs the hospice volunteer and provides support as needed. If the volunteer has not attended the funeral, the Coordinator encourages him or her to engage in an appropriate symbolic activity that will assist the volunteer to let go, to say goodbye and if need be, to grieve. The Coordinator also recognizes that the hospice volunteer may well need time away from hospice responsibilities in order to engage in life-affirming activities. They decide together how soon to begin talking about another placement. Volunteers may be willing to visit another client after a brief period if their previous placement has been short, or it may be a year or more before they feel ready if the previous placement has been a lengthy one. When arranging new placements, the Coordinator works closely with each volunteer and his or her prospective client.

The Hospice Volunteers

In my initial overtures to the hospices, I was struck by certain qualities that I encountered over and over again in Hospice Coordinators, the Coordinator of Volunteers and the hospice volunteers alike. Excerpts from my fieldnotes document my growing understanding of what those qualities were:

> *Presentation to hospice volunteer's support group meeting:*
> [Hospice volunteers] were invited to come and speak to me [at the end of the meeting] if they were eligible and willing to participate, or had questions. . . [They] were so warm . . . an extraordinary quality of presence came from them - and they were personable right away, as if they already knew me . . . Their wanting to help was almost palpable.
>
> (Fieldnotes - Feb. 1, 1994)
>
> *Conversation with the member of the hospice unit for a local church:*
> She was so warm and friendly on the phone - this special quality that I am coming to expect from hospice workers - a radiance. . . . What is it in her voice? The wisdom and capability that comes from long years of experience, an inclusiveness, an automatic acceptance of me. She has taken it as a given that what I do matters, and she is very willing to talk again later, should I need further suggestions . . . one more indication to me of that generosity.
>
> (Fieldnotes - Feb. 24, 1994)
>
> What is it about hospice volunteers? I've now spoken with Anna, the hospice volunteer for Case 1. . . . she sounds so confident on the phone, and I think has been highly involved with the family and their difficulties. . . . The Hospice Coordinator at *(name of hospice)* does not have any eligible hospice volunteers . . . but has said that she is very interested in my research and would help me in any way that she can.
>
> (Fieldnotes - Mar. 14, 1994)

The remarkable generosity with which Hospice Coordinators, Coordinators of Volunteers and the volunteers themselves gave their time is illustrated by the following passage, written after a phone call was made to Anna, the hospice volunteer in Case 1, one month after her interview:

> Anna told me that she would welcome me calling again - any time. . . . When she said this I no longer thought, "Oh, how extraordinary" - I found myself thinking, "Here it is again" [the recognition of] this gift of time and caring that I am coming to expect from hospice volunteers - that is given so freely. I am coming to understand that this is a part of who these people are.
>
> (Fieldnotes - May 12, 1994)

My initial sense of disbelief that hospice personnel really were as committed, warm and generous as my fieldnotes recorded was completely suspended as the research continued and the amount of contact I had with them increased. When, over a year later, I discussed my initial reactions with one Coordinator of Volunteers, she responded by telling me that when she accepted her current hospice appointment a few years ago after working previously with clients in difficult circumstances at several other social service agencies, her mother said, "You always pick such morbid jobs, dear" (Fieldnotes, June 18, 1995). The Coordinator explained that she was confronted again and again by the fact that hospice volunteers were an extraordinary group of people. She maintained that she continued to find her hospice position uplifting rather than depressing, and is convinced that the immense satisfaction she derives from it is due to her regular contact with the volunteers.

In the course of the research, I also began to understand that the hospice volunteers I met held a strong philosophical and/or spiritual position that sustained them as they committed themselves to visiting a succession of hospice clients. The following excerpts from my fieldnotes illustrate this point:

> Kerry said that the most important thing was your humanity. That [if] you bring your humanity into the room . . . then whatever else you do is guided by it, and it would be right for the situation.
>
> (Fieldnotes - Case 4, interview 1)
>
> Anna talked about her philosophy of working with children when there is a dying parent or grandparent - and how she feels that we need to normalize death - we need to be honest with children. We mustn't protect them . . . it's very important . . . for them to know this is a normal process. She said, "We are all going to die".
>
> (Fieldnotes - Case1, interview 1)

In the course of their interviews, the hospice volunteers articulated their motivation for their ongoing commitment to hospice work in various ways, as these three passages illustrate:

> **R:** . . . I have one last question and that was just - what was it like for you to live through that time with the family? What was it like for you?
>
> **Kerry:** Oh, of course it was emotional. Because Sheryl was a very likeable kind of person. She was so vulnerable and - she was just so vulnerable. You know, that's the thing about people, you know, they - . And you go into their homes - you are their guest, and yet they're willing to share so much with you. And just, you know [be] really appreciative. . . . But as we were waiting for the doctor - I mean, it was like waiting for the impending word - the doom. We knew what was coming. And she said

> . . . "If anything has come out of this," she says, "I've learnt how many people are wonderful out there." So - it was really great - yes *(cries).*
>
> (Case 4, interview 1)

> **Sue:** . . . I think you do [hospice work] forever, kind of, you know? Yeah, I really do see it as . . . I get a lot out of it. . . . it puts my life in perspective. I mean I tend to - there's an incredible intensity about me and sort of, you know I tend to exclude a lot in order to focus on something *(voice goes up).* And working with people that are dying that balances things out and it makes you appreciate more - and your health, flowers, the birds, what we often take for granted. Yeah, and I guess my *(unintelligible)* whole issue with death too I - you know it's an inevitable thing, and seeing people that are dying that - . . . I just find it very empowering. And I - I don't find it, I don't get you know - upset. It's like I see their strength, you know and what they're dealing with. And it's like "so what if this doesn't work out?" Like it puts my life in perspective.
>
> (Case 2, interview 3)

> **R:** . . . the last thing I really wanted to ask you about is what was it like for you to live through this time with the family?
>
> **Peter:** Yeah. To me, I found it, can I use the word - exciting?
>
> **R:** Of course you can.
>
> **Peter:** Yeah. Because to me, you know, it was a real privilege and it was - the sort of thing you don't always get the opportunity to do, or to really get close to - a situation like that. And I really felt that I was contributing . . . I felt that I was receiving a lot, and yet I was able to give in that situation.
>
> **R:** Peter, it's really interesting to hear you say that - that you felt you were receiving - as well as giving, you know.
>
> **Peter:** Yeah. I think that it's a common thing and when we sit in our hospice gatherings, our support group meeting that it comes up very frequently that you - at times you almost feel like you receive more than you give. Yeah - it is a very deep experience.
>
> (Case 3, interview 1)

Although the hospice volunteers and Coordinators who initially gave me time or who formally participated in the research project came from diverse backgrounds and were of very different ages, they shared a similar constellation of qualities. The most salient for me were their remarkable sensitivity and responsiveness to others. The spontaneous warmth and generosity they possessed were apparent in the way they extended themselves towards me and the time they willingly gave. Their equanimity in the face of their clients' deaths seemed to me to be informed by their acceptance of their own mortality. A strong philosophical and spiritual stance underpinned their commitment to hospice work. The hospice volunteers interviewed were firmly convinced that their presence had made a difference to the client and his or her family and took deep satisfaction from their understanding that this had been the case.

CHAPTER 5

Results: Case 1

Introduction

This chapter presents the first of two distinct case studies focussing on the experiences of two children each of whom had a parent with advanced cancer. The second case-study is presented in Chapter 6. The two case studies deal with the final period of approximately six months up to and including the moment when the parent died. In each case study the child's experiences are examined as perceived and reported by adult participants who were in regular contact with the child. The descriptions I present form only one of numerous possible interpretations of the participants' reports. Someone with a different background and different attitudes would undoubtedly interpret the same data in a different but non-contradictory way (Hammersley, 1990, p.14). The descriptions given here are highly selective. In the course of their interviews, the participants invariably discussed aspects of their own experiences during the period when the parent had advanced cancer which were not directly relevant to the experiences of the child. In addition, they often related difficulties that ensued either for themselves or for the child in the period immediately following the parent's death. All of that material has been omitted from the two results chapters.

Pseudonyms chosen by individual participants are used throughout Chapters 5 and 6. The discussion of each code and/or category includes passages from interviews with all the participants to whom it was applied. This means that when Richard's anger is discussed, for example, the comments of each participant who had reported witnessing his anger are included. In this way, a composite picture of the child has been built - one far richer than any single participant could provide. Extensive quotations from the interviews permit the participants to speak in their own words. These are augmented by preliminary notes and analytical comments. In the final section of each case study, I present the recommendations made by the participants for specific services that they wished had been available for the child. Chapter 6 concludes with a discussion of the effects of the research process on the participants from both cases. In Chapter 7, I will discuss the salient issues common to both cases in relation to the current literature.

Case 1

Background Information

The child in Case 1 is Richard, a nine-year old boy whose father died the summer after he had completed grade three. Richard has one sibling: his brother Robin who is six years younger. Both children are healthy and active, although Richard has been overweight since well before his father's death. The mother and father were both of European ancestry, born and raised in working class homes in eastern Canada. Richard's father, Ralph was considerably older than his mother, Elizabeth. As a young man Ralph had been in the armed forces. After his marriage to Elizabeth, he was employed as a salesman until he became too ill to work. As a young woman, Elizabeth had worked for a large chain of retail stores. She was devoted to her family and did not work outside the home after Richard's birth. Ralph had been married before; Elizabeth had not. Richard's father was diagnosed with cancer in the autumn of 1991, when Robin was a baby. He died in the summer of 1993. Richard had had no previous experiences of the death of family members.

At the time of Ralph's death, the four members of the family had lived for several years in a small but comfortable rented two-bedroom apartment in a three-storey building set well back from a suburban street. Elizabeth was good friends with a neighbour down the corridor who had a child the same age as her younger son. The two women were in the habit of exchanging childcare; the neighbour willingly looked after Robin when it was necessary. During the final stages of Ralph's illness, the family had difficulty obtaining sufficient support to ease the tremendous demands that were being made of Elizabeth, who was the primary caregiver for Ralph at the same time that she was responsible for parenting her sons. Neither Ralph nor Elizabeth had any relatives living in the province who could help them. Richard's school proved to be an important source of support for both him and for his mother. It was the parents of a school-friend of Richard's that looked after him during his father's final week alive.

The Participants

Case 1 is based on interviews with 4 participants: the hospice volunteer (Anna), Richard's teacher in the school year preceding his father's death (Jessie), the school counsellor (Jane), and his mother (Elizabeth). In this section I will briefly describe the professional experience of the first three participants, discuss their responsibilties to the family, and report on the nature of all four participants' contact with the child.

Hospice Volunteer

The hospice volunteer is a middle-aged married woman, originally from Britain, with two grown children of her own. Anna gives an impression of strength and capability, laced with common-sense. She has been a hospice volunteer for five years and in that time has had approximately eight cases. Her responsibilities to visit with and be a support specifically for Elizabeth rather than Ralph were unusual. Medical personnel were concerned that Richard's mother lacked adequate support and recommended that she have a hospice volunteer for herself. Elizabeth had a painful but not serious medical condition, for which surgery was postponed several times in the months preceding her husband's death. Anna started her visits in late 1992, and saw Elizabeth for almost a year. She describes her role:

> **Anna:** . . . when I [first] saw Elizabeth, I said, "Elizabeth, I'm here for you and nobody else". . . . I wasn't there to take care of the children or - definitely not . . . So whatever Elizabeth wanted to say - you know - if she had any guilt feelings and she could get it off her chest and you know - she knew it wasn't going to go any further. So I only even met Ralph once.
>
> (Case 1, interview 1)

Anna and Elizabeth usually visited in the car at Richard's school between 2:00 and 3:00 p.m., while Elizabeth was waiting to pick him up. Robin would be with them. They would also talk on the phone. The frequency of Anna's visits increased as Ralph's death grew near:

> **Anna:** . . . when I first started to visit her, and because I couldn't ever go to her home - it started off by once a week. But when Ralph was getting very ill and he was in and out of the hospital - she would go and sit at the hospital all day. Well then I - you know - for the last month, maybe three weeks, I've forgotten, I was with - at the hospital all the time with Elizabeth. I would go and just -
> **R:** So you just gave a lot through that time -
> **Anna:** Yeah.
>
> (Case 1, interview 1)

The interview with Anna focussed primarily on Elizabeth. Anna portrayed her as an accomodating and selfless person, who tried to maintain calm in her family despite the difficulties of their situation. She found Elizabeth sweet and friendly, and felt that she would readily have made good friends with other mothers if she had not been so single-minded in her devotion to her family. In the following excerpt, Anna discusses the huge number of demands with which Elizabeth was inundated and examines how she managed to cope:

> **Anna:** I don't know how she - as I say, I think she's always been a very giving

person so she didn't realize what was happening that - you know - that there was so much being piled on her - but she - she **coped**, you know? She never - she would - I don't remember her really being down. Now I have worked with a lot of people. . . . There's always times when people get very, very low, 'cause . . . most of the time I'm visiting the person who is dying - so it was expected. But even with Elizabeth that - she knew that when Ralph went that she didn't really have too much security and she had two very young children to bring up. I never remembered her worrying about herself - you know - what would happen to her afterwards - never ever - she always - I think she just lived for the day, you know and she coped with -

R: One day at a time

Anna: And that's how she survived.

(Case 1, interview 1)

In the process of evaluating her own experiences with the family, the hospice volunteer discussed how easygoing and likeable Elizabeth was. This passage also provides insight into how Anna viewed her role with Elizabeth:

Anna: No, it wasn't [difficult], because when you get along with the person, like, Elizabeth and I got along very well - and I think everybody gets along with Elizabeth. No it wasn't difficult - I felt kind of - it was very awkward - like during the summer months when Richard was home the whole time. It was very difficult for me to get time with Elizabeth - that we could have a chat.

R: Okay - so that was the hard part.

Anna: - because - but when you first meet somebody and when you sort of - especially a type like Elizabeth when you first meet her everything is fine - so you have to sit and talk and chat and then you just sort of start to pump - "Well Elizabeth, how do you feel? What did you do?" And then eventually she will open up.

R: Your job is drawing her out.

Anna: - and you start finding out that it wasn't fine for her. She was having a rough time . . . And I always thought I got straight goods . . . she never elaborated too much or she never went the other way, never complained too much. I always think that what I heard from Elizabeth was what really was happening.

(Case 1, interview 1)

In the following passage, Anna illustrates how important the support that she provided was to Elizabeth:

Anna: . . . right at the end, I was the one she phoned when Ralph - you know, died, because she had nobody. She did have - there's a neighbour who lives on the same floor that used to look after Robin that was very good, and there was another lady from the school and she would come up sometimes to the hospital and sit with Elizabeth -

(Case 1, interview 1)

Anna had had limited contact with Richard. In the following passage, she discusses the reason:

> **Anna:** . . . - oh he didn't like me - when he saw me, he would immediately - turn his head and walk [in] another direction.
> **R**: Richard did that.
> **Anna**: Richard. He does this - *(gestures by turning her head away)* - so immediately he doesn't like anybody he turns his head - and he won't look at them - he just sort of goes - somewhere else.
>
> (Case 1, interview 1)

The interview with the hospice volunteer provided valuable background information on the family's situation and specific details of how that situation had impinged on Elizabeth. Anna was unable, however, to provide more than a few details of the child's experience.

School Teacher

The child's school teacher and school counsellor had had extensive contact with Richard. As two seasoned professionals, they were able to assess his behaviour and to weigh his reactions to the profound difficulties of his situation against their experiences with scores of other children. These two interviews provided invaluable perspectives on Richard's experiences that augmented his mother's viewpoint. They also provided tangible evidence of the long-term support that the school had provided to both Richard and his mother.

Jessie, the teacher, is a soft-spoken, older woman who has had almost three decades' experience as a primary school teacher. She has worked in several different schools for the same district over those years. The interview took place mid-morning, during her free period, in one corner of the temporarily empty classroom. Jessie had an extremely compassionate, sensitive, and respectful attitude towards Richard. The following excerpt reveals how she arrived at her view of him:

> **Jessie:** I tried to put myself in his place. And think - oh - I'm sure I wouldn't - I know I probably wouldn't have handled it half as well as he did, if I'd been his age, you know. I'm sure I wouldn't have.
> **R:** Yeah. He really was handling it.
> **Jessie:** I think so. Actually, he handled it quite well.
> **R:** That's wonderful. That you didn't put adult expectations on this child but just -
> **Jessie:** No. No, it wouldn't have been fair. Lots of adults might not have handled it as well as him, let's face it, you know.
>
> (Case 1 interview 4)

Jessie also stated how she regarded Elizabeth:

Jessie: . . . And I really admired Richard's Mom, because it was a tough thing to go through and she had the two kids - and she always kept a brave face on it. I really admire her. . . . Yeah, she's just wonderful. Those boys are lucky that they've got a Mom like her.

(Case 1, interview 4)

The interview was an emotional experience for Jessie. Several times, tears welled up in her eyes as she remembered Richard's difficulties and her own overwhelming sense of helplessness. The following is one example:

R: Jessie, I really thank you for wading through this material ' cause I imagine it's not easy -

Jessie: Oh that's okay. It is kind of hard to - you know - because I felt so - . It was tough for him at the time and you know, what can you do really? Except just have a sort of - a loving place where he can come and know that he's safe, all day. And be as consistent as you can. But it's hard.

(Case 1, interview 4)

Jessie had had contact with Richard most weekdays throughout the year that preceded his father's death. The interview, however, took place a year after Richard had left Jessie's classroom. At the conclusion of her interview, she discusses the effect of the intervening year:

Jessie: . . . I've tried to remember as much as I can. But you know, you get so taken up with the next class, that you sort of - everything gets pushed to the back of your mind.

R: Yes. Well of course - it **has** to *(said loudly - then both speak together. R chuckles softly).*

Jessie: You have to do that to survive.

R: You can only hold so much in your brain.

Jessie: So, yeah *(tone is serious).* But - those were the things I noticed so -

(Case 1, interview 4)

For all Jessie's concerns about her memory, the incidents with Richard that she described were clear, poignant and imbued with sensitivity for the child's situation.

School Counsellor

Jane, the school counsellor, originally trained as a high school teacher, and worked as a counsellor in senior high schools for some time before returning to university for her Master's degree in Counselling Psychology. Over the last two decades, she has counselled junior and senior high school students, and has also worked in career counselling at college level. For the last seven years Jane has been an area counsellor for the school district, working in elementary schools on an itinerant basis. At the time of the interview, her work with Richard and his family encompassed a three-year period. Throughout the interview, Jane referred to notes she had made after sessions with the child, discussions with the mother, or team meetings with school personnel. In her articulate analysis of the child's situation and the family's current circumstances, she carefully considered the profound difficulties Richard and his family had confronted during the period she had worked with them.

At the start of the interview Jane explains the limitations of her position:

> **Jane:** . . . I don't think the role of the school counsellor is to do therapy, really with children. I don't see that as my role. I don't think the school's the setting to do real deep grief work with a child. I mean it's hardly fair to take him out of class for fifteen minutes and get into some, you know, deep grief, and then send him back to class. I mean it just isn't the setting. But I think what we do can be therapeutic, whereas it may not be psychotherapy it is *(unintelligible)* and I think just that being there and listening and helping things, that's my perception of my goal, anyway.
>
> (Case 1, interview 5)

Jane's initial sessions with Richard occurred soon after his father was diagnosed in the autumn of 1991, when Richard was in grade two. The counsellor's consultations with his teachers and his mother at that time revealed that he was showing signs of stress - "holding his bowels, not being able to go and getting cramps" (Case 1, interview 5). Jane describes another presenting concern:

> **Jane:** . . . The teachers perceived him as being quite stubborn. Like he didn't - he told me he didn't want to learn to read.
>
> **R:** So he wouldn't do what they asked.
>
> **Jane:** No . . . He was resistant to the whole idea. There was a concern that he wasn't learning to read. Well he said, "I don't want to learn to read, so let's play puppets".
>
> (Case 1, interview 5)

When Richard refused at that time to discuss his father's illness, Jane respected his choice. She gives an overview of the weekly 20-minute sessions she held with him over several months:

> **Jane:** . . . he loved to come and see me. And he thought this was fun time you know, like [it was] really great. And I kind of let him do what he wanted, which was you know, easy for me. . . . He loved to draw - he did lots of that sort of thing. He did not want to talk about Dad at all. . . .I'd sort of probe, you know, and put out little feelers and he denied totally that there was anything wrong with his Dad. He said, "Dad's fine. I don't want to talk about it." So - that was the end of that. So we really didn't do any grief work. . . . No - but I just thought, "Well that's fine, I'll be a support for him".
>
> (Case 1, interview 5)

As Ralph's illness progressed, Jane continued to make herself available to Richard. At the same time, she made clear that he was free to choose whether or not to attend sessions with her. The teacher recalls the arrangement:

> **Jessie:** . . . And [Jane] had a deal with Richard that if things were going rough for him and he really wanted to talk to her, and she was there that day, just to come. . . . Or she would drop in and say, "Hi, Richard, I'm here. Do you want to talk to me?" or, you know, "How are things going?"
>
> (Case 1, interview 4)

Although Jane saw Richard periodically through the following year and a half, it wasn't until the spring of 1993, when Ralph was gravely ill, that she started to see Richard again on a regular basis at Elizabeth's request.

The counsellor also provided direct support to Elizabeth, and gave her information on hospice services. Jane volunteers the following remarks on Richard's mother's extraordinary selflessness:

> **Jane:** - at different times I'd see her, she'd be so grateful that I would phone, and you know, she just seemed to think, "Well - isn't that wonderful that you'd even care enough to phone, or anything". And I'd think, "Gee, of all the people to phone she'd be probably number one in needing us".
>
> (Case 1 - interview 5)

Elizabeth related that in the spring of 1993, when various treatments had failed to halt the spread of Ralph's cancer, Richard began to discuss the details of his father's illness with Jane. The importance she attached to this event provides evidence for the substantial support she derived from the school counsellor's interventions with her son. She states:

> **Elizabeth:** . . . twice a week [Jane would] see him, and even though there's nothing forthcoming, she'd still try and always [ask] - "How's your Dad?" He'd look at her like, "Why're you asking?" Or he'd say, "Fine, fine". But this was the first time he said, "Not very well. He's not doing very well". And she goes, "Do you want to talk about it?" And then he did. He went into depth, saying, "Well this is what Daddy, you know, Daddy had the radiation and it didn't work. Now Daddy's got to go for chemo" - and he told her as much as he wanted to tell her. But she got on the phone right away - "Elizabeth, I can't believe that he's talking to me". I said, "Well, keep it going", I said, "Whatever you can get, just - ". I said "You don't have to share it with me unless you feel to share it, but just" - I says, "I need somebody else on the outside".
>
> (Case 1, interview 3)

Although Jane did not remember her phone call to Elizabeth, she agreed that, "There may have been some interviews where [Richard] opened up a little bit more" (Case 1, interview 5). In the following excerpt, the counsellor discusses a possible reason for Richard's willingness to talk:

> **Jane:** I think he felt safe with me.
> **R:** Well you'd established that.
> **Jane:** Yeah. And I think that you know - I didn't feel that successful with him because it never seemed that we were dealing with the issues, overtly, but possibly just being there was valuable for him.
>
> (Case 1, interview 5)

In the autumn following Ralph's death, Jane saw Richard for the first two months of school but discontinued the sessions when he lost interest in coming. Richard's new teacher also didn't think he needed to continue seeing the counsellor. At the end of her interview, Jane assessed the outcome of her sessions with Richard. The following passages summarize two distinct aspects of her thinking:

> **Jane:** . . .. I was hoping that he might talk about his feelings more but - I wonder how much of that is my own agenda. You know, and I can't really measure whether I was helpful to him or not, to tell you the truth.
>
> (Case 1, interview 5)
>
> **Jane:** And maybe the artwork was therapeutic for him. I truly believe that children do work through feelings in maybe a subconscious way, symbolically. He did a lot of plasticine work, too. . . . And he did a lot of, just seemed to love to get in and do things and I never looked at the symbolism of them necessarily, the things he created but I'm sure maybe for him on some level that was - being helpful.
>
> (Case 1, interview 5)

Although the school counsellor was uncertain how effective her counselling sessions with Richard had been, his mother and teacher both stated that Jane's work with Richard had proved an important source of support for them.

Mother

Richard's mother, Elizabeth is an easygoing, extremely friendly and personable woman in her early forties. She had moved out west in her early twenties to take a highly responsible position in the retail business. Married in her mid-twenties, she continued to work until Richard was born about five years later. Elizabeth had admired her husband, who had lost the use of a limb in a car accident just before she met him. She states that: "he had a wonderful spirit . . . nothing ever stopped him" (Case 1, interview 2). Her relationship with Ralph remained loving and respectful throughout the course of his illness. Both the hospice volunteer and the school counsellor commented on Elizabeth's accommodating nature. In her interview the school counsellor stated: "I think it's very easy for her to put her needs and feelings secondary" (Case 1, interview 5).

Since their births, Elizabeth had had the major responsibility for parenting the two boys. Early in her first interview she expresses her reservations about Richard's lack of quality time with his father when he was small:

> **Elizabeth:** . . . [Ralph] did not spend much time with Richard, because being in the *(omit)* business - it's feast or famine, sort of thing . . . . But when he did spend time with Richard - it was - he'd really overdo. Like, I mean - because he was trying to make up for lost time. . . . [so] he gave Richard all sorts of rewards. . . . Every Friday, there was a pizza. Well poor Richard - well he would stay up - he's only little guy - two, three years old - waiting. "Daddy's going to come home with a pizza" - he knew it. . . . But I kept saying - "No, you know what he really needs is quality time - when you taking him to a soccer game, you taking him to this, that". I used to get a little angry, a little annoyed because of that, but he was giving all he could give. And that's the only way he could fit it into his lifestyle, his schedule. . . . I know Richard feels it now thinking back, but at the time he never -
>
> **R:** He never said.
>
> **Elizabeth:** No. Not at all. No, just whenever Daddy did spend that time with him, that was his quality time. Even if it was just for a drive over to the supermarket, and they did it together.
>
> **R:** Okay. So he got some.
>
> **Elizabeth:** Oh yeah. But not as much as he should have, but he did get some.
>
> (Case 1, interview 2)

Elizabeth was as open as she judged advisable with Richard about his father's diagnosis of cancer:

> **Elizabeth:** . . . I said, "I know it's very hard for you to understand that but Daddy has cancer" . . . and I said, "They're going to cut the tumour out, but" - he said, "So will it be all gone then?" I said, "I'd like to say yes", I said, "But I'm not going to lie to you" - I said, "When they do cut these things" - and I said what happens. And I drew pictures. I said, "these little cells - they bounce". I said, "When they cut you, they kind of spread", I said. "Just like the wind blew it". . . . "And it can spread up here" - I said, "It might go in other parts of the body".
>
> **R:** What a beautiful job you did of explaining it -
>
> **Elizabeth:** Well I don't know. But it was hard at the time. But it just comes as naturally *(voice goes up).*
>
> (Case 1, interview 2)

Throughout the course of Ralph's illness, Elizabeth continued to keep Richard as informed as she felt was appropriate. She was careful not to give him more hope than she herself had; he knew when that hope was diminishing and was told when his father's death was imminent.

Elizabeth was religious. Although neither she nor her sons attended church regularly, her faith in God and her use of prayer helped to sustain her through immense difficulties. The following passage indicates her belief that God had responded to her prayers when Ralph's death was imminent:

> **Elizabeth:** . . . So I went outside with a couple of girls and I prayed. I said, "Today's *(omit date).* I mean, this is Richard's birthday. Please don't let [Ralph] go today . . . if you take Ralph today, how are we ever going to celebrate Richard's birthday? - a birthday's a celebration." And I says, "Please, give us more time". We were given a month . . .
>
> (Case 1, interview 2)

Elizabeth stressed the importance of imparting her religious beliefs to her sons. She explains the appropriateness of introducing the concept of heaven to her children when their pets died:

> **Elizabeth:** . . . you know they always said, "Well where do pets go?" Like Richard's had hamsters and he's had birds. And I said, "They're all in heaven".
>
> **R:** Okay. . . . Heaven - he knows it as a place where they go.
>
> **Elizabeth:** I think it's right - I think it's the right thing to do by children. Not just to say, "Okay they're dead and they're gone". 'Cause that's too final. 'Cause then all of a sudden the kids all of a sudden associate life with that. And they just say, "Well when we die, that's it - gone. It's over". So you have to let them know that there's another place -
>
> (Case 1, interview 3)

As Ralph's health continued to deteriorate, the number of demands made of Elizabeth multiplied. She states that "I tried to be for everybody . . . [a] peacemaker and all this sort of stuff" (Case 1, interview 2). In the excerpt below, she discusses the effect of those demands:

> **Elizabeth**: . . . it was so hard on me because I - I couldn't give anymore. I gave as much attention as I could to Richard, to Robin, to Daddy, to everybody. And I was going - wow, there's not much left of me. And it was hard. . . . And now, I'm sitting back and I - I do go back to certain incidents and I think - well maybe I could have handled this differently. Maybe I should have gave more to Ralph. But I know - I know I gave as much as I could . . . I'm looking back at it now and I say, "Well, no, I gave to everybody". And I said, "I did not take time for myself, I really didn't".
>
> (Case 1, interview 2)

Some of the difficulties with which Richard's mother were confronted were financial. Ralph found the prescribed pain-killers insufficient and used alcohol to subdue his pain. He drank a 26 oz. bottle of hard liquor every day. Elizabeth relates her struggles to pay for Ralph's medication and the alcohol he demanded on a limited income:

> **Elizabeth:** . . . "Ralph", I said, "This is ridiculous, because the medication you're on, and the alcohol - the alcohol is taking away the effects from the medication". I said, "You've got to" - I said "It's not working". "Fine! Then

> I won't take my medication". So we did that too - he just drank, and then he was in **more** pain so I'd then have to get **two** twenty-sixes because the pain was so intense. . . . our family doctor just said, "Hey let him do it his way". . . . So we came to that agreement. I said, "But financially it's so hard on me. I can't deal with it."
>
> (Case 1, interview 3)

The hospice volunteer made the following comment on the relationship between the family's financial difficulties and Ralph's drinking:

> **Anna:** . . . even though Ralph was not a perfect husband by any means, [Elizabeth] still had love for him, so she'd never run him down. She got upset because rather than going and buying groceries he demanded the booze. So every day, she was having to go and buy liquor knowing that really, they couldn't afford it. That would hurt her. If it had been me - I would have *(sound and gesture of exploding)* - but see she didn't . . . as long as the children were getting . . . I don't think she ever spent any money on herself -
>
> (Case 1, interview 1)

Ralph's medication affected his hearing; he could not tolerate his sons' noise. Elizabeth would take the boys out of the apartment so he could have quiet. On one of their numerous visits to the amusement arcade in the local mall during poor weather, Richard revealed his understanding of the connection between his father's drinking and their financial difficulties. Elizabeth relates:

> **Elizabeth:** And it was heartbreaking when I'd say, "Richard, I've only got five dollars [for the slot machines]". I says, "So just - make the best of it", sort of thing. Because, I mean, I had a budget, and it was always hard 'cause Richard would say, "Other kids, they get ten dollars, they get" - whatever. And I'd say, "Richard, but they're not in the same situation". So he always, he knew that there was a money problem. And then he'd say - he'd come out and say to me - "Well Mommy, if Daddy didn't drink so much we'd have that money".
>
> (Case 1, interview 3)

Elizabeth and Ralph had decided that he would spend as much time at home as possible. Home care was interspersed with periods of hospitalization while he received treatments. Although some assistance was provided by home care nurses, the bulk of the caregiving fell to Elizabeth. In Ralph's final week, Elizabeth had to make "a lot of hard calls" (Case 1, interview 2). She had him hospitalized against his will. In the following excerpt, she explains her reasons:

> **Elizabeth:** This is the last road . . . the home stretch now . . . the ambulance is here at the house because I knew - this was it. He couldn't talk and he's falling constantly and it's just a mess. The kids have seen Daddy - all the time - and it's too hard. And I made that decision and I was - . He

> wanted to die at home but I said, "No, I'm not going to let this happen . . . I'm not having Richard and Robin see this".
>
> (Case 1, interview 2)

Elizabeth was concerned that her sons might become fearful of their home if they witnessed their father dying there. After arranging for their care and ensuring that they would be brought to the hospital each day, Elizabeth moved to the hospital so that she could "be with Ralph totally" (Case 1, interview 2). She shouldered responsibilities usually left to the nursing staff; she sat awake at his bedside through many nights. As she had intended, she was with Ralph when he died in the early hours of the morning. Later the same morning she drove to the house where Richard was staying to tell her son of his father's death.

Richard's mother was a keen and astute observer of her son's behaviour, and sensitive to his moods. The two interviews she gave provided a wealth of information about the child's feelings during the period that preceded his father's death. Elizabeth was also frank about her own difficulties through that time. The two different aspects of her experience were inextricably linked; the conversation wove back and forth between them.

The Themes

Elizabeth gauges how much and when to tell Richard

From the time Ralph was diagnosed with cancer, Elizabeth adopted a policy of openness with Richard that was congruent with how she had treated both her sons before Ralph's illness. She explains:

> **Elizabeth:** Everything that's touched their life I have to expand on as much as I can . . . many people will say, "Oh they're just a kid, they're just a kid". They're not just a kid. And that's the biggest thing that - respect is the whole thing.
>
> (Case 1, interview 3).

Richard was told when his father's cancer had recurred, when chemotherapy had failed, and when Ralph's long-term survival began to seem unlikely. Elizabeth picked times when she thought Richard would be receptive and judged carefully how much information to give him. She was respectful of the pace at which he dealt with his feelings about his father's cancer. At the same time, she addressed his tendency to shut himself off from his feelings by encouraging him to express himself and by showing him her own feelings. Elizabeth's discussions with her son entailed a difficult balancing act. The following passsage reveals the sensitivity with which she strove to achieve that balance:

> **Elizabeth:** . . . First it was hope for him. You could see there was hope, there. And I told him - I said, "Well Richard, [surgery] might work and it might not. And if it doesn't work, they've got radiation". So I had to explain what radiation meant. And I said, "The radiation will burn off these cancer cells. Kind of keep it at bay and maybe it'll keep it away completely. There's no guarantee or anything", I said, "I don't want to make anything too dismal, but I don't want to make it too bright either". I said, "We don't know what we're dealing with right now". I said, "When I know, I'll tell you". And I said, "And I'll just give you as much as can". And I did - I gave him only as much as I knew he could deal with. I'd watch the expressions, his feelings.
>
> **R:** You really gauged it very carefully.
>
> **Elizabeth:** It was hard!
>
> **R:** Elizabeth, how did you gauge his feelings?
>
> **Elizabeth:** Oh, I can read Richard very well. I can just see that he's getting kind of twitchy or he gets kind of -
>
> **R:** He gets fidgety?
>
> **Elizabeth:** Yeah. Or he'll just shut you off. "I don't want to talk about it". And he'll say it to you - "I don't want to talk."
>
> (Case 1, interview 2)

Elizabeth described numerous occasions when Richard had talked to her about his feelings. She learned to respect the point at which he chose to stop:

> **Elizabeth:** . . . if he wants you to know he's a little bit sad, he'll tell you a little something. And then he'll decide when he's had enough conversation with you. . . . He'll bring it up. And then I'll just say, "Okay, let's talk about that". And then he'll say, "I don't want to talk anymore. It makes me sad". So I say, "Okay Richard", and I stop. Because you can't keep plugging at him or pulling at him because he's not the - he'll shut the door.
>
> **R:** There's no point, right?
>
> **Elizabeth:** He'll just shut the door completely.
>
> (Case 1, interview 3)

Richard was reticent about showing his sadness in front of his mother, but Elizabeth knew intuitively when he was crying:

> **Elizabeth:** . . . I can't explain these feelings. It's a mother's thing, I guess. I just - I went - I didn't even have to hear the sound, but I knew. And I'd go in [to his room], and then sure enough, he was crying. And then he'd turn his head and say, "I want to be alone". And he'd get very angry -
>
> **R:** Oh, he didn't want -
>
> **Elizabeth:** He didn't want me to see him.
>
> (Case 1, interview 2)

During Ralph's final months, Elizabeth would cry at the hospital in Richard's presence. She describes his reaction the first few times this happened:

> **Elizabeth:** . . . he'd get so embarassed. He said, "Mom! Stop it!"
> **R:** Oh, really. He didn't want you -
> **Elizabeth:** I was building up so much - I had to be - on guard. So much time, I always had to have that big shield up all the time, protecting my children, protecting myself and not showing my emotions and - sometimes it was very difficult to keep it in. And he kept saying, "You're embarassing me. People are staring at you". I'd say, "Good, let them". I'd said, "If they say anything - they're ignorant Richard . . . this is a hospital. If they can't understand somebody crying, they have a problem." So he thought about that and then a couple of times it was okay for him, too. [Although that was] very rare.
>
> (Case 1, interview 2)

The following excerpt illustrates how Elizabeth encouraged Richard to cry when he was sad:

> **Elizabeth:** . . . you had to hold him - I talked to him at several points and said, "Richard, you've got to cry". "I don't want to cry". I said, "You do". Which was wrong, but I said, "You need to". I said, "I need to". I said, "We'll both cry together. "You go ahead, I'm not". I said, "Well that's okay, I will". And I did. "Go ahead," he says, "Like Mommy I'd don't feel to cry right now, I'm not going to".
>
> (Case 1, interview 2)

When Richard showed anger by hitting his brother, throwing things on the floor, or making loud noises that irritated his father, his mother encouraged him to express himself in less hurtful ways.

> **Elizabeth:** . . . And I told him, I said, "It's okay to feel angry. It's a natural normal thing". I said," Maybe I should go break a couple of dishes". And he said, "Would you do that?" And he was almost excited., And I said, "Well, I don't think I would, but I could". I said, "I'm angry". . . . I said, "It's not going to change the way Daddy is . . . but you do have anger to let out. I have anger to let out". I said now, "But right now I don't feel to. Maybe you do?" "But" I said, "I don't want you doing it that way". I said, "Do you want to go in your room?" I said, "You got a whole lot of those old plush things - like teddybears and all that - go beat them up. Punch your pillow, do something like that. But don't be really destructive - I don't like that".
>
> (Case 1, interview 2)

When Ralph's chemotherapy failed, Elizabeth explained the implications to her son, emphasizing the things that Richard and his father could still do together, and the ways in which he could help. Elizabeth prepared him for the difficulties ahead and the likelihood of his father's death with a mixture of care and caution:

> **Elizabeth:** . . . I explained to [Richard] that the chemotherapy didn't work and I said that - so Richard says, "Well what does that mean? How long does Daddy have?" And I says, "Well, in terms of how long, the doctors can't

> tell you and I can't tell you. I don't know." I said, "Richard, what we have to do is spend as much quality time with Daddy as we can." I said, "He'll be strong but then he'll be weak." . . . I did give him as much as he could take, without destroying everything for him.
>
> (Case 1, interview 2)

Richard's mother's openness and honesty with him about his father's illness was tempered by her concern that she not overload her son with too much information. Elizabeth did all she could to prepare Richard for his father's death. She normalized his feelings and underscored the necessity for him to express them. She was particularly concerned to help him channel his anger in non-destructive ways. Despite his mother's love, concern and understanding, Richard continued to struggle with intense feelings during his father's final months.

Richard's feelings, thoughts and behaviour

The different feelings that the adult participants saw Richard express through the final months of his father's illness ranged from anger through sadness to acceptance. The participants described his reactions to minor incidents that would not have troubled him before Ralph's illness. They also provided insight into the thoughts that accompanied some of Richard's feelings. They painted a picture of a child who had become more sensitive; more reactive; more prone to misbehaving.

At school Richard's initial reaction to his father's diagnosis was one of anger. He was involved in some fighting on the playground, although the school counsellor stated that they did not see a pattern of aggressive behaviour at that time. After a few months, Richard's behaviour levelled off; at a school-based team meeting in early 1992, it was decided that the school counsellor did not need to continue seeing him. Jane summarizes the team's discussion:

> **Jane:** . . . the teachers felt things were sort of okay, you know what I mean. He still wasn't achieving real well in school and he had this "stubborn streak", as they called it. But we felt he was okay.
> **R:** Doing okay, meaning it was contained and it wasn't -
> **Jane:** Yeah. There was no overt signs that he was distressed. He wasn't acting out or showing any signs of depression or, you know - he seemed to be coping.
>
> (Case 1, interview 5)

It was a year later, when Ralph's chemotherapy had failed and Richard realized that his father was not going to continue living that his mother, teacher and counsellor all reported him showing sadness in addition to anger.

The organization of this section according to Richard's different feelings allows the participants to speak to each feeling in turn. It gives an artificial impression for two reasons, however. The first is that Richard's feelings and his thoughts were inextricably linked. The second is that although all participants reported incidents when Richard expressed a single feeling, his mother also discussed occasions when his feelings ran together, with outbursts of anger leading to sadness and tears. The following passage gives an example of the tangle in Richard's feelings as his mother recalled them:

> **Elizabeth:** . . . Oh, he had tears in his eyes. He would not cry for the longest time. Those eyes would well up, but he wouldn't drop a tear for the longest time. And then he'd say - he was angry. He was very angry -
>
> (Case 1, interview 2)

The hope Richard had immediately after his father was diagnosed was followed by an extensive period when the predominant emotion he expressed was anger. In the excerpt given below, Elizabeth describes the relationship between his anger and his sadness:

> **Elizabeth:** The anger came - well I guess the anger came - I don't know, let me see - anger was there before the crying. Because the crying really - the crying came later because then the crying **changed.** Then he started crying for **nothing**.
>
> **R:** Oh, okay. So he was angry first -
>
> **Elizabeth:** Yeah. He was angry first. Yeah, angry, and he showed - he expressed all his anger in every which way he possibly could. You know, and instead of embracing, he pulled the other way, but that's normal. I assume that's normal.
>
> **R:** Like embracing you, cuddling up to you, is that- ?
>
> **Elizabeth:** Yeah. Or giving Daddy a hug. I mean, Daddy needed those hugs so desperately. I mean, he gave it to him throughout - when he went to the hospital, when he was at home and stuff like that. But there was other times that instead of being angry, he could have came and sat on the couch with Daddy. You know, talked to him, hugged him. But instead he would - just be angry. And you know, it's hard to talk about, but at the same token - when he would get that way, I would get angry back too.
>
> (Case 1, interview 2)

In the course of her interview, Elizabeth gave examples of occasions when she tried to defuse Richard's anger. The above passage represents the only indication she gave that there were times when she reacted to the anger he expressed with her own.

The participants portrayed a complex picture of a child who, on the one hand experienced strong feelings which simply erupted out of him, and who, on the other hand struggled to exert control by refusing to talk about those feelings. The participants described a pattern: periods of intense feeling alternated with periods in which Richard tried to shut his feelings off.

Richard's anger

The predominant emotion that all four participants witnessed Richard expressing was anger, although three of them also related occasions when he showed sadness. His mother indicates how his anger was related to his realization that his father was not going to live:

> **Elizabeth:** . . . Well you see there was anger when Ralph first was diagnosed with cancer. But [Richard] was not - bad. And then when he found out that Daddy was not going to be getting better, the anger, the true anger of losing his Dad took hold of him . . . he would say to Daddy. He'd say, "I hate you." But he wouldn't say, "Because you're leaving me". But that was there, and it would almost surface - I could see it. And he'd do things to get Daddy upset only because of the fact that he was angry. His Dad is leaving him. Now that's a common, normal reaction. So that's when the anger started to surmount and all that sort of stuff.
>
> (Case 1, interview 3)

Elizabeth also describes the changes she saw in her son's behaviour as a result of that anger:

> **Elizabeth**: There was a lot of swearing which he never, ever did.
> **R:** He didn't do the swearing before Ralph was sick?
> **Elizabeth:** Never, never, never, never. This is all brand new. And so I - I attributed it all to -
> **R:** This is about a year and a half after Ralph had been sick?
> **Elizabeth:** Yeah. It all started building. And he would do things to hurt Ralph, sometimes, like to show Daddy that he was mad that he was leaving. "You're sick. You shouldn't be sick - you're the man that should be going to baseball games, should be doing" - the difficulties with things that you can't do anymore. And he did need - a lot of things he would do just to irritate Daddy. Like Daddy would be on the phone - so he'd make a lot of noise. Knowing that Daddy's on the phone - well he knows better than to do that.
>
> (Case , interview 2)

In the following two passages his teacher discusses Richard's angry behaviour at school:

> **Jessie:** Well, I saw a lot of anger in him last year.
> **R:** Now is this right from the start of the year?
> **Jessie:** Right - I think right from the beginning . . .
> **R:** How did the anger show itself?

> **Jessie:** Well often he would do little things to misbehave. And other kids would try to be understanding to him, but he would, you know sort of reject them sometimes.
>
> (Case 1, interview 4)

> **R:** What sorts of things was he doing on the days when you felt, "This is not the real Richard"?
>
> **Jessie:** Well he would sort of try - he would pick fights with people over little things that didn't matter, that normally wouldn't have bothered him. And because he's an overweight boy, some kids in other classes would occasionally give him a bad time. So, you know, sometimes that was a problem. But usually, he dealt with that fairly well.
>
> (Case 1, interview 4)

The excerpt given below summarizes the days when Jessie found Richard "a difficult guy to handle" (Case 1, interview 4):

> **Jessie:** . . . there'd be the odd day when he would come in with a really **growly** look on his face *(both laugh).* And he wouldn't be very happy about the work he had to do.
>
> (Case 1, interview 4)

The counsellor discusses the discrepancy between the anger Richard expressed in his drawing and his lack of verbal acknowledgement of his anger when asked directly how he was feeling:

> **Jane:** . . . I saw him quite regularly, I think, through March and April [of '93]. . . . Dad was quite ill then. But mostly the referring problems would be aggression on the playground. And he'd get angry. And I remember one time he came in and he'd done some - he was very angry that week . . . he was just sort of lashing out and losing his temper . . . He came in and I said, "How are you feeling today Richard?". And - "I feel fine". And I said, "Well shall we draw, would you like to draw?" So he drew me this red car with - it had teeth, it was the angriest red car - I had it on my wall for the longest time. People said, "What a remarkable car". I mean this was so angry and yet his verbal response was -
>
> **R:** He was okay.
>
> **Jane:** "I'm fine", you know, "I'm just great", you know. So he wasn't in touch at all with what his inner -
>
> **R:** And yet his drawing expressed it.
>
> **Jane:** The art did, yeah. So I think art therapy would probably be, you know - a skilled art therapist would probably be able to work with him more effectively than someone who deals in words. 'Cause he certainly never talks about his feelings.
>
> (Case 1, interview 5)

The incidents the participants described showed that Richard was extremely angry during the period when his father was dying, and was struggling to find ways to express that anger that were both right for him and acceptable to the adults around him.

Throughout the course of his father's illness, Richard's feelings of anger came and went.

Richard's sadness

Elizabeth discusses how Richard would deal with his sadness both before and after his father's death:

> **Elizabeth:** When he's sad, he shuts himself in his room on his own. He'll just go in there quietly. Oh, he doesn't want to share his tears or his sadness with anybody. And you know, I let him have his time to himself. And then, when he's ready to come out, he'll come out on his own. And I'll say - you know, I won't bring it up - I'll wait till maybe he'll just give me a little indication and then we'll talk about it. But I have to pull it out. He doesn't offer it.
>
> **R:** Sadness is private for Richard.
>
> **Elizabeth:** It's very private. And he won't share it.
>
> (Case 1, interview 3)

In the above passage, Elizabeth also reveals her respect for her son's desire to keep his feelings of sadness to himself.

Richard's teacher mentioned a specific incident at school that upset him. She provides insight into Richard's thoughts as well as his feeling:

> **Jessie:** . . . I think he'd been playing with some of his friends at recess - they were playing soccer and something had happened. And he came back into the room, and he was in tears. Several times he was in tears last year. And I remember we went out in the hall, and he said, "Oh, I haven't got any friends. Nobody likes me."
>
> (Case 1, interview 4)

Jessie contrasted days when Richard showed anger with the following:

> **Jessie:** Or there'd be a day when you could tell he was really upset and he wouldn't be so much angry as his face would be red and he would be sort of - on the verge of tears. There were a few days like that, too.
>
> **R:** Oh, poor little guy!
>
> **Jessie:** And somebody maybe would have said something to him that just sort of set him off, you know. . . . Kids would inadvertently say something that would just, sort of, push him to the edge. Occasionally there were days like that, yeah.
>
> (Case 1, interview 4)

Although the frequency with which the participants reported Richard expressing anger is higher, it would be erroneous to conclude that the child spent more time feeling angry than sad. Elizabeth's description of him crying alone in his room and getting angry if she intruded reveals his attitude to his sadness. Richard was more willing to show his anger in public; he tried to keep his sadness to himself.

Richard's reluctance to talk about his feelings

Both at home and at school, Richard was reluctant to talk about either his thoughts or his feelings about his father's cancer. His mother discusses how he would express his anger, but refuse to tell her what had occasioned it:

> **Elizabeth:** I said, "Let's talk about what's going on. What do you really want?" And I'd say, "What is the matter?". And he'd say, "Nothing, nothing!" And I'd say, "Well Richard, you've got to talk about it". I said, "I'm hurting, you're hurting", I said, "But we're not getting anywhere because you're not telling me what's going on". . . . He didn't want to talk to me. He did not. And I'd have to - so I just kept talking, whether he listened or not.
>
> (Case 1, interview 2)

When Elizabeth followed Richard into his room after an outburst he would demand that she leave. The following passage reveals her concerns that he might hurt someone else by acting his anger out:

> **Elizabeth:** . . . He gets so mad at me. He'd say, "Get out of my room. I can't be alone. I can't do anything. You're in here". And I'd say - "But I have to. You cannot go around - you're like a time bomb. I don't know what's going to happen here". You know, it was true. Because I didn't know, and if he didn't say some of this stuff, he's going to work it out. And I don't want him working it out on somebody else, either. You don't know what's going to happen.
>
> (Case 1, interview 2)

Richard was also reluctant to discuss his feelings about his father with either his teacher or the school counsellor. The teacher recalls how she dealt with his refusal:

> **Jessie:** . . . [I learned to] talk about something that he's doing or something that he's interested in. So I **didn't** talk to him a **lot** about his Dad. . . . Because he didn't want it. He didn't want it. I know Jane tried to draw him out too, but he really didn't want that. It was like it was a closed door. And he just wasn't ready to open it.
>
> (Case 1, interview 4)

The school counsellor recalls how Richard continued to be reticent about his father's illness over a year after her initial sessions with him:

> **Jane:** I was available, if he needed help. And I saw him in December ['92] with another little boy, they both came in and we - I did some games and things with them and that sort of thing. And he was still unwilling to discuss death or talk about death.
>
> **R:** Okay, so did you ask and then - ?

> **Jane:** I would ask, you know. And I'd always get a closed response.
>
> (Case 1, interview 5)

Richard discussed his feelings with his mother, Elizabeth, more readily than with the school counsellor. Jane describes the circumstances that motivated Elizabeth to enlist her help in Ralph's final spring:

> **Jane:** In March [of '93] I got a phone call from Mom, and she wanted me to see Richard again. She said he was upset that the kids at school knew about his Dad. He didn't want them to know. And I think at that point Jessie had told the class that Dad was very ill because she wanted to help Richard, and he had had these aggressive behaviours and so on. Dad was very ill - at that point. . . . But he didn't want anybody to know. He had one friend at that point I think, Dean. And he didn't mind telling Dean, but he didn't want the kids to tease him. He didn't want to share it, he didn't want to talk about it . . .
>
> (Case 1, interview 5)

The above passage also reveals that Richard had one friend with whom he did talk. It was Dean's parents who looked after Richard during his father's final week in hospital. Jane had regular sessions with him during March and April of '93. She concludes the above passage by stating:

> **Jane:** . . . his way of coping was very much to deny and to - I never found Richard in touch with his feelings at any time that were open.
>
> (Case 1, interview 5)

Richard's cycle of thought and feeling

Periods when Richard was angry alternated with periods when he was sad. His mother describes the recurring cycle in his thoughts and feelings:

> **Elizabeth:** . . . he said, "Well it's not fair. My Daddy's dying - he's leaving me". He says, "Look at all my friends", he says. "You know, they all have fathers". I said, "Well Richard, maybe your little select group all have fathers" I says, "But there's ones that don't". And I said, "But you know they've learnt to deal with it". And I said, "You're going to have to deal with this too". He says, "But it's unfair". I say, "I know it's unfair". I said, "A lot of things are unfair, but you can't change [them]". And so it's - like I said, it's gone in cycles. He's up and then he's down. And then I have to pull him back up again.
>
> (Case 1, interview 3)

The situation was complicated by the fact that Ralph would also get angry at his son. In the late spring his father deliberately tried to make Richard hate him, in the hope that Richard would then miss him less when he died. Elizabeth voiced her opposition to Ralph's "foolish" plan (Case 1, interview 2), but there was a period of several months when Ralph acted on it . Elizabeth discusses the confusion in Richard's feelings that resulted. She also relates her own struggles to deal with his reactions:

> **Elizabeth:** . . . [Ralph]'d say things that he had never in his entire life had said - but *(unintelligible)* say a lot of mean stuff too, but this was his plan. . . . Richard would come in from school. And he would throw his bag down, and he'd walk in here and he'd kick off his shoes. And he'd just leave his shoes like this. And Daddy would say, "Richard, pick up your shoes", he says, "You know, you don't just kick them off, you know, you take them off at the doorway". And Richard ignored Daddy. And Daddy said - "You heard. Pick up your shoes - you don't act this way". And then Richard never responds so Ralph said, "Okay". And his plan would kick in and he would say, "You big fat cow" or he'd say, "Tub of lard" or he'd -
>
> **R:** Really insulting.
>
> **Elizabeth:** Oh, yeah. That didn't work. Well it did work. Richard would - went right to his room, slammed his door and cried and cried and cried. He says, "Mommy, Daddy's saying such horrible things". I said, "Richard, it's not Daddy", I said, "It's Daddy's cancer. It's affecting him", I said, "He's not thinking properly right now", and I said - "Think think think. He would never talk to you this way. Remember I told you", and I said, "You know, 'cause I sort of explained to you that the cancer did already go to his brain and all that" - but this was the hardest - this was out of control at times.
>
> (Case 1, interview 2)

The fact that Ralph was not consistent in his treatment of Richard through this period also affected her son, as Elizabeth points out:

> **Elizabeth:** But it was off and on. It wasn't constant. . . . So [Richard] got mixed up with these emotions and those emotions - and he's love hate love hate. It was hard. . . . Richard was very forgiving.
>
> **R:** So it all went in and out like - ?
>
> **Elizabeth:** Yeah. Well, a couple of times he wasn't so forgiving - when this stuff was happening, which was part of Ralph's ploy. Richard would go into his room and crying and screaming and then he'd say "I hate him. I hate him. I hate him". I'd say, "Why do you hate him?" He'd say, "Well look how he talks to me". I'd say, "Why do you hate him?" And he says, "I hate him because he's leaving". I'd say, "That's it". I wanted to hear it. I needed to hear it.
>
> **R:** You were digging it out of him.
>
> (Case 1, interview 2)

The above passage also demonstrates how Elizabeth persisted in helping her son to connect the feelings he was having with his father's imminent death, despite his reluctance.

Richard's use of food

Richard's problems with his weight were exacerbated by his father's illness. Elizabeth comments on the connection between Richard's use of food and his feelings:

> **Elizabeth:** And I have - you know, when Ralph was very very sick, Richard in the fridge, or the cupboard was his best friend. When he was sad with Daddy - like Daddy and him would have an argument *(voice goes up),* he would run to the cupboard and he'd go in there and get crackers. And it was so spontaneous - soon as Daddy got upset with him . . . he went to the cupboard. Cookies, crackers, now anything - it was food. That was his instant comfort zone. And that's normal for a lot of people. That's how they - they cope.
>
> (Case 1, interview 3)

Elizabeth was both tolerant and understanding of her son's use of food as a source of comfort during this period.

Richard demanding of his mother - Elizabeth gives in

Both the hospice volunteer and the teacher observed Richard being extremely demanding of his mother. Both indicated that she had shown forbearance in dealing with him. The hospice volunteer speculates that Ralph's behaviour towards his sons might have affected their relationship with their mother:

> **Anna:** . . . when [Ralph] was very, very ill - I mean this man was terribly ill - he sort of - couldn't tolerate the children so he yelled and screamed at them a terrific amount - and said terrible things . . . And consequently the children were - Robin particularly and I think Richard although Richard is not so approachable - was very clinging to their mother because of all this - that was going on with their father, they clung to her, so -
>
> (Case 1, interview 1)
>
> **Anna:** . . . [Richard] would not allow - let his mother out of his sight. He wanted her there the whole time. . . . But as I say, I don't know if that was any different because he might have been that way before.
>
> (Case 1, interview 1)

When the teacher invited Elizabeth to accompany the class on a field trip, she was delighted to accept. Jessie discusses Richard's behaviour that day:

> **Jessie:** Now I remember that we divided into three groups . . . Richard was in [Elizabeth's] group. And I remember he was quite whiney that day. When we were looking at different things at the *(omit location),* if he couldn't see he would complain and carry on. And I just sort of tried to ignore it. And his Mom would take him aside and talk to him for a few minutes. And again, the other kids were very tolerant, you know. . . . he was quite clingey that day . . .
>
> **R:** Do you think he was more clingey because she was there?

> **Jessie:** I think he was. I think he sort of needed that contact with her.
>
> (Case 1, interview 4)

Richard began to seek from his mother the kind of care he witnessed her giving to his father. He demanded that she do things for him that he had previously done for himself. Elizabeth relates one example:

> **Elizabeth:** . . . Richard started diverting the wrong way. I mean, he'd see me dressing Daddy - but Daddy couldn't. Well, then all of a sudden he got lazy - he's not getting dressed for school in the morning. I said then, "Okay Richard, if you don't get dressed then you're going to be late". [Richard would say], "I don't care". Well he did care. He'd start screaming - "Get me dressed, get me dressed". I said, "Richard, you're old enough to dress yourself. This is getting ridiculous". And I said, "You've got to dress yourself" . . . I said, "You're just being lazy". And it was. Or he was just seeing how much I could split myself up. 'Cause see I had to dress [Robin] obviously - he's a little guy. And Daddy - I had to dress Daddy too. But, you know, it became a problem . . .
>
> **R:** How did you handle it at the time? Did you - you know did you start -
>
> **Elizabeth:** I dressed him. I dressed him because I didn't want the frustrations. It's upsetting Ralph - Ralph couldn't stand the noise and so I had to -
>
> (Case 1, interview 2)

Elizabeth coped with Richard's angry outbursts by acquiescing. She also discussed how, on hospital visits she persuaded him to come upstairs after he had refused:

> **Elizabeth:** . . . I would spoil him. I would say, "Okay Richard, I'll get you some pop. Something so you can just sit there. You don't have to be part of the conversation". And I gave him things - I mean a lot of the time bribery just to go and stuff like that, which I shouldn't have done either, but . . .
>
> (Case 1, interview 2)

The hospice volunteer recalls an incident between Richard and his mother at the hospital:

> **Anna:** . . . he would get bored so he would bang the door - the room - and he'd bang it. And then - he would -
>
> **R:** Did you see this happening, Anna?
>
> **Anna:** Oh yes. Yes. Oh yeah. He just wanted attention.
>
> **R:** And what would happen? He's banging the door, he's -
>
> **Anna:** Elizabeth would take him down to the - cafeteria, and get him something to eat -
>
> (Case 1, interview 1)

In the interests of keeping the peace and minimizing overt conflict, Elizabeth offered Richard food he liked, and gave in to his demands if she possibly could. Richard in turn became accustomed to having the demands he made of his mother met. Elizabeth was unable, however, to provide Richard with money she did not have; when he asked for things she could not afford to buy, she was forced to refuse.

Richard accepting of Ralph's illness and helpful to him

Once Richard had learned that Ralph's chemotherapy had failed, he had periods when he was more accepting of his father's illness and tried to do things to help him. His mother recalls:

> **Elizabeth:** . . . I explained those things to him [about chemotherapy] and then when - I know he accepted it. . .
> **R:** Okay. So how do you know he accepted it? How did he let you know that - ?
> **Elizabeth:** Well, just by the way he responded to me and to Daddy. The way he responded to Daddy. He - he went willingly. Like if I said you know, like, "Daddy's having a bad day today". Then he'd go and he'd say, "Daddy, can I get your slippers?", or "Daddy can I - would you like this?", or " Would you like the - want a glass of water?". Daddy had a big thing for water.
>
> (Case 1, interview 2)

Elizabeth gave examples of days when Richard was loving and warm to his father.

> **Elizabeth:** . . . You know, and days he was with Daddy, like, when he was [not angry] it was wonderful to watch them connect. I mean, it really was. I mean, you could see Richard just trying to hang on to something. You knew he couldn't, but then the days he wasn't, he was angry . . .
>
> (Case 1, interview 2)

In this passage his mother also addresses a recurring theme in her interviews: Richard experienced many different feelings, none of which were to last long.

During his final months Ralph spent more time in hospital. Richard asked to visit alone with his father on several occasions. His mother explains:

> **Elizabeth:** . . . And there was times that he had quality time with Daddy - but he kicked me out of the room. "I want to be alone with Daddy". . . . Oh, that's a riot.
> **R:** I wouldn't have expected that from what you've just told me.
> **Elizabeth:** Oh yeah.
> **R:** Is there one of those times that sticks in your mind?
> **Elizabeth:** Well, the one that's closest to the end. Well, there's two of them - but one in particular - it was just Richard and I went. We got a babysitter, a babysitter for Robin. And we got up to the room, and Richard insisted, "I'm going to the room first". I said, "Okay, fine". So he went in first and gave Daddy his kiss first. Like Mommy always kissed Daddy, so he gave Daddy the first kiss. And then Daddy's asking me questions and I'm talking to him and something and Richard said, "Mom would it be too much to ask that I spend time with Daddy and you go away?" . . . "Mommy, you go down to the cafeteria" and he says - "Go have

something for yourself and then bring me something back, but take your time".

(Case 1, interview 2)

Driving home afterwards, Elizabeth asked her son how he thought his visit with his father had gone. She relates Richard's answer:

> **Elizabeth:** . . . He said, "Well, good. And you know what I"d really like?" I said, "What's that?" He said, "Would you drop me off and go home, and come back and get me?" And I started doing that. See he'd already got over a lot of that anger, and now he's dealing with it.
> **R:** So when was this happening? This is extraordinary. I wouldn't have expected this from what you've told me. Is this right near the end?
> **Elizabeth:** Yes, near the end. Well - April - or March, April. *(Works out details)* I would say in April this had started. [Richard] knowing that [Ralph] doesn't have much time . . .

(Case 1, interview 2)

As Richard accepted that his father was not going to go on living, he sought opportunities to spend time with him in an effort to become more closely connected to him. Elizabeth explains in the above excerpt that this could not have happened any earlier; Richard had to deal with his anger first.

Childcare

During Ralph's stays in hospital, Elizabeth experienced great difficulty obtaining childcare for Richard so that she could visit her husband. There were occasions when she was forced to bring her older son to the hospital with her although he did not want to come. Elizabeth discusses her conflict between Richard's periodic reluctance to visit the hospital and her need to spend time with Ralph:

> **Elizabeth:** . . . it was a tug of war. Richard would say, "I'm not going to see Daddy." And I'm at the hospital. And I say, "You've got to come up and see Daddy". Well, he doesn't have to, does he?
> **R:** No.
> **Elizabeth:** So, I'd be watching out the window.
> **R:** There was no other place for him.
> **Elizabeth:** No, there was days he didn't want to be there. But I had no choice. I mean, I had all these - I had already run out of all my resources. I couldn't afford babysitters all the time . . . because Ralph wanted me at the hospital all the time. But - no - plus favours from friends - they would look after - I mean they'd only do it to a certain point, too . . . [So] I'd be looking out the window watching Richard. He's in the car, he's out of the car, he's standing around. And I couldn't stand it because I had to be there with [Ralph].
> **R:** You were torn.

Elizabeth: Yeah, it was so hard.

(Case 1, interview 2)

Elizabeth stated that the availability of free childcare on the hospital premises would have resolved her conflict with Richard. In her words:

> **Elizabeth:** But I wish they had even at the hospital just *(unintelligible)* for the kids to go to - without even coming upstairs to the room, you know. . . . That way they're there, but they don't have to be confronted with the situation if they don't wish to be. . . . So that would have been a nice idea . . . because I'm not the only one - I mean, other people that - you bring your kids and all of a sudden they don't want to go. Or they go upstairs and then they're so noisy, because they don't want to be there. . . . Volunteers - to look after your kiddies for you, would have been wonderful . . .

(Case 1, interview 2)

Elizabeth had been the primary caregiver for Richard since he was born; Ralph's illness did not necessitate a change in caregivers for her son. The issue of childcare became acute when Ralph was hospitalized, and Elizabeth could no longer look after her sons and Ralph at the same time. Having decided that her place was at her husband's bedside through his last days, she had her neighbour look after Robin; Richard stayed with Dean, his friend from school. Although she saw her sons each day at the hospital, Elizabeth rarely left Ralph's room. Neither Richard nor Robin had previously been away from their mother overnight.

Normalcy

Throughout his father's illness, Richard relished opportunities to take part in normal activities; going to a movie or a restaurant with his father when he was well enough, playing soccer with the other boys at school. In the spring of 1993, after Elizabeth had told Richard that Ralph's survival was unlikely, she encouraged him to do things with his father and facilitated their outings by providing transportation, as Ralph could no longer drive. On Father's Day, Ralph and Richard went on a fishing trip together despite the hardship this entailed for Ralph. Of the special times they had together, Elizabeth recalls:

> **Elizabeth:** . . . I said, "Whenever Daddy is feeling good we're going to take advantage of it - we'll go places". And I said, "If you want it to be the family - fine. If you want it to be you and Dad, that's fine too". . . . So, it was always him and Daddy - they would go to different things together. . . . Richard insisted on that time with him, which was good. I'm glad

he did.

(Case 1, interview 2)

The interviews with the teacher and counsellor revealed that Richard regarded school as a refuge from the day-to-day trials of his home, a place where he could engage in a variety of activities with other children. Jessie discusses Richard's attitude to school:

> **Jessie**: . . . lots of days I did feel that he was glad to come to school.
> **R**: Oh really
> **Jessie**: To sort of be removed from the situation.
> **R**: How did he show that? Was he - how did you know that he -
> **Jessie**: I don't know - it's just - sometimes the way he came in the door, he'd sort of look kind of relieved and - you know -
> **R**: Un huh. So it was just - it was the look on his face.
> **Jessie**: Yeah. I would say more a look on his face. 'Cause there were lots of things that we did in class that he really enjoyed . . .
>
> (Case 1, interview 4)

Not only did school provide Richard with the opportunity to simply be a child, it also provided occasions when his mother could spend time with him temporarily freed of numerous other demands. His teacher discusses the importance to Richard of his mother's attendance on the class field trip mentioned earlier:

> **Jessie:** . . . It was good for [Richard] to know that his Mom cared enough to come, and basically - you know. 'Cause they see a lot of other parents coming to this and that. And he probably thought sometimes, "Oh, I wish my Mom could come but Dad's so sick - she's got to stay home", sort of thing. And that day he felt good that she could come too.
>
> (Case 1, interview 4)

In the light of her understanding of Richard's need for school to be different from home, the teacher discussed the importance of creating a safe environment at the school for all children. Jessie returned to this point several times, emphasizing that she saw the creation of a "safe haven" (Case 1, interview 4) as an essential task for teachers, and one she shared with other staff. In her words:

> **Jessie:** . . . But I think most people on our staff, you know, sort of give their kids that feeling too. That, you know, this should be a safe haven, sort of thing. Like I say - lots of days, I felt like it was a haven for him. So he could sort of . . . push it all back. What was going on with the illness and the worry, back, in his mind for a while.
> **R**: And be a kid.
> **Jessie**: And be a kid. And even if he was a naughty kid sometimes, fair enough. Everybody's got to let their hair down.
>
> (Case 1, interview 4)

In this excerpt the teacher also reveals her understanding of and tolerance for Richard's periodic bouts of misbehaviour.

In the following passage, the counsellor expresses her conviction that Richard's reluctance to discuss his father's illness with her was directly connected to his view of school as a refuge from his worries. Of her sessions with him, she states:

> **Jane:** . . . he always would want to take charge, you know when he came in . . . And I think that was part of it is that he would do what he wanted, or say what he wanted and he didn't want to necessarily be unhappy. I think he sort of thought of coming to me as a fun thing, an escape thing, a nice light experience. So that may have detracted from it. And as I say I don't really see the school setting as place for grief therapy and I never pushed it.
>
> (Case 1, interview 5)

It would appear that Richard's attitude towards school limited the use he made of the support that his teacher and counsellor extended towards him. Although they both made clear to him that they were available, Richard rarely chose to discuss the difficulties of his home situation and his worries about his father with either of them. It seems that his desire to participate in normal school-based activities almost always outweighed any inclinations he might have had to talk about his father's illness at school.

Schoolwork

Richard's teacher thought that the minor problems he encountered with schoolwork in the year she taught him were similar to those of other boys his age, and were unrelated to his father's illness. She states:

> **Jessie:** There were some days when he had a struggle to get his work finished on time, I recall. But I don't really think that that had anything to do with what was going on at home. I think that that's just Richard. You know, that sometimes - he would daydream. Well lots of kids do . . . and I think that in lots of ways he was a typical grade three boy. That he didn't always organize his - like his desk would sometimes be an absolute mess. He had a hard time organizing himself and his possessions and get[ting] things completed on time. But - look at some of the desks in the class now - it's the same story. So that's not unusual for kids this age.
>
> (Case 1, interview 4)

In the following passage his teacher explains that Richard's difficulties with reading predated his father's illness:

> **Jessie:** . . . the learning assistance teacher, who had him everyday for learning assistance - 'cause she would see him firsthand every morning, and know whether he was going to have a good day or a bad day just from little things that happened. 'Cause he was having a struggle with reading, you know, and has had for a while. . . Right from grade one - that he's had some learning assistance, you know, to help him with his reading. He's not really low, at all. But he's, you know, has problems with some areas.
>
> (Case 1, interview 4)

The teacher did not observe any dramatic changes in Richard's schoolwork in his father's final months of life; the slight drop she did see in the last month of the school year she did not think unusual. Other children too, she stated "do slip in June because . . . the year is just that much too long" (Case 1, interview 4). It is likely that Richard's continued ability to perform well academically related to his expectation that school was a place in which to carry out normal everyday activities.

Richard's last visits with Ralph in hospital

About two months before he died, Richard's father abandoned his plan of trying to make Richard hate him and became warm and loving towards his son once more. At the same time, however, he began to ignore Elizabeth. She explains:

> **Elizabeth:** . . . Well now I got shut out. **I got shut out of this.** . . . he wouldn't talk to me *(voice goes up).* Days'd go by and he wouldn't talk to me. Richard would walk in [and Ralph would say] - "Hi sweetheart. Come in honey. Tell me how you had - what kind of day you had" *(said gently and lovingly)* . . . And, you know what was really bad - this was - I guess it was in - this was in August, yeah August. It was [Ralph's] - the last week before he died. And Richard begged Daddy to talk to Mommy.
>
> (Case 1, interview 2)

When Elizabeth hospitalized Ralph in his last days she was breaking the agreement, albeit out of concern for the welfare of their sons, that they had previously made that he would die at home. Ralph showed his anger by refusing to respond to her. Elizabeth describes how, at the hospital, Richard attempted to mediate between them:

> **Elizabeth:** . . . I tried to talk to Ralph - he refuses to talk to me - and I'm getting upset, because I mean, I've done everything and all of a sudden its to no avail. I said, "Richard", I said, "You talk to Daddy". I said, "I don't know what to do". So I went [out] in the hall there. . . . So here's Richard, standing beside the bed. And Dad said right away - he wouldn't talk to me, nothing - and he says, "Hi Richard", he says,"Sweetheart". He says, "Come on, sit down with Daddy" and he says, "I love you son" and you know, they get on *(cries).* Anyways - that part's hard *(cries).* . . . He says, "Richard, I love you. Daddy's sorry he's sick. There's nothing I can do

> about it". He says, "But Daddy's always loved you", and he told his son he said he was sorry for hurting him. And then Richard says, "Well okay Daddy". *(Elizabeth is speaking very slowly through tears.)* And then Richard says, "Daddy, but, you know, you're hurting Mommy. You know, you can't do that." He said, "Mommy's **always** been there" - he says, "you won't have Mommy - just talk to Mommy". . . . Please, just talk to Mommy when she comes in".
>
> (Case interview 2)

Ralph, however, would not talk to Elizabeth when she returned despite his son's pleas. She states:

> **Elizabeth:** . . . [Richard] says, "Daddy why are you being mean to Mommy? Talk to her". He says, "You can talk - you talked to me". And [Ralph] says - "Well there's nothing to say".
>
> (Case 1, interview 2)

Richard has memories of his father being extremely loving and warm to him in his last days. What it was like for Richard to act as the mediator between his distraught mother and his dying father can only be surmised.

Richard had a final visit with Ralph later the same week. Dean's parents, with whom he was staying, brought him to the hospital at Elizabeth's request. The following excerpt from fieldnotes explains what happened:

> When Richard got to the hospital, he at first refused to see his father at all. Elizabeth insisted - she said, "It's your last chance to say goodbye Richard, and if you don't go in and do this, you will regret it for the rest of your life." Then Richard agreed to go in, but only if all the other people who were in the room with his Dad left. . . . He was alone with his father for about half an hour. . . . Ralph on that last day managed to talk to Richard, but he talked to nobody else.
>
> (Fieldnotes - Case 1, interview 2)

Through Ralph's final days, Elizabeth continued to treat her son with the same spirit of openness and honesty that had informed her attempts to explain his father's diagnosis of cancer to him two years earlier. She ensured that Richard was not only given the opportunity to say goodbye to his father, but also that he understood the significance of that opportunity. She conveyed her respect for Richard's wishes by clearing the hospital room of Ralph's friends and giving her son the time alone with his father that he requested.

Support for Richard

Throughout the period when his father was gravely ill with advanced cancer, Richard's mother Elizabeth provided the primary source of support for him. The constancy of her concern and the quality of care she provided for him were embedded in almost everything she discussed in her interviews. The parents of Richard's friend Dean provided short-term support by looking after him during his father's final week. Richard derived significant, ongoing support from the school, particularly from his teacher, the school counsellor, the principal, the learning assistance teacher, and his classmates.

His teacher describes Richard's relationship with the other boys in his class:

> **Jessie:** . . . some of the boys he played with stuck with him through thick and thin.
> **R:** Oh, really.
> **Jessie:** They were really very understanding boys . . . They were 8 and some of them had turned 9. Most of them were 8, yeah. So - you know, I had a lot of boys in my class last year. And while they did typical boy things and got into trouble, and scrapped every so often and all the rest of it, when it came right down to it, they were a pretty understanding, kind-hearted bunch of boys. . . .
>
> (Case 1, interview 4)

Jessie discusses how she took the opportunity afforded by Richard's absence one day to explain to his classmates that his worries about his father might make him more irritable with them:

> **Jessie:** . . . I remember saying, "Just back off. Don't stop being his friend, because he needs you more than ever, but don't get on his case about things because he's really having a tough time." And they accepted that quite readily - so - .
> **R:** That's really good, with that age group.
> **Jessie:** Yeah. It's surprising what kids that age can understand, yeah.
> **R:** So, I get this picture that he had friends who stuck by him even though he was difficult.
> **Jessie:** Yeah, he did. He did, even though he was difficult sometimes.
>
> (Case 1, interview 4)

After discussing the support both she and Richard had obtained from the school counsellor, Jessie made the following comment about the principal's role:

> **Jessie:** . . . and actually, our principal too was a very supportive person. . . . And very understanding. So you know, if - often he would talk to Richard in the hall too, so, yeah 'cause he's very soft-hearted. For kids that have got problems, like Richard had . . .
>
> (Case 1, interview 4)

The following passages illustrate that support for Richard was also apparent in the way Jessie and the learning assistance teacher adjusted the demands they made of him:

> **Jessie:** . . . And - lots of days I felt, "Hey this isn't the real Richard at all", but you know how would I act if I was - if I was in his shoes? So I tried to be

really fair. And I still demanded work from him, but I tried to, you know, be fair about it.

(Case 1, interview 4)

Jessie: . . . [The learning assistance teacher] was - she was very understanding, too, and she tried to be accommodating and tried to be fair, but still not let him off the hook as far as work . . . She still expected to him maintain, you know, a good standard of work.

(Case 1, interview 4)

Towards the end of her interview, the teacher again emphasized that the school staff "really tried to make allowances for [Richard], because it wasn't a normal situation for a kid to be going through at his age (Case 1, interview 4).

Several times the teacher reiterated her conviction that schools needed to provide a consistent environment, a "home away from home" in which children like Richard could feel "safe, secure, wanted and loved" (Case 1, interview 4). She discusses her own feelings of inadequacy when confronted with Richard's situation:

Jessie: There were times when I felt a bit frustrated, you know, because I thought, "Oh what can I do, to help you?" But you know, short of putting my arm around [him], or giving him a little pat as I went by - we're not really supposed to be even doing that these days - but let's face it - that's the thing that some of these kids need the most.

R: Yeah - they need the touch.

Jessie: They just need somebody to come and put their hand on them, with love, and know that things are okay.

(Case 1, interview 4)

In the following two excerpts, both the teacher and counsellor describe how other members of staff also contributed to the highly supportive school environment:

Jessie: The previous teacher had talked to me about [Ralph's illness]. I don't remember that Elizabeth really said very much, because she just assumed I knew. His previous teacher was good about filling me in as much as she could, 'cause she's really a caring person, too, And the principal too was aware of it, so -

R: So you all watched over him, you know.

Jessie: Yeah. We tried to, because that's the kind of a staff we've got. . . . you know, we didn't make a big deal about it, but everybody on the staff really tries to pull together, so it really helps.

(Case 1, interview 4)

Jane: . . . I think the school have been very supportive to Richard. I think he's been very fortunate in the teachers he's had, and . . . I think this particular school, my sense is that it's a very together school, and the staff are together and they're very caring people and so it's a climate where a

> child that's experiencing a loss can feel supported.
>
> (Case 1, interview 5)

In addition to the inestimable support he received from his mother, the school provided Richard with a continuous and reliable source of support. School staff made it clear to Richard that they were available if and when he might choose to come and talk to them.

Additional services for Richard

In the following excerpt, the hospice volunteer stressses that if additional services had been available to Richard outside the school or the home, he would have refused to accept them:

> **R:** . . . how could it have been different for Richard during the period when his Dad was dying? What sorts of services might have been able to help him - had they been there?
> **Anna:** I don't think that there - I don't think that Richard would have accepted -
> **R:** Oh, okay. He wouldn't have taken help even if there had been anything.
> **Anna:** Because he just wants his mother.
>
> (Case 1, interview 1)

Consistent with Anna's opinion, Richard refused to attend a local grief group for bereaved children when Elizabeth tried to take him after his father's death.

Conclusion to Case 1

The four participants in Case 1 together presented a complex portrait of a child struggling with the powerful feelings he experienced during the period when his father had advanced cancer. Richard's behaviour was often a direct reflection of the conflict in his feelings. Despite extensive support from his mother and from the school, the difficulties he encountered during this period were profound. No one feeling Richard expressed was permanently dealt with; anger would give way to sadness only to be experienced again later. Richard was also affected by the issues of childcare and finances with which his mother was struggling as a direct result of his father's illness.

It was crucial to Richard that he have a place in which he could escape from the numerous difficulties he confronted in the course of his father's illness, and simply be the nine year old boy that he was. Both the teacher and the school counsellor asserted that school had provided the safe haven that Richard needed - an essential counterpoint to the relentless predicament of his home situation.

Chapter 6

Results: Case 2

Background Information

The child in Case 2, Graham, is a six year old boy who was in grade one at the time of his mother's death. Graham has one sibling, a brother Lawren, two years younger, who has a neurological disorder that has necessitated special attention and medical care since his condition was discovered within a week of birth. Lawren was in hospital for the first six months of his life. Graham is in good physical health and has no medical problems. The participants perceived Graham as a timid and anxious child, who had high expectations of himself and was easily frustrated.

Graham's mother and father were both Caucasian: both left their families of origin in other countries when they emigrated to Canada as adults. The father, Paul, has two grown daughters from a previous marriage; the mother, Christine had also been married before but had no other children. Several participants remarked that Christine had been extremely intelligent, an athlete who had later returned to university for her degree. Paul is a highly qualified professional who had met Christine when they were working for the same communications firm.

The children were born when their mother was in her thirties. Christine continued to work until the birth of their second son, Lawren. She was diagnosed with cancer when Lawren was six months old. At that point, the family began to employ nannies to help Christine look after the two children because, as Paul put it, "[she] could not cope, you see - it was impossible" (Case 2, interview 2). During her final autumn, Christine went into hospital a few times for brief periods, but lived at home until her last week of life. She died in hospital approximately four years after diagnosis. Graham had not experienced the previous deaths of any other family members.

In contrast to Richard in Case 1 whose background is working class, Graham is from an upper middle class family. They had lived for several years in a roomy older house on a tree-lined street in a prosperous neighbourhood profuse with well-kept lawns and lavish gardens. The school Graham attended was small, situated close enough to his home that he and his mother often walked there together during her final autumn.

As with the family in Case 1, the family in Case 2 was fairly isolated. Christine's and Paul's immigration to Canada as adults meant that the support close relatives might have provided was not available to them. Most of the friends they had had before Christine was diagnosed with cancer had disappeared afterwards. As she had explained to her friend Jan, "They just can't handle it" (Case 2, interview 4). The family derived support from several neighbours, Paul's older daughter from his previous marriage, a couple of personal friends, the nanny, hospice volunteer, Graham's teacher, and the mother of a friend of Graham's, who also became a good friend to Christine herself. Christine's siblings visited from overseas immediately before her death and stayed for a short time afterwards.

The Participants

Case 2 is comprised of interviews with 5 different participants: the nanny (Ashley), the hospice volunteer (Sue), the mother of a friend of the child (Jan), the school teacher (Sarah) and Graham's father (Paul). I will discuss the professional background and responsibilities to the family of the first four participants and will examine the amount of contact all five had with the child.

Nanny

Ashley, the nanny began working for the family in the summer immediately preceding Christine's death that autumn, and stayed on until the following spring in order to provide continuity for the children. In her early twenties and recently married, Ashley had taken a year off university to support herself and her husband while he completed his studies. She has since returned to university to complete her own degree. The nanny struck me as highly sensitive, with a strength and determination I thought unusual in one so young. In the following excerpt she describes her first meetings with the family:

> **Ashley:** I had two interviews with them; one just with her and then one with her husband there as well. And she was just - I was very nervous around her, because she was just very poised and dominant and strong. . . . she wanted to get someone really good to be with her kids. But then in the second interview she sent the kids out of the room and she told me that she had cancer. So - but I didn't know it was terminal.
>
> **R:** That was amazing that she let you know right then. Like that was - what was that like for you sitting there?
>
> **Ashley:** I found, and I think when she phoned me up the next day and told me that I'd gotten the job, I felt - what happened was I responded very well.
>
> (Case 2, interview 1)

Ashley lived out, but worked in Graham's home each weekday from 8:30 a.m. to 5:30 p.m. She describes her experiences during her initial weeks with the family:

> **Ashley:** . . . there was a lot of stress, not between Christine and I, but on me when I first started because . . . she wanted things just so with the children and she was very watchful. And she was always there, like because she wasn't working, it was like she was always in the house and she would watch me with them or she'd be upstairs, so I'd always have this pressure . . . It was really hard to take just because I knew, because I respected her so much and I wanted to do well.
>
> (Case 2, interview 1)

Trust developed gradually between Graham's nanny and his mother. In mid-autumn, they began to talk more openly with each other about the differences in their characters, as Ashley describes:

> **Ashley:** . . . [Christine] said she would notice that I worked much better when people needed me *(laughs, then both laugh).* . . . we figured out that she hates to need and I need to be needed *(both laugh)*.
>
> (Case 2, interview 1)

As Christine's condition deteriorated, Ashley volunteered to take over more of the household tasks. Christine relinquished her responsibilities with considerable reluctance, and voiced the following concern:

> **Ashley:** And she was just like, "Now is this too much for you? You're here for the kids. I don't want you to lose your energy for the kids" (Case 2, interview 1). That was her main worry, was the children. She was very stressed out all the time.
>
> (Case 2, interview 1)

As the autumn wore on, Ashley began to stay a little later in the evening to prepare dinner for the family before she left. She describes Christine's response:

> **Ashley:** . . . she always made sure I was out by six because she didn't want me to get tired *(voice goes up).*
>
> **R:** . . . she was really gauging how much time and energy you put into the work - and she didn't want you doing a lot for her and taking away from the kids.
>
> **Ashley:** She was concerned over the children. . . . That was her most top priority was the children. Top priority, through and through, you know.
>
> (Case 2, interview 1)

The nanny's experiences with Christine reinforce the composite portrait painted by the participants of a woman who fought to retain as much control of her life as she possibly could for as long as she could, and who continually placed her children's needs first.

When Christine learned that her cancer had metastasized she offered to release Ashley from her commitment to the family. Ashley describes their conversation:

> **Ashley:** . . . she was crying. She told me [the cancer had spread] and she just said, you know, "Are you going to be able to handle this? Do you still want to stay on? I'll understand if you want to leave". And I told her, "I will stay". And yeah, I was starting crying. And so I told her I would stay. . . . By then we'd spent a lot of time talking. I just really felt a lot of respect for her *(voice goes up)* . She taught me a lot, you know. She was a good Mom - very good. And I knew how much she loved [her children] . . .
>
> (Case 2, interview 1)

The nanny was profoundly affected by Christine's illness, her impending death, and the predicament of the two children. Christine in turn was thankful for the dedication and skill with which Ashley worked with her sons, as the hospice volunteer relates:

> **Sue:** . . . she would talk about how wonderful Ashley was with the kids. . . . she was very - very appreciative and knew that she couldn't do it without Ashley.
>
> (Case 2, interview 3)

The hospice volunteer revealed that Christine understood that her illness made Ashley's position an extremely demanding one:

> **Sue:** . . . [Christine] was aware of the double role that Ashley was performing. I mean [Ashley] at some level, [she] was there for the kids but, you know - she knew about Christine too, although Christine didn't talk to Ashley that much at the beginning. At least, that was my understanding, was that she was the nanny for the kids. But at the same time, you know, when you're in a house, you can't help but -
>
> (Case 2, interview 3)

The mother of Graham's friend also commented on the difficulties of Ashley's situation:

> **Jan:** . . . Frankly the demands on Ashley were *(shakes her head in gesture of incredulity)* - I mean being in that situation day to day and as close as she was with the sensitivity she has. It was very draining for her.
>
> (Case 2, interview 4)

Ashley's exceptional level of dedication to the two children was motivated, at least in part, by her respect and admiration for their mother. Although she had responsibilities for both children, much of her energy and time was devoted to engaging Lawren, who was developmentally delayed, in learning activities. Ashley's descriptions of her daily interactions with Graham and her insight into his feelings and behaviour provided the backbone of information about the child from which this case-study developed.

Hospice Volunteer

Sue, the hospice volunteer is an elementary school teacher who had been on temporary leave from teaching the year she visited Christine. She had become interested in hospice work following the death of a family member. Sue was close to Christine in age, lived nearby and had two small children of her own. This was one of her first hospice placements. She visited Christine from September until her death in the late autumn. Sue exuded an air of practicality and efficiency, answering my numerous questions with an edge of curiosity mixed with complete frankness about what she didn't know. Although she had had limited contact with Graham, she provided invaluable insights into the extraordinary determination possessed by his mother, whom she described as fighting "tooth and nail" (Case 2, interview 3). She also reiterated comments made by the other participants that Christine had been a very private person. In the following two excerpts she describes her relationship with Christine and the frequency of her visits:

> **Sue:** . . . I just felt very connected to her the very first time that I met her. And we talked a lot about kids . . . see that was our commonality. Because our kids were so close in age. . . . [And] we talked about meals and you know, just - yeah, just chatting away.
>
> (Case 2, interview 3)

> **Sue:** . . . [Christine] just wanted someone to go out for tea with, or someone just to talk to. Someone that was unrelated to her cancer, she was just tired of the cancer. So that worked out well, 'cause we would just - I was available anytime, basically.
>
> **R:** So would she call you and go out?
>
> **Sue:** Yeah, she would call me and I usually touched bases with her. . . . And she just lived *(gestures)* . . . so it was perfect. So I could just sort of nip over and take her somewhere she needed to go.
>
> **R:** . . . How many times a week would you see her?
>
> **Sue:** Well I'd see her [a] couple of times a week. It varied . . . it really depended on how she was feeling, what her needs were. Yeah, so there wasn't any . . . it was very flexible. Sometimes it was morning, sometimes it was afternoon.
>
> (Case 2, interview 3)

Sue usually visited Christine in the daytime when both children were at school. She only met Graham once. She did recall seeing his books and remembered Christine telling her that he was learning to read. The hospice volunteer also assisted her in planning Graham's sixth birthday party. Sue's responsibilties, however, were specifically to Christine rather than the children.

Sue's description of her final visit with Christine in hospital a few days before she died reveals Graham's mother's overriding concern for the well-being of her sons:

> **Sue:** . . . she said to me, "I'm dying". And that's the first time she's ever said that. And she was sort of going in and out and she said, "My children are looked after". And that was her key thing - and I think up until then she

didn't feel that everything was quite right for them.
(Case 2, interview 3)

As the following passage makes clear the hospice volunteer found visiting Graham's mother extremely rewarding:

> **Sue:** . . . it was quite - it was a wonderful - it was wonderful being with her. . . . I felt very - I mean, how could you not sort of be empowered yourself *(laughs gently)* by this courageous woman?
> (Case 2, interview 3)

Mother of Graham's friend

Jan, the mother of one of Graham's friends, is, in her words "an older Mom" (Case 2, interview 6), a professional who had periodically worked part-time since the birth of her son, Ross. He attended the same school as Graham, but was one grade ahead. Jan spoke slowly and deliberately, with a sense of confidence that lent weight to each word. She was firm about structuring the interview in a way that made sense to her and explored the development of her friendship with Christine before discussing her relationship with Graham and her son's friendship with him.

Christine had made the initial overture to Jan the previous spring. She had heard Graham talking about his new school-friend and had met Ross when he had asked to join a ball game she was playing in the schoolyard with her son. When Christine asked if the two boys could visit, Jan was open to the idea. As she put it, "I was looking for a friend for my son, too" (Case 2, interview 4). The two women and their sons got together a few times that spring, but it wasn't until the autumn, when the boys were again seeing each other regularly at school, that the friendships between the two women and the two boys flourished.

On their second visit, Christine told Jan that she had cancer, but did not indicate how serious it was. She expressed her firmly-held conviction that she would survive. Later, she explained that her illness need not become a burden to Jan because she had other sources of support. Jan stated that "[Christine] didn't want people feeling like she was dependent" (Case 2, interview 4); it was simply companionship that she sought. In the following passage, the mother of Graham's friend discusses how her relationship with Christine developed:

> **Jan:** And in the fall - I got involved in this relationship without questioning it. And friends of mine . . . did question why I would ever get involved in this. Because it did get harder. And I don't think I realized what I was

> getting into at first when I did. I liked Christine. She was a friend. And I think that's what worked for her too. We wouldn't sit talking about her disease. We would talk about kids, we would talk about her life in *(country of origin)* and what she used to do. . . . it was almost like she would lift out of it for a while because we would be genuinely getting to know each other.
>
> (Case 2, interview 4)

Jan derived satisfaction both from being a friend to Christine and from knowing that she could be of help to her. She describes her experience of their relationship:

> **Jan:** . . . I saw it as a unique opportunity, albeit not always easy. I enjoyed being with Christine, but it certainly entailed moving into a completely different space.
>
> (Case 2, interview 4)

In the autumn, the two children began to play together after school on a regular basis, often at Graham's house as Christine liked to have them and Ross liked going there. The two women would visit while Ashley supervised the children. The two boys also played at Jan's house. Jan describes the frequency of the visits increasing from once to twice a week and explains that "as time went on, it was more" (Case 2, interview 4). As Jan grew closer to Christine, she began to drive her home from school in the morning and to take her to medical appointments in the day. Jan describes a turning point occurring in their friendship mid-autumn, when she learned that the results of a recent test to which she had driven Christine were clear:

> **Jan:** . . . I just gave her a big hug and said, "Ashley told me that it's okay and I'm" - I just said, "I'm so glad". I must have had a tremendous look of relief on my face. And she just said - she just looked at me and said, "You really are. I can see, you really are. You're into this - you've been drawn into this. I hope it's okay, but I can" . . . she needed to see that emotionally I really was, and she was just so grateful and gave me a hug. . . . So I guess that sort of switched things.
>
> (Case 2, interview 4)

Jan also discussed why very few people knew of their friendship:

> **Jan:** . . . [Christine] was very private and I'm not sure many people knew what my place in her life was, other than Ashley. Paul knew to some extent, but not a lot. She only had so much energy, and I don't imagine she would have sat and talked about this much.
>
> (Case 2, interview 4)

Jan's relationship with Graham, then, was embedded in the context of her friendship with his mother, which exerted a profound effect on her interactions with the child, as the following excerpt makes clear:

> **Jan:** . . . I mean I spent a lot of time with this child. . . . But I think because I became a friend of Christine's and got into that part of it certainly not in the same position as family is but it's not like being an outsider . . . who isn't emotionally affected by what's going on. And I mean, I suspect other people, I know even Sarah [the teacher] who was dealing with Graham day to day was really affected by what was happening with Christine as well. It's very hard not to be -
>
> (Case 2, interview 6)

As the autumn wore on, Jan found that she needed to pace herself: the increasing amount of time she was willingly devoting to Graham and his family had to be weighed against her responsibilities to her own family and her other activities. She explains :

> **Jan:** . . . I'd get to the point where I'd feel - full. And I realized that I had - that I could only give more if I spent a couple of days away . . . And I had my husband and my son and a whole bunch of other things.
>
> (Case 2, interview 4)

Jan wanted her son Ross, who like Graham was a "quite a loner in his class" (Case 2, interview 4), to have a friend. She was aware that Graham's home situation might make the development of a friendship between the two boys more difficult, and found she was more considerate of Graham's feelings than she might otherwise have been. Jan sought, however, to achieve a balance between considering the effect on Graham of his mother's illness and setting limits on his behaviour as she would have done with another child. She states:

> **Jan:** . . . I think I went in and out of stages of dealing with Graham. I mean, if you let it your heart can just bleed for the child from the minute - from the word go. And I found whenever I got feeling very sorry for Graham, I couldn't [be] with him as effectively . . . you let certain things go by, for sure, for a child in these circumstances.
> **R:** So you were more tolerant.
> **Jan:** Oh, I was much more tolerant.
>
> (Case 2, interview 6)

At the same time that Jan was making increasing amounts of time available to Graham and his family, she was concerned to protect her own son. She discusses this issue:

> **Jan:** . . . they played - enjoying themselves as normal children. I wouldn't have - I couldn't have exposed Ross to it for too long if they hadn't. I couldn't have. And then for the most part they just had a really nice little time and seemed to get on well, and it seemed to be a fairly equal give and take in the relationship.
> **R:** So you were weighing that out, you were kind of watching it?
> **Jan:** Oh I had to. I had to.
>
> (Case 2, interview 6)

Jan was available to Graham and his family because, as a friend, she was aware of their needs and wanted to help. At the same time, dealing with Graham could be quite demanding, as she relates below:

> **Jan:** . . . Graham wasn't - it wasn't always easy with Graham. . . . it took energy. . . . Not at their house it didn't, but outside it did.
>
> (Case 2, interview 4)

In reflecting on her experiences with Graham and his family, Jan considers the difficulties she encountered before concluding with the statement: "[I] would do it again . . . I'm glad I did it" (Case 2, interview 4).

School Teacher

Sarah had been Graham's teacher for both kindergarten and grade one. It was in the late autumn of his second year in her classroom that his mother died. Jan remarked that she thought it had been good for Graham to have the consistency that Sarah provided. The teacher's astute understanding of his nature and temperament was filtered through nearly two decades of experience teaching children in elementary schools. Her professional ability to assess his responses to his situation proved an invaluable adjunct to the perspectives afforded by the four other participants. Sarah provided a detailed picture of the kind of child Graham was when he first came to her class and described the changes that she saw in him in the months that led up to his mother's death. The stories she told of her interactions with him in the period immediately following the death provided eloquent illustrations of the extreme sensitivity with which she had treated him.

The interview was held in her empty classroom at the end of the school day. The children's highly individual and expressive artwork, displayed on the walls, provided tangible evidence of Sarah's comment that "we do art every day" (Case 2, interview 5). The following excerpt from fieldnotes describes the difficulties the teacher confronted in the months preceding Christine's death:

> [Sarah] felt stretched in so many different directions - being very concerned for Graham, and for Christine, who was her own age, and for Graham's father, Paul. She was also still dealing with her feelings about her father's death the previous year. The one year anniversary of his death occurred in the same month that Christine died.
>
> (Fieldnotes, Case 2, interview 5)

She describes the intensity of her reactions to Christine's predicament:

> **Sarah:** . . . I was kind of hoping against hope that Christine would be right, and that she would just *(pause for emphasis)* whip it. . . . she wanted it so much. And I felt [that] if anybody deserved it, you know, "You do,

> lady". And once in a while I would just kind of cry, because I could see that, you know, she was losing the battle.
>
> (Case 2, interview 5)

Sarah was outspoken in her admiration for Graham's mother, who continued to attend events at the school until her last weeks:

> **Sarah:** She died in the middle of December . . . And it went very quickly I think from September to December. The cancer just spread very rapidly. And I know that illness was making a lot of physical damage on her - she was losing weight and tired and - but she kept going. She would come, you know, and. . . [ask me] what I thought was best for Graham. . . . I'm not sure if it was Hallowe'en or Remembrance Day, we had an assembly. And the kids had prepared songs and poems and everything.
>
> **R:** Did she come for that?
>
> **Sarah:** She came, yeah. And she would not sit down, and you know, we did the presentation, and I could see that she was just getting really tired and someone came to tell me that - Graham had not noticed she was there - and would I tell him where she was, because she was at the end of her rope and just wanted to leave, but not before he had seen that she was -
>
> **R:** - was there.
>
> **Sarah:** So - and it was [like that] to the very very end.
>
> (Case 2, interview 5)

Sarah describes how she involved the entire class in making a mural that she planned to take to Graham's mother in the hospital:

> **Sarah:** Well, what we were doing the afternoon she died, we were drawing a mural. I was going to take it to the hospital room to - it was kind of a goofy Christmas mural *(both laugh gently)* . . . And everybody, you know, was excited. (We did the mural) because it looked like Christine might spend Christmas in the hospital and everybody was kind of excited about doing something for her, you know. And - that's the day she died . . .
>
> (Case 2, interview 5)

On reading this, Ashley remarked that Graham had had the mural put up in his bedroom, and that it was still there the following spring. The teacher provided a constant and unfailing source of support for Graham both before and after his mother's death. The highly perceptive and appropriate guidance she offered him was pivotal in assisting him to cope with and eventually grieve his loss.

Father

Graham's father, Paul is a courteous and somewhat reserved older man, in his early fifties, who welcomed me into his home. He addressed my numerous questions with forthrightness and seemed to appreciate the opportunity to talk about the events surrounding Christine's death. His answers indicated that he possessed a powerful intellect and a carefully considered philosophical position. Paul stated that he and Christine were highly compatible. In his words:

> **Paul:** Yeah, well I really respected her, totally. I mean that was - that's *(laughs)* very mutual too, you know. We were both each other's biggest fan-clubs and that was constantly there.
>
> (Case 2, interview 2)

He discusses his initial reaction when Christine's cancer was diagnosed:

> **Paul:** I had terrible awareness of it. . . . Well I knew at the moment she'd been diagnosed that it was hopeless, I just knew it. I mean there was no hope. She was too far along. . . . I knew from my *(unintelligible)* because I'd been consulting with - for a company that had had - developed a cancer detection device, and so I knew the stages. So I lived for four years knowing that . . . And she couldn't understand why I got such a shock, you know, the very moment that the doctor diagnosed this thing. . .
>
> (Case 2, interview 2)

Paul continually weighed his knowledge that his wife's chances of survival were statistically poor against the hope both of them drew from the experiences of those with cancer who had survived against the odds. He says:

> **Paul:** . . . we kind of worked for four years on making her as strong as possible, you know. I think that was her personal reaction to having this disease - was to try to stay fit . . . [It was] psychologically very very difficult. You know, we had lots of - I mean we were so close that there was no doubt about anything going wrong with my marriage, there was never anything there. It was just kind of working with this person, and working with yourself, too. And just kind of going with the road together, . . . I was facing this cancerous problem and then the sort of baby who was totally kind of gaga for the first six months, and it was total torture, you know for both of us.
>
> (Case 2, interview 2)

Paul was not affiliated with any form of organized religion. He discussed how he had derived strength to deal with the immense and ongoing difficulties of his situation by using his parents as models. Watching his mother work with steely determination in "a long-term systematic way" (Case 2, interview 2) to nurture the abilities she detected in her children had had a profound effect on him:

> **Paul:** I grew up with it, I know how it works and I know that you can fight incredibly severe obstacles with that approach - because there's probably very little that can resist it. . . . and so that's how I work - and Christine was aware of this . . . We'd try to cover every angle from a long term point of view.
>
> (Case 2, interview 2)

His father, as a survivor of World War II in the Far East, provided him with an equally important model of what can be achieved through long-term perseverance.

Paul explained that he took over more of the parenting responsibilties for Graham once Lawren was born. The nanny reported that the parents were dividing the responsibility for their children in a similar way when she began to work for the family three years later: Paul tended to spend the time he had available with Graham; Christine devoted more of her energy to caring for Lawren.

The family had no serious financial issues with which to contend. Paul describes their purchase of a vacation home:

> **Paul:** Well when we finally did make a big plan, we bought this house in *(location),* you know. We suddenly found that financially that we could do it. And so we just did it. And that was a really good thing, that was the last summer and I think Christine really - well we both thought we should do it now before it becomes impossible to do it. Because in the winter we both figured that she would really be sick. . . . so we had this wonderful two months.
>
> (Case 2, interview 2)

Graham's teacher related that for Mother's Day the spring after his mother's death, Graham drew a picture of himself and his mother picking rocks and shells off the beach near their summer home.

Paul discussed the many different demands with which he dealt in the months that preceded Christine's death:

> **Paul:** . . . when you've got an ill parent that needs looking after by the well parent - that's a bigger strain than what I've got today - by a long way.
>
> **R:** So there's less demands on you now than there were.
>
> **Paul:** Absolutely. Absolutely. Now you just put yourself in my shoes, you know. The responsibility of making sure Christine was going to, you know, everything was going well for her. Coping with her, you know, because she - she would cry, she would be stressed out and so on. I've got to deal with all of that and I'm thinking, you know - concern myself with the children. What happens is . . . it's not enough of me and there's not enough hours in the day, or anything like that.
>
> (Case 2, interview 2)

Graham's father's ability to address his sons' needs was under severe competition, not only from the demands he describes above but also because he continued to work full-time until the last ten days or so before Christine died. As he represented the sole source of income for the family, he had no option. Jan explained that Graham "needed his Dad more" in Christine's last weeks and that Paul "was getting more actively involved" (Case 2, interview 6) in parenting both his children.

Jan explains why she and Ashley allowed the two boys to play a little more boisterously after Christine was hospitalized than they had been allowed to do when she was at home:

> **Jan:** . . . we never let the lid fly off it, but we certainly let them do more running and whatever. And we really felt they needed to do it. So Graham was being allowed to blow off a little more steam. And we also knew that when Paul came home he wasn't going to have any energy for **anything**. So get it out of them. And there was always a conscious effort to calm everything down before Paul came home and to be gone. To have us gone. You know, Ashley knew what she had to do to calm it down.
>
> (Case 2, interview 6)

The above passage indicates the consideration with which the two women attempted to ameliorate the little they could of the overwhelming demands confronting Paul.

Graham's father presented a clear and detailed understanding of his son's thinking processes. He had, however, had limited time and energy to devote to Graham in Christine's final months. In his interview, Paul did not express the same kind of insight into Graham's feelings that the nanny, teacher, and mother of Graham's friend presented. It was through the interview with Paul, however, that I grasped the many factors that had contributed to Graham's parents' decision not to tell Graham of the seriousness of his mother's illness.

The Themes

Graham's character

Unlike Richard, the child in Case 1, who was 7 when his father's cancer was discovered, Graham was only 2 1/2 years old when his mother was diagnosed. He was unlikely to have ever remembered a time when she was not sick. The participants in Case 2 provided numerous perspectives on the kind of child Graham had been prior to his mother's death. There were no comparisons they could profitably make, however with the kind of child Graham had been before his mother's illness, when he was an infant. Paul discusses his insights into his son's character:

> **Paul:** Yeah, this kid's a bit different. He's always been extremely aware, and a really common sense, smart kid . . . the moment he was born he kind of had this appearance about him. I always like to tell him this.

R: Yeah. What was it like?

Paul: Well, it's his expression in his face and the way he looked around and he said, "Hey, how did you guys get here before I did?"

R: *(Laughs)* That was the expression?

Paul: Yeah, that's the way he came across . . . And he's always been wise like that, you know, he's always been this with-it kid - yeah with-it kid . . . And very sensitive, so you have to be careful with that, you have to watch it, you have to be more watchful.

(Case 2, interview 2)

Paul also stated that his son is determined and persistent, as well as quite competitive.

In the following passages both the hospice volunteer and the mother of Graham's friend discuss conversations they had had with Graham's mother about him:

Sue: . . . she'd talk about, like [Graham's] interests, how he was, you know interested in dinosaurs and - . . . she told me he was reading which I was pretty impressed with you know. *(Pause)* She worried about him. . . . she would basically say, you know, "I'm concerned about him". My impression was he was a very quiet, serious little boy.

(Case 2, interview 3)

Jan: . . . And we talked about the children a lot . . . talked about Graham a lot - I think she worried about Graham - the social stuff was hard. But you know, I had the similar concerns with Ross and we'd talk about those and - . Graham was very bright . . . Graham and Paul spent hours and hours reading things on science and chatting and stuff . . .

(Case 2, interview 4)

Jan discusses the differences between her son and Graham as well as the similarities:

Jan: They're both quite bright little guys, actually. Different interests, different inclinations. Graham's going to be quite - I think - he's probably got the scientist in him. Ross's probably got more of the, you know, the humanities - logical problem solver sort of in him . . .

(Case 2, interview 4)

Graham's teacher described how he taught himself the Roman numerals and commented that "he just kind of thrives on learning" (Case 2, interview 5). She was also able to provide the following insight into the relationship between Graham's intellectual abilities and his feelings:

Sarah: . . . he intellectualizes everything. And he keeps kind of emotions out there. . . . And he would research areas . . . I'm not sure - it's very hard to say if it's - I think it's part of his nature and I think it's also part of his coping skills. Where, you know there is stress for him. I think he copes by learning about something new, or really researching rocks or - last year he was just really, really interested by all kinds of rocks . . .

(Case 2, interview 5)

Graham's response to his father's explanation of the cause of his mother's death also reveals his need for information:

> **Sarah:** . . . [Paul] had a long talk with Graham and explained, you know, scientifically, how cancer works, and that you cannot catch cancer. And I think that's how you have to appeal to Graham, you have to give him facts . . . Otherwise, I think he frets if he doesn't know, you know, how things work. He likes to be able to analyze -
>
> (Case 2, interview 5)

The teacher pointed out that although Graham was an extremely bright child, he didn't like to brag or appear "in the limelight" (Case 2, interview 5). She was also aware that the characteristics he possessed had implications for how adults treated him:

> **Sarah:** . . . he's very mature. And he's very proud. And you know is very quick to see a put down, or - not to put down but patronizing *(voice goes up).* He doesn't like any kind of hint of being treated [like a] child -
>
> (Case 2, interview 5)

In the course of discussing how the two boys played together, Jan related the following information about Graham's physical ability:

> **Jan:** Graham is a very good runner, he's quite athletic. . . . Graham's got Christine's athletic ability. I think there's no question about it. He's pretty good at every sport. He picks up every sport he touches fairly well.
>
> (Case 2, interview 6)

His teacher reported that Graham's physical coordination and manual dexterity developed rapidly in his kindergarten year; although poor in the autumn they were excellent by the following spring.

Christine and Paul gauge how much to tell Graham

Christine and Paul decided quite soon after she was diagnosed that Graham was not to be told that his mother had cancer. Through the four years that followed, a host of different factors convinced them to continue to uphold their initial decision.

The two of them worked together to maintain a hopeful, positive attitude to Christine's cancer: they expected that she would live. Even when medical evidence indicated that her chances were poor, Christine "kept that door of hope open" (Case 2, interview 4). Both Graham's parents were influenced by stories of long-term survivors of cancer. Paul and one of his daughters from his earlier marriage actively searched for medical break-throughs; Paul and Christine together did all they could to ensure that she kept herself healthy. All participants spoke with awe of the determination with which

Graham's mother fought to live. In the following excerpt, Ashley reveals the essential connection Graham's parents saw between their attitude and Christine's survival:

> **Ashley:** . . . [there was a] real belief [in the family] that positive thinking could make her well *(voice goes up).* They were really into that. The positive thinking, and the naturopath, and just working on that. So she never wanted to, she felt like I think, if she said she was going to die then she would. But if she believed she wouldn't, maybe there was a chance.
>
> (Case 2, interview 1)

The information his parents gave Graham about his mother's illness was congruent with their own position. Paul explains:

> **Paul:** . . . she didn't believe [that she was going to die] herself. None of us did. That was the other thing we did - we did not - we just didn't let that. Like we believed there was always an option, like every day, you know, you're living. There's the option that your body's going to twig to what the hell is going on here . . . so Graham didn't have to be told because we didn't really believe that we knew that she was going to die. We always left this one path open that she was going to live . . .
>
> (Case 2, interview 2)

The teacher examines the situation from her perspective:

> **Sarah:** . . . I guess [Paul] told you that Graham didn't know.
> **R:** Yes, he did.
> **Sarah:** That - it was Christine's decision and I guess that was very - for her - she is a fighter . . . I think that, you know, with some relatives as well - that they think that telling people is going to kind of make everything crystallize, and it's going to become -
> **R:** People will be digging their grave for them before they're in it.
> **Sarah:** Um hmm. So Graham did not know and Christine until the very very last weeks or so, made sure that she came to interviews with me. And at the time, I don't know how she did it -
> **R:** She kept going.
> **Sarah:** Yeah. She just kept going and you know she really had the minimum of strength. . . . she did not want to leave those kids and Paul.
>
> (Case 2, interview 5)

Although Sarah indicates that it was Christine's wishes, the decision that Graham not be told that his mother was seriously ill with cancer was actually shared by both parents, as Jan makes clear:

> **Jan:** . . . One of [Paul's] great frustrations that day [at the hospital in Christine's final week] was the pressure he was receiving from hospital staff and others to tell Graham that his mother was dying. *(Pause)* And I decided I wasn't - I didn't have a viewpoint on . . . I knew from Christine. Christine talked about that too.
> **R:** This is Christine's wishes.
> **Jan:** This is Christine's **and** Paul's.
> **R:** Yeah. Together.

Jan: This is **their** wishes.

(Case 2, interview 4)

In Christine's final days, Jan assured Paul that he could trust himself to do what he knew was right for his son.

Paul explained that Christine did tell Graham that she wasn't well, but did not at any point tell him that the name of her disease was cancer. He describes what Christine told Graham when she was first diagnosed. Graham was then just 2 1/2 years old:

> **Paul:** . . . She did tell him about what was happening to her body and that's why she was going to the hospital, the doctor all the time, and so on. She was very matter of fact about it. But just keeping away from scaring him *(voice goes up)*. . . . she told him what was happening and - but didn't ever give him the sense that she was going to die.

(Case 1, interview 2)

In the following passage, Jan discusses her understanding of what Graham was told and not told as he grew older and his mother's condition deteriorated:

> **Jan:** And then as time went on I think there was a Terry Fox run at the school or something . . . Graham came home and, you know, heard about the cancer and stuff and you know. And sort of asked his mother . . . I think the story is he might have asked "do you have cancer?" And Christine - when she told me the story - "no". I mean she just wasn't going to impose on Graham. . . . I knew very early in the game that Graham did not know.
>
> **R:** So did not know cancer is - *(unintelligible - two voices together)*
>
> **Jan:** Yeah. Did not know cancer and did not know the implications of cancer.

(Case 2, interview 4)

In response to the above excerpt, Ashley, who had been present when this conversation occurred, explained that Graham had been very worried that Christine might lose her leg as Terry Fox had done, but did not actually use the word "cancer". In the excerpt below the nanny describes how the family talked to Graham about Christine's illness:

> **Ashley:** . . . he was told that Mommy had an owwie, and Mommy was sick a lot. . . . It was never spoken of, dying was never spoken of.

(Case 2, interview 1)

The way in which Graham talked about his mother indicated how he was attempting to make sense of what was happening. The nanny and the teacher relate the following examples:

> **R:** Did he ask you any questions that sort of let you know that he was thinking about Mommy's owwie or did he just - ?
>
> **Ashley:** No, he never asked me questions because he always knew everything *(laughs)*. I mean he would just say, you know, he would talk a

lot about, "When Mommy was really sick" and, " When Mommy didn't have hair", and oh and, "When Mommy used to go to *(location),* you know" . . . she had a doctor out there. He talked a lot with me about her, actually but he just - he never, I mean, obviously he never really understood what was going on, you know.

(Case 2, interview 1)

Sarah: . . . he often talked about Christine in those months before she died. You know, he would say that she had gone to the hospital or she was tired or she was resting. But he's kind of offhand about how that kind of -

R: Offhand? Like - can you give me an example of how he would say it? You just -

Sarah: Well I think - yes, like "no big deal". "She's resting". "She's tired". You know, no big deal.

(Case 2, interview 5)

The decision Christine and Paul made not to tell Graham about the nature and severity of his mother's illness was continually reaffirmed as Christine's condition changed. It was a decision that required much deliberation and was based on their understanding of the kind of child Graham was at the time. Christine and Paul gauged the information they gave their son very carefully in order to ensure that he could, in his father's words, "live being with the situation the way it was" (Case 2, interview 2). They were very concerned not to overwhelm him with fear by using the word "cancer". The participants describe how Christine related these concerns to them:

Ashley: . . . She told me right from the beginning, "You never mention - don't mention that I'm sick". So, like, "Don't talk about it, we don't want to talk about, we don't want to make the children anxious about anything, so we just don't talk about it. Graham's got enough to worry about than worrying about me, because he's a worrisome little boy". So when she was extra sick or tired I was just to say, "You know Mommy's owwie's hurting a bit more today. Can we just keep it quiet?"

(Case 2, interview 1)

Jan: Well I know Christine once said something to me about, "This - he just couldn't - this child couldn't live with it. He would be so full of anxiety and anticipation that he couldn't - that it would be - ". I think they felt it would be very destructive for him. . . .

(Case 2, interview 4)

In the following passage, Paul reiterates the importance he and Christine attached to protecting Graham:

Paul: . . . Christine did a really good job of keeping his awareness just at the awareness level without getting him scared. He never was scared . . . she was very very good with him, very good with him.

(Case 2, interview 2)

In response to this passage, Jan remarked that when she took Graham to visit his mother in the hospital he treated it as an ordinary event and showed no fear. Ashley reported that the one time she had seen Graham frightened had been the morning he saw his mother taken out of the house on a stretcher when she was hospitalized for the last time. Paul recalled only one occasion when Graham asked him about the possibility of Christine dying. He relates his response:

> **Paul:** . . . there was one time when he asked if Christine's going to die. And I know that we always said - I always said the same thing - "I don't know".
> **R:** Okay, so you didn't give certainty when you didn't have it.
> **Paul:** I didn't have it myself, either way.
>
> (Case 2, interview 2)

Christine spent the final week of her life in hospital. Graham went to visit her almost every day, but was not told that it was extremely unlikely that she would ever return home. His father and nanny describe the situation:

> **Paul:** He always had his mother here and then one day she wasn't here anymore and then I told him. And that moment's very clear in my mind.
>
> (Case 2, interview 2)
>
> **Ashley:** *(Sighs - then speaks very slowly and carefully).* Nothing was told to him about death. Christine didn't want, until she had died. The day she died, he was told.
>
> (Case 2, interview 1)

Although some participants had reservations about Graham's parents' decision, all respected and upheld it in their day-to-day interactions with the child. In the following excerpt, the teacher expresses her concerns:

> **Sarah:** I found it really very, very difficult. . . . I wanted them - I wanted Graham to learn about what was happening . . . . I was often choked up . . . I don't know who's right and who's wrong, but, you know, at the time I felt that he should know. And I wanted to at least wanted Christine to write something that could be given to Graham, maybe on various birthdays . . . but by the time I had come to that kind of way to kind of bridge the way I felt about it and the way Christine felt about it, I went to see her at the hospital, and she was too sick. . . . And I didn't even mention it to her because she was just, you know, too sick.
>
> (Case 2, interview 5)

On reading the above passage, Sarah pointed out that as a result of her high regard for Graham's mother, she was mistrustful of her own ideas and remained uncertain that what she had wanted for Graham would in fact have been correct for him. The situation was particularly difficult for the teacher because she was also constrained from preparing Graham's classmates. Paul responded to this passage by explaining that Christine had been advised by medical personnel to take extensive photographs and videotapes of herself together with the children. The two boys now possess a bank of photos and videos that they will be free to draw on as they grow.

In the excerpt that follows, the nanny discusses her issues:

> **Ashley:** I really wished that I could share with him and that I could have been able to do some, even a drawing or some sort of therapy and just not - I think I found it a bit frustrating.
> **R:** You wanted to tell him more than you were allowed to tell him.
> **Ashley:** Right.
>
> (Case 2, interview 1)

She also, however, states the following opinion:

> **Ashley:** I felt that [Graham's parents] did the best they could. I feel, I mean, when someone is dying . . . I think they become more open, and I think as a mother what Christine was doing was trying to protect her children as much as she could. And that's the way she knew how to do it. Because she understood them.
>
> (Case 2, interview 1)

In the following excerpt, Jan explains her position:

> **Jan:** . . . - you know - because of the approach [Paul and Christine] took - people had to -
> **R:** You had to respect it.
> **Jan:** Yeah. . . . And it never occurred to me not to.
>
> (Case 2, interview 4)

In the two passages below, Jan discusses how the approach his parents took influenced her conversations with Graham, particularly after Christine had been hospitalized for the last time:

> **Jan:** . . .I tried to keep it as normal as I could and I had to deal with it by not talking about [Christine's illness] at all. . . . I mean before that we talked about his Mom was in the hospital and his Dad was back and forth and - I mean we'd still talk about a bit of that.
>
> (Case 2, interview 6)
>
> **Jan:** . . . The fact that Graham didn't know, did make it difficult. It made it difficult - it made [the issue of Christine's dying] **impossible** to raise. It made it **easier** in the sense that you weren't trying to talk to somebody about their mother's impending death . . . but there was this knowing what was about to befall this child and his not -
>
> (Case 2, interview 6)

Graham's reaction when his father told him that his mother had died confirmed for Paul that he and Christine had been right in their decision not to tell their son any sooner. Jan relates the situation as Paul described it to her:

> **Jan:** And Paul sat down with him and said that, "Mommy isn't coming home [from the hospital]. Mommy died today". And Graham cried and cried. And then they - I don't know all of the dialogue but they did go upstairs and Paul told Graham all about the illness. When it had come . . . you know he had pictures - sort of children's pictures of the human body on, you know - that he looked at and talked about it and where it was. And Graham wanted to know all about the cancer, and how it got there and how it did its thing and where it moved from here to there. . . . I think - Paul was quite satisfied with how it worked. . . . And felt that his feeling that Graham shouldn't know the facts before Christine died, was right. Because I think he felt that Graham would have to dive into it. He said - the number of times he said to me - "I know my son - he's my own flesh and blood. I knew what he would do with it". And didn't - you know - give him that burden of having it - all that information before it happened would have been - was not right for him. Paul felt very strongly - very strongly about this.
>
> (Case 2, interview 4)

The material from the hospital support staff that Paul read on children and grief in the days immediately preceding Christine's death had stressed the importance of allowing children to express themselves in whatever manner they chose. He was therefore equipped to be supportive of his son's request that he draw what his father had just explained:

> **Paul:** He said, "Well, I've got to draw that". So he drew all that. . . . And he stuck it up, or had me put it up on the wall. It's still there, in his room. It's just part of his room now.
>
> (Case 2, interview 2)

In the drawing, Graham depicts his mother lying in her hospital bed with an intravenous bottle above her. Red lines running to different parts of her body show where the cancer began and how it spread. When Paul read this section, two and a half years after Christine's death, he reported that the drawing was still up on Graham's wall.

As a direct result of reading this, Paul asked Graham if he had known in Christine's final months that his mother would die. Graham replied that he hadn't. Paul then asked his son if he would like to have known. Graham's reply was adamant: "No - that would have been really scary" (Fieldnotes, June, 1995).

Graham's feelings, thoughts and behaviour

The comparisons that Richard's mother made in Case 1 between Richard's behaviour before and after his father contracted cancer were not possible for Graham, who was still an infant when his mother was diagnosed. Graham's feelings, thoughts and behaviours would have been coloured by both his mother's illness and his brother's special needs as far back as he could remember. During the final six months of his mother's life, the participants observed that Graham was timid in new situations, and easily upset. They also discussed the few occasions when Graham showed anger.

Graham holds back

Several participants commented on Graham's dislike of physical contact, his sense of privacy and his hesitancy in new situations. In the excerpt given below, his teacher focusses on his refusal of anything he might construe as "mushiness" (Case 2, interview 5):

> **Sarah:** And he's not the kind of kid that likes to be hugged or - he doesn't really enjoy that kind of physical contact and kissing.
>
> (Case 2, interview 5)

The nanny found that although Graham turned to her for support and attention when he was afraid, she was unable to use touch to comfort him. She states:

> **Ashley:** . . . he had a wall around him. I could never - he never all that time I was there let me touch him, but maybe a few times. I think I only hugged him twice in nine months' time.
>
> (Case 2, interview 1)

Jan's initial impression of Graham was of a "a very reticent, reserved little boy who was nervous" about coming over to her house for the first time to visit Ross (Case 2 interview 6). In the passage that follows, she expands on this description:

> **Jan:** . . . he and Ross - I think they had a good time. I think Graham was certainly a hold-back - there was a hold-back - there was a guardedness about Graham that you don't see nearly as much now.
>
> (Case 2, interview 4)

Sarah discusses how Graham's attitudes toward himself changed as he progressed through his first year in her classroom and his confidence in himself increased:

> **Sarah:** He has changed so much - that it's hard to break when and why from - because when he came to kindergarten he was the kind of boy who [was] very, very hard on himself, and was always saying that he couldn't do things and couldn't - and in tears and -
>
> **R:** So he had very high expectations of himself.
>
> **Sarah:** Um hmm. And very insecure. . . . Anyway, [Christine] was fine for that whole year. And I tried to get him to just try his best. And he just, by the end of the year he had come along so much.
>
> (Case 2, interview 5)

Some of the changes in Graham that the participants witnessed probably occurred simply because he was growing and developing. Others were more likely to have been responses to his experience of his mother's deterioration. The participants speculated whether certain aspects of his behaviour belonged to the first category or the second, but none of them possessed any certainty on this issue.

Graham easily upset

From when she first came to work with the family, Ashley found that Graham was easily upset. She observed that as Christine's condition worsened, he was even more likely to react with fear, anger, or frustration to the slightest incident. She describes the situation in detail:

> **Ashley:** *(Sighs)* [Graham was] like a little man. Taking care of his brother. Worrying about his mother. He was always - he just felt - it just felt - seemed like there was so much pressure on him. . . . He was worried all the time. You know he was - I could tell just by his fear of so many things, you know.
>
> **R:** What things did you see him being afraid of?
>
> **Ashley:** Well just anxious . . . He was just possessive of me. He got jealous of his brother a lot. . . . I could just tell he got upset really easily and angry really easily *(voice goes up)*. Frustrated with himself if he didn't do things just so. And always, you know, hush hush, because if Christine was taking naps, you know, we'd have to be quiet around the room. So there was a lot of strain on him - I felt. . . . I could never win, like he always [would] have to win . . . so I would have to pretend. Because I learned that really quick one day when I first started, and we were playing a game out in the field, and I beat him. And he just ran crying to his room, just sobbing . . . and he told me not - that I was better than him and he just didn't want to play anymore.
>
> **R:** . . . Did that happen very early on?
>
> **Ashley:** Actually, it did happen early on, but as she got sicker, I found it was more so that way. It was every little thing.
>
> (Case 2, interview 1)

Jan recalls Graham's unexpected reaction when she took him home after he had spent an afternoon in early November playing with her son Ross:

> **Jan:** . . . [the two boys] were outside playing baseball and they were having a good time. Graham's an excellent baseball player. And they were outside playing baseball. And I took him home - actually I took him home and he burst into tears when Paul answered the door. And I don't know - they hadn't had a difficult time. They'd had a fine time. He might have - you know - it might have gone on longer than it ought to have and he was tired. Or - I don't know what you read into that. Mom was in the hospital. He knew he was [at our house] 'cause Mom was in the

> hospital. . . . And Paul said, "Oh, don't worry about it. This happens. This happens often".
>
> (Case 2, interview 4)

It is apparent from the two examples given above that Graham was more easily upset than the participants would have expected from a child who was not contending with a seriously ill parent. Ashley stated that were times when she found Graham's reactions difficult to understand and that he was not a particularly easy child to look after. She also relates that Graham often had minor physical complaints:

> **Ashley:** Oh his tummy would hurt a lot and he would just need - Christine would say, "Oh Graham's tummy hurts - he's going to stay home today", and he's not that sick, you know *(laughs softly)*. But . . . I think she knew that he was just stressed. . . . I think a lot of times he felt Lawren got a lot more attention than him, so we'd spend days together on his sick days.
>
> **R:** So you would do things just for him?
>
> **Ashley:** Oh, uh um. And I think he really longed for that. That's one thing I noticed a lot, he really needed the individual attention quite a bit.
>
> (Case 2, interview 1)

As the above passage illustrates, both the mother and the nanny understood the stresses Graham was experiencing and were responsive to his needs.

Graham shows anger

Graham began to express anger just before his mother died and continued to do so for several months after her death. In the following excerpt, Jan reports her observations in the weeks immediately preceding Christine's death:

> **Jan:** . . . Graham had a very difficult time and of course with kids it doesn't come out directly. It comes out behaviourally. And it started just before Christine died - Graham started getting - he wasn't always the sweet little child he was before. There was a lot of anger. And it came often towards my son.
>
> (Case 2, interview 4)

Graham expressed his anger verbally, but did not hit out. On reading this, Jan commented that she noticed Graham's periodic outbursts of anger at Ross simply because they had not occurred before at all. She explains:

> **Jan:** It started a little bit before [Christine's death Graham saying to Ross about] being an idiot and stuff. It was anger - it was uncertainty, anxiety and anger. . . . But it was - it's hard - you know it was difficult - and I know Sarah's had her difficult moments too. It wasn't easy. And we've never talked about it in great detail but we've both said, "No, it wasn't easy". There was some behaviour there that was difficult to deal with. And you know where it's coming from and yet you can't let it continue.

> Especially where other children are involved.
>
> (Case 2, interview 4)

Graham's understanding of his mother's situation may have been limited by what he was told, but his occasional outbursts of anger at other children indicate that he was reacting, albeit in an indirect manner, to the immense difficulties of his home situation.

Graham's relationship with Christine

Although there were some differences in the way Christine and Jan parented their sons, Jan believed that they were "comfortable with each other's approaches" (Case 2, interview 4). She describes the differences:

> **Jan:** . . . I don't think I was over - I don't feel I've been overly protective of Ross. I think I'm probably a little more on the protective than the unprotective side . . . if zero is not very protective of your child at all, and one hundred is really overprotective, I was probably sixty, sixty-five, seventy. I think Christine was a little further along the line.
>
> (Case 2, interview 6)

One incident she relates is indicative of Christine's protectiveness towards Graham:

> **Jan:** . . . Ross had an electric train. A Playmobile one that he got for Christmas when he was in grade one. And the boys were going to play with that. And [Christine] said "you know, Graham doesn't know - doesn't deal with electricity. He's not used to plugs and things". And I said "well I'll keep that in mind and I'll keep my eye on them".
>
> (Case 2, interview 4)

The two women shared specific values which they were in the process of imparting to their sons:

> **Jan:** . . . I think we both wanted to raise, you know, polite kids with a respect for authority . . . certainly the values were similar with the schooling and stuff. And we didn't have a lot of - neither of us had a lot of patience for really aggressive, boisterous kids that would come in. . . . And gosh - what else did we have? We had a lot in common for them, I think. A concern for, you know, education.
>
> (Case 2, interview 6)

A theme Jan returned to many times was that Christine's illness imposed limitations on the kind of behaviour she could tolerate in Graham and his friends. The following passage represents one example:

> **Jan:** [Christine was] really wanting Graham to have a friend. Really wanting [it] to work out - and it had to work out for Graham and frankly it had to work for her too, because she couldn't have boisterous, aggressive kids in the house. It was just not something she could deal with. She had described having certain other children over and it just couldn't - it just - the energy wasn't there . . . And I think Graham went all sort of wingey

> and you know got caught up in it, and it was not something that Christine could deal a lot with.
>
> (Case 2, interview 4)

Although Jan felt that "the lid was kept on" in Graham's home (Case 2, interview 4), she also pointed out that the atmosphere was a little more relaxed when Graham and Ross were playing together:

> **Jan:** . . . [they] got into little pillow fights and things too. I'm sure they did. I'm sure they did stuff up there [in Graham's room] that we didn't know they were doing. Nothing serious but, I'm not sure it would have been stuff that would have been tolerated if it had been known *(voice goes up).* Just because there wasn't a lot of extra energy to put into it.
>
> (Case 2, interview 6)

Christine's illness also had a direct and long-term effect on the quality of her interactions with her son, and the kind of physical contact in which she could engage. Ashley gives the following description of the situation:

> **Ashley:** . . . Graham has been dealing with that since he was two years old with his Mom being sick and that's got to have some sort of an effect.
> **R:** Really. So Mom had an owwie all that time.
> **Ashley:** All that time, you know and up and down. And oh, you know, "Is she better now?" "I wonder how much I can touch her", not being able to touch her.
> **R:** So he would say that to you? "I wonder how much I can touch her?"
> **Ashley:** Well, no, I'm thinking you know. . . . Just from watching him crawl onto her lap and [she would say], "Oh, be careful" and he would have to stay so far away. And sneaking around her room when she's sleeping. I mean it's got to take its toll on a child. And Mom not being able to run or wrastle around. I mean she did as much as she could, tickling and - but she made as much physical contact as she could.
>
> (Case 2, interview 1)

In addition to the limitations that his mother's cancer imposed on the kinds of activities permitted Graham at home, and the kind of contact she was able to have with him, several participants mentioned that Christine could occasionally be short-tempered with her older boy.

> **Paul:** Well she shouted, she shouted sometimes and so on - Graham remembers that but, you know, clearly didn't have very much *(unintelligible)* . It was incredibly stressful for her.
> **R:** Yeah. When she did yell, was it like more towards the end?
> **Paul:** Not necessarily. *(Pause)* I think it was consistent throughout -
>
> (Case 2, interview 2)

> **Ashley:** But she also was - had a temper and she would get tired at a certain point and then she would yell *(voice goes up as question).* . . . And I

> don't know how much that had to do with being sick. I think it had a lot because she had a lot to deal with.
>
> **R:** So that he would get over a certain point with her and then she would just -
>
> **Ashley:** Right. And then she would just - snap.
>
> (Case 2, interview 1)

Paul does not think that this aspect of Christine's relationship with Graham is necessarily related to her illness. On reading this, he explained that Christine had once told him: "You don't have to worry. My sister yells at her kids much more than I do" (Fieldnotes, early June, 1995). He also said that medical personnel had encouraged her to express her feelings rather than to continue to bottle them up as she had been accustomed to doing.

For Graham, the rules had been laid out very clearly by his mother - he knew precisely what he was and was not allowed to do, and he obeyed those rules. The following example took place on an afternoon in early November. Graham's mother had gone into hospital that morning for what was to be a brief stay. When he arrived at Jan's house she asked if he would like to go to a movie with them. She discusses his response:

> **Jan:** . . . he sat down on that bottom step there and said, "I can't" or "I - don't think I - I can't do that - I don't - no - I don't know - I don't think I can"*(said in high fast, breathless voice).* He wasn't comfortable. He said, "I don't think I can do that". And he said, "I'm not allowed to go anywhere my Mom doesn't know that I'm going". "I can't go anywhere that my Mom doesn't know that I'm going". And I said *(spoken slowly in contrast),* "Well, your Mom's got a pretty good rule there, Graham. Got a pretty good rule". And I said, "You know, I think your Mom would think this is okay". "Well I have to know. I have to **know.** I can't go anywhere my Mom's not going". He wasn't comfortable with it.
>
> (Case 2, interview 4)

When Jan told Christine about this incident, Christine was firm with her that "just taking [Graham] . . . wouldn't have gone over with him at all" (Case 2, interview 4). She trusted her son to observe her rules even when she was not present. After Jan explained that she would not ask Graham to break a rule his mother had set, Christine altered it: she gave Graham permission to go places with Jan without her prior knowledge.

Childcare

Graham was accustomed to having a nanny to look after him, but he also expected to spend periods of time with his mother. The following passage illustrates that both the nanny and Christine were acutely aware of the need for him to build a connection with Ashley before his mother's death:

> **Ashley:** . . . And I also wanted to bond with him more than I could, so on days when he took off [school] that was special for me too, because . . . I knew what was coming. I didn't know when, but I just - I was worried about how he was going to be.
> **R:** How he was going to be after his mom had died?
> **Ashley:** Right. Like - how he was going to handle it.
> **R:** So you saw that it was very important for that bond to get built with him.
> **Ashley:** And **she** saw it incredibly.
>
> (Case 2, interview 1)

Ashley observed that Christine withdrew from her children in her final month. She spent more time alone in her room resting and sleeping. This may well have been a conscious effort on her part to prepare her children for her death; but she was also running out of energy. Ashley explains:

> **Ashley:** . . . she went into the hospital about a month before she died, or just over a month and after that she was very anxious that I - that she not spend much time with the kids. She would spend more and more time in her room and -
> **R:** So she came back out of the hospital, but she wanted to start separating?
> **Ashley:** Separating herself. And I really felt that already starting, even when I started [working for the family], but even more so after that first time she went into the hospital. She started separating herself.
>
> (Case 2, interview 1)

As Christine's death grew near, Paul spent as much time as he could with Graham and also began to take a more active role in caring for his younger son, Lawren. Ashley observed that he began to come home from work earlier, and took over the responsibility for feeding the two boys and putting them to bed.

Normalcy

There are two distinct aspects to the category of "normalcy" for Graham. The first was Christine's determination to interact normally with her son for as long as she could. This included walking Graham to school most mornings, providing a sixth birthday party of which he could be proud, ensuring that he was well taken care of and that he had friends to play with. The second was the part played by members of the family's support system in making Graham's environment as normal as possible under the circumstances.

In the passage below, Jan gives an illustration of Christine's overriding concern to do all she could with her son:

Jan: . . . Christine walked Graham [to school] for the longest time. . . . I think she chose what she wanted to do with [her children] and what she didn't think she could do with them. But she walked.

(Case 2, interview 4)

As another indication of Christine's determination to be as normal as she could with Graham, Sue relates that she was limping one day because she had tried to jump over a post while playing with her son.

Both Sue and Jan described the sixth birthday party Christine gave for Graham in her final autumn. It is apparent from Sue's description of the planning that Christine put a great deal of energy into this event:

Sue: . . . it was really important [to Christine] that you know, that [Graham] have a special birthday party. So we spent a lot of time planning . . . we decided that they would do gingerbread houses so I got her some alum for the icing and showed her how to do them. Yeah, it was very very important that he have a very typical six year old's birthday party. Ashley and her husband, I think were there and they did a lot of it. They did the work . . . and then [the children] made the gingerbread houses, then we had games and - . Yeah, that took a lot of planning - we spent a lot of time talking about that.

R: How did Graham react to having that? Did she talk to you about it afterwards?

Sue: Yeah, that he was thrilled, he loved it. Yeah, it was a very - yeah it worked out really well.

(Case 2, interview 3)

Ashley remarked that Christine derived great pleasure not only from the party itself, but also from Graham's involvement in planning it with her (Fieldnotes, June 26, 1995). Jan focussed on describing the joy she saw radiating from Christine's face when she delivered her own son:

Jan: . . . oh this birthday party was - was wonderful. . . . Christine was very into this. This was something she was really going to do . . .They'd got the games planned out and they'd got the little bags for the kids - you know that they were going to do gingerbread houses. She was all happy that it was organized. I dropped Ross off - I took him to the door and I dropped him off and there was Christine . . . and she was smiling and beaming. *(voice quiet and intense with feeling)* . . . And this party was so important to her. And I didn't stay. It wasn't a party parents stayed at. But I got in the car, and I looked back and I saw her in the window with the kids. . . . I just saw this flashing smile a couple of times. And I'd seen the flashing smile before, but I hadn't seen it with that kind of energy.

(Case 2, interview 4)

Being able to participate in Graham's birthday party was a moment of triumph for Christine. As Jan stated, "I'm sure there was a part of her that feared that she wouldn't get there" (Case 2, interview 4). For Graham, the fact that he could have a birthday party planned and presented by his mother, like any other six year old made an important contribution to maintaining as normal a life for him as possible. His mother died approximately one month later.

The friendship between Graham and Ross provided many occasions when Graham could simply play and be. Jan describes the boys' activities:

> **Jan:** . . . They played chess sometimes. . . . They did the train. At Graham's house they'd often play in his room. Graham had - has a bedroom full of Leggo and Playmobile and he's got this wonderful closet that - it's one of these closets in a sloping roof that Paul fixed up for him so it's full of shelves and little bins and buckets for Leggo and stuff. And Ross just loved going up there and playing with that. . . . That's what they'd do. I mean a couple of times - the first time they played together Christine and I went in and they were on the bed sort of in each other's - one was in the corner and the other was lying almost in his arms. Just goofing around, and chatting.
>
> **R:** *(laughs)* I love it.
>
> **Jan:** They definitely did normal kid things. They did normal child things. For sure.
>
> (Case 2, interview 4)

Out of the numerous occasions when the two boys played together, Jan describes one example notable for the palpable delight it gave to both the women:

> **Jan:** . . . We heard this chatter chatter chatter - loud loud - this hilarity [upstairs] . . . And Christine went up the stairs . . . and it was just hilarious. Hilarity going on up there. She didn't like it to get too hilarious too often, because it's hard to calm it down afterwards. . . . And - I went up behind her because I - don't know - I thought "it's going to take two Moms to get this one", you know. . . . [Christine] went into the room. And she was about to say something and as I got to the top of the stairs she was closing the door and walked away. And she came and said *(in incredulous whisper)*, "They're playing **chess**!" *(laughs)* And we both - we're sort of like two Moms going, "Gee, we don't want to stop **that.**" So we sort of laughed at the top of the stairs and went, "Oh my gosh". And tiptoed downstairs. And she said, "And what they're laughing about is instead of saying 'check and mate' they're going 'chicken mate! chicken mate!' at each other". But we both got such a delight out of this playing chess *(laughs)*.
>
> (Case 2, interview 4)

In the two excerpts that follow, Jan summarizes what she thinks Graham and his parents derived from his friendship with her son:

> **Jan:** . . . I think before Christine died, the times - well there was normal in his household, as normal as it got, when Ross went over and played and they goofed around. And I think they went upstairs in that bedroom and

> shut it all out. . . . a number of times [Graham] would come over here and get really involved in playing. And it was a normal-type place for him to come.
>
> (Case 2, interview 6)

> **Jan:** . . . and that's what we offered Christine and Paul, as much as anything - was that chance to have Graham . . . out doing something normal.
>
> (Case 2, interview 6)

The participants made clear that the ability of the family to proceed as normally as possible for as long as possible was as important to Paul's and Christine's peace of mind as it was to Graham's well-being. It would appear that the satisfaction that Christine derived from knowing that she was doing all she could was closely connected to the concern Paul expressed that the home environment be kept as steady as possible for the sake of the children.

Graham's visits with Christine in hospital

Graham was accustomed to visiting his mother when she was in hospital, and was taken regularly by either the nanny or his father. On one occasion, Jan took both Graham and her own son to visit Christine:

> **Jan:** . . . that same stint in the hospital, which was probably four or five days long - [Christine] needed someone to bring Graham in to see her. And I offered. I said, "I'd be glad to do that". And she said, "well, you know could you bring - would you bring Ross and Graham?" And I said, "sure". I mean I think I said it quite willingly. And she said, "You know I'm just on *(omit)* - I'm okay". And I trusted her judgement on that. And she said, ". . . it would probably be good for Graham to have - a friend know what's happening, to his Mom and what he's doing".
>
> (Case 2, interview 4)

The above passage illustrates that even when Christine was in hospital undergoing medical treatment, her consideration of Graham's needs did not abate.

Jan discusses the implications for her own son of Graham's not knowing the nature of his mother's illness:

> **Jan:** Ross didn't know how sick Christine was at this point 'cause I knew that Graham didn't know. I had to be very careful what I said - well I certainly said she wasn't well. He knew she wasn't well and didn't have a lot of energy. But I didn't indicate where it was going.
>
> (Case 2, interview 4)

She gives a detailed account of the visit:

> **Jan:** . . . So we went in. And Christine was looking weaker - she was definitely looking weaker. But she was . . . delighted to see Graham and Graham

> was delighted to see her. And they probably didn't have the same kind of visit they normally would but they were - the boys were playing and joking and Christine [had] said [earlier] "Oh the boys will be - Ross will be fascinated with all the equipment". She said "I'm hooked up to all these things". . . . And she actually got up and took the boys for a little walk. Now she was moving pretty slowly. I knew that things were - heading down fast. She was moving very slowly. But the boys enjoyed it and then I knew when enough time had been done.
>
> (Case 2, interview 4)

The unexpected discussion between the two boys in the hospital cafeteria afterwards illustrates that visiting Christine had not dampened their other interests. It also gives a poignant illustration of Jan's assertion that Graham was very matter-of-fact about the visit:

> **Jan:** . . . the woman in the cafeteria - I mean she had to know that somebody was visiting a sick parent. So she gave them cookies and - they sat there and had the most unbelievable discussion about: how did the dinosaurs get onto earth? I couldn't believe it. . . . They both had these theories of how the dinosaurs came to be . . . you know, these theories of evolution . . . I was stunned . . . The woman in the cafeteria was just looking at - and I just, you know - what can I say? I didn't dare say a word, you know, it was too interesting what was coming out of them.
>
> (Case 2, interview 4)

In the final passage below, Jan indicates that Ross's presence contributed to normalizing the visit. She states:

> **Jan:** And we left [the hospital] - and then they got quite rambunctious and antsy. They were okay about - I mean this was part of Graham's life. And Ross went in there like it was part of Graham's life and they were two - they were six and seven year olds being six and seven year olds.
>
> (Case 2, interview 4)

Christine relished hearing details of the boys' discussion about dinosaurs when Jan related it to her over the phone that evening. "She loved to hear about things like this" (Case 2, interview 4).

About a month later, Paul took Graham to visit his mother in the hospital for what was to be the last time. In Paul's words:

> **Paul:** . . . [Graham] saw her on the last day that she was alive. I took him in *(unintelligible)* - the last evening - the night before she died. . . .
>
> **R:** Do you know what it was like for him to visit her - just what he was like coming into the hospital or reacting?
>
> **Paul:** He - you know I think he was, he wanted to take things along to her and he wanted to talk to her and - so on like that. And there was definitely that, you know, he was talking to her and trying to - relate to her. But at the same time obviously very cautious because here was Mom, and she

> wasn't able to talk really all that well. She was sedated, and so on. So I think he was relieved to see her. Definitely - he was very happy to see that she was there, no matter how she was, she was there. . . . I took Graham pretty well every day. He kind of knew, you know - by this time he'd got used to the fact that she was not a well person, and that he went to see her wherever she was . . .
>
> (Case 2, interview 2)

Support for Graham

His mother's concern for Graham and her attention to his well-being provided an important source of support for him even though she herself was gravely ill. The high esteem in which she was held by the nanny and Jan served to solidify the frequent support the two of them gave to the child. The school teacher also made a substantial contribution to Graham's support system. As his mother became less available to him, Graham turned increasingly to his father for the time and attention he was missing. He also drew on the particularly close relationship he had with one aunt who Sarah stated "was there for him a lot" both immediately before and after his mother's death (Case 2, interview 5).

In the following passage, Jan indicates that Graham talked with both his teacher and his nanny, two people he knew and trusted, about his situation:

> **Jan:** I think Ashley had a remarkable relationship with Graham and Graham spoke to her quite freely.
>
> **R:** See so he had people he could talk to - he could talk to Sarah, you know.
>
> **Jan:** He had - yeah - and he did talk to Sarah. . . . And I know when he stayed home from school, he talked to Ashley about it.
>
> (Case 2, interview 6)

Graham's lack of knowledge of the seriousness of his mother's illness had profound implications for the support services that could be offered to him. Jan explains the limited role available to the school counsellor:

> **Jan:** . . . now Sarah told me this. . . . The counsellor really didn't know Graham. But the counsellor - Sarah did get Graham talking to the counsellor [a few days before Christine died] . . . Just - I mean they couldn't talk about Mommy dying, 'cause this child . . . didn't know, right? But they did - I think Sarah felt it would be a good idea for Graham to just know who he was. . . . Graham's a smart little cookie. He would have wondered why on earth he was meeting this counsellor. . . . I think that's the extent to which the school counsellor was involved.
>
> (Case 2, interview 6)

The above passage demonstrates a crucial point: the support available to Graham had to take a form acceptable to the family.

The nanny, the mother of Graham's friend and his teacher all described situations when they made special allowances for him. The following passage represents but one example:

> **Jan:** What did I make allowances for? I think I didn't write it off as, "Gosh, this kid's nervous and just you know, and he's really cautious" and I just went out of my way, I think I went out of my way to try to help him be comfortable. I probably checked with him - all along, I probably checked with him more often than I would with other children as to if things were okay. Were certain things okay? And he would tell me if they weren't.
>
> (Case 2, interview 4)

Graham's teacher reports that his classmates were extremely "kind and respectful of his temperament" after his mother's death. They had been unable to show any of those qualities earlier because they did not know that Graham's mother was dying (Case 2, interview 5).

Additional services for Graham

The hospice volunteer was concerned that the children were not receiving any formal, outside support to augment that provided by the family, friends and the school. She thought that an art and play therapist would have made an important contribution to the children's ability to cope with their situation. She states:

> **Sue:** I can't remember whether I said anything to [Christine] about whether the kids were getting outside support. . . . I don't think [the parents] wanted it. . . . I mean it was a concern of mine at the time, 'cause I, you know, just felt the kids needed something . . . I mean, I think if I were in that situation I would have my kids at a play therapist's - or an art therapist. . . . I think it'd be really important for the kids to have some way to release their - *(pause)* -
>
> **R:** To be able to communicate -
>
> **Sue:** To communicate, even if they do it through art or clay or whatever. I just think they pick up things actually, they know what's going on in the family. You know even if words aren't said the children sense what's going on. Yeah I thought - oh, 'cause I think I said to my hospice co-ordinator, "Is anything being done for the kids?" . . . I know, now - I'm sure nothing was being done for them.
>
> (Case 2, interview 3)

In conjunction with describing the drawing Graham had made of his mother immediately after her death, the nanny expressed the opinion that art therapy might have been helpful to him:

> **Ashley:** Well, just seeing that drawing really broke my heart. He really liked to draw, and I think even some sort of art therapy or something like that would have been nice. Just - I don't know - it's really hard to pinpoint what he was feeling inside -
> **R:** Some way of expressing what was inside him.
> **Ashley:** - with drawing and something - because he's very quiet.
> (Case 2, interview 1)

The teacher, on the other hand, who had grown to know Graham extremely well in the two years she had taught him, thought that increased opportunities to engage in social activities with his peers would have been more helpful:

> **Sarah:** For Graham, I don't know, I think he had, you know - because he didn't know what was happening, I think he got as much as he could. . . . I think anything social . . . like maybe, you know, he would have maybe something like the Cubs or the Beavers, might have been good. But - some kids like art therapy. I don't think that Graham would enjoy that.
> **R:** Okay. It doesn't work for all kids.
> **Sarah:** . . . You know, just - not that he would have talked about it, but just being able to, I think be [in] a social situation and away from home where it's too close, I think is beneficial.
> (Case 2, interview 5)

Similar to Sarah's position on art therapy for the child, Jan expressed the opinion that group counselling "has never occurred to me, or therapy, as being highly beneficial for Graham" (Case 2, interview 6). In the following passage, she discusses the limitations that would also apply to other children in Graham's position:

> **Jan:** . . . this situation is a tricky one. 'Cause you want the support and yet when a family isn't asking for it, or hasn't spoken to the child -
> **R:** And you really brought out to me, if there had been a possibility of a group, Graham would never have been part of it before Christine passed away. It would not have been an option, so.
> **Jan:** Not as far as [Christine and Paul] were concerned, at the time.
> (Case 2, interview 6)

For the reasons Jan gives, the nanny's opinion that it would be helpful for any parent dealing with advanced cancer and his or her child "to be able to go together to see someone or to have some sort of discussions and therapy"(Case 2, interview 1) would not have been applicable to Graham's situation.

Paul discusses how the overwhelming demands made of him in the months preceding Christine's death impinged directly on his ability to spend time with Graham:

> **Paul:** . . . you know, you just don't look at trying to help the kids - compared with this major, major problem that this parent has, you know . . . the ill parent, not the surviving parent. . . . Sure I was unhappy and so on, but I

> did not have this big problem. Christine had the big problem. . . . the thing that we did was to keep things steadily going - going steadily. And from outside the home for Graham to have benefitted more? . . . it might have been nice for him to have been able to go a lot more to some of his more favourite things. Like he really likes hockey games, so - that kind of thing.
>
> **R:** - he didn't get so much of that then.
>
> **Paul:** No. He still doesn't. . . . in some sense these children end up being somewhat at a disadvantage, compared with, you know.
>
> **R:** Compared with children who don't have an ill parent.
>
> **Paul:** Absolutely. I mean, there's half the cylinders of the family, or three-quarters of the cylinders of the family for that child are gone.
>
> **R:** Right, because your energy is with your wife.
>
> **Paul:** Absolutely, you know.
>
> (Case 2, interview 2)

Paul also explained that Graham's experience of receiving insufficient attention and time from him before Christine's death had not altered afterwards: . . . "that's been a continuum of experience for him, that things never changed all that much, you know" (Case 2, interview 2).

Jan reiterates the recommendation that was also made by Sarah and Paul that Graham would have benefitted from more opportunities to participate in normal activities with other children his age. She states:

> **Jan:** . . . I mean I think seeing how comfortable Graham is with a wide range of friends [since Christine's death], and involved in them, somehow the opportunity to have done more of that - earlier. . . . And yet, I think Christine did everything she could to make that happen . . . The demands on that household were tremendous and I guess some opportunity to have been in more situations where the demands weren't always there.
>
> (Case 2, interview 6)

The participants presented different opinions on whether or not Graham might have benefitted from some form of therapy or counselling. When the fact that he had not been told about the severity of his mother's illness was considered, however, the participants pointed out that he would not have been a candidate for therapy in any form. At the same time, it is obvious that his mother's cancer was having an effect on him. Graham's parents were keen to take advantage of any opportunities that were available for him to participate in activities that he particularly liked to do. They were both acutely aware of the limitations of their own abilities to provide those experiences for their son.

Conclusion to Case 2

Since Graham was 2 1/2 years old, he had been living with a brother with special needs, while his mother was at the same time engaged in an ongoing series of struggles with cancer. The fact that he was told neither of the severity of his mother's illness nor of its possible implications was a protective device: his parents were determined that his life be kept on an even keel. Rules and routines were carefully observed so that Graham knew what to do and what to expect. In the face of the powerful forces of uncertainty that were to eventually end in Christine's death, Graham's family strove to maintain as normal an environment as possible for their two children.

The five participants in Case 2 sometimes presented quite different memories of the same event; together they provided multiple perspectives on the child's experience. As in Case 1, the occasions when Graham could shut out the stresses of his home situation and simply be the small boy that he was were important to his well-being. Both the school and his friendship with Jan's son were instrumental in providing him with those occasions.

Summary: Cases 1 and 2

The four participants in Case 1 and the five participants in Case 2 provided a variety of different perspectives on Richard's and Graham's experiences during the period when each had a parent with advanced cancer. The different participants in each case-study not only saw different aspects of the same child; they also perceived similar aspects differently depending on their background, experience, and the nature of their relationship with the child. The contribution of each participant to the complex portraits of the two children presented in these two chapters augments and enriches that presented by the others. It also increases the rigour and trustworthiness of the resuls.

The differences in class that operated between the two cases were exacerbated by the profound differences in financial circumstances experienced by the two families once the father in Case 1 and the mother in Case 2 contracted cancer. Richard in Case 1 is from a working class family whose four members were accustomed to living on a single income. Once Ralph became ill and that income was lost, Richard's family had no financial security. Graham in Case 2 is from an upper middle class family whose financial circumstances did not radically alter after his mother was diagnosed with cancer. Graham's father Paul continued to bring home a generous income that allowed the family to maintain a similar standard of living to the one they had had before Christine became ill.

The way in which the parents in the two cases discussed parental illness with Richard and Graham and prepared them for the possibility that their father and mother, respectively, might die, was also different. Richard understood from the time of his father's diagnosis, when he was 7 years old, that his father had cancer and that the chances of his long-term survival were poor. Graham, on the other hand, who was only 2 1/2 when his mother was diagnosed, knew that she was not well, but was not told the name of her illness and did not understand its seriousness. The parents in both cases, however, went through similar processes in order to arrive at their different decisions. They gauged how much to tell their sons about their parent's illness and when to tell it very carefully. Their decisions were closely informed by Richard's and Graham's ages at the time of diagnosis and by the kind of children they understood Richard and Graham to be.

For the reasons described in Chapter 3, the voices of the children themselves are missing from these two case-studies. It is as if an extensive treasure hunt had been conducted; substantial clues to its whereabouts have been uncovered in diverse locations, but the treasure itself has not yet been found.

CHAPTER 7

Discussion

This research project can be regarded as a series of filters interposed between the child's actual experiences and what has been reported here. The perceptions presented by the adult participants of the child's experiences form the first filter. My documentation, interpretation and analyses of the participants' words provide the second filter. The third will be comprised of the meanings constructed by the readers based on their understandings of what I have written.

Issues in Generalization

Qualitative research, which is built on nonprobabilistic sampling procedures, does not permit generalization of its research findings in the positivist sense (Merriam, 1988, pp. 173-177). The primary goal is to increase understanding of the specific cases investigated, rather than to attempt to generalize beyond the boundaries of the study (Merriam, 1988, pp. 47 &173). Some ethnographers, however do strive for comparability and translatability of their findings as an alternative (Goetz & LeCompte, 1984, p.8). Comparability requires that the group studied be described accurately and in detail so that other researchers may decide what constitutes a similar group (Goetz & LeCompte, 1984, p.9; Merriam, 1988, p. 177). Translatability dictates that the research methods, codes and analytic categories used in a particular study be explicitly identified so that they may be applied in a meaningful way across other groups (Goetz & LeCompte, 1984, p.9). Hammersley (1990, pp.27-29) differentiates between the focus of a research project, which gives its significance in a wider context, and the actual case studied, which is narrower in scope. He argues that even a work explicitly limited to a single case may actually have implications for a more widely relevant focus.

In the current study, perceptions of the experiences of two children, each of whom had a parent with advanced cancer, have been presented from the multiple perspectives afforded by different adults who were in regular contact with each of them. The detailed analysis of each case (Chapters 5 and 6), and the inclusion of a thorough description of the research methods employed (Chapter 3) make it possible to draw implications from these two cases that may apply to other children in similar situations who also have a parent with advanced cancer.

Implications drawn from the two case-studies presented here, however, can only be applied tentatively and with reservations to other children. This thesis focusses on two boys, both of whom had European ancestors. There were considerable differences between the two children in socioeconomic status. Richard in Case 1 was from a working class family. Graham in Case 2 came from a middle-class background; both his parents had been to university. Differences in age, both at the time of parental diagnosis and at parental death, differences in temperament, religion, school performance, and age and health status of the younger sibling also existed between the two boys. Case-studies of girls who came from similar backgrounds to either Richard or Graham might have presented quite different profiles which would be at least partially due to the difference in gender. Children drawn from other ethnic groups would undoubtedly have presented cultural differences that may have had a profound effect on the issues addressed in this chapter.

Caregivers, hospice volunteers, school personnel and health care professionals need to approach the child with a parent with advanced cancer with a willingness to actively listen to what the child has to say and to ask open-ended questions that will encourage the child to express his or her concerns (Corr, 1995, pp. 13-14). They need to keep in mind the guidelines for interacting with these children that have resulted from recent research while at the the same time refusing to assume that anything research may have established necessarily applies to that particular child.

The Themes

The following discussion is based on salient themes that emerged through data analysis of the two cases on which this research project is based. Previous research findings have been incorporated as relevant. A basic incongruency exists between current theories and knowledge of children with a parent with advanced cancer which seek to establish factors common to these children and the unique experience of each individual child. This chapter can be viewed as providing a very rough and inaccurate map of the territory. Although it is hopefully more useful than having no map at all, it should not be confused with the territory itself, which is far richer, more diverse and profuse with the unforeseen and unexpected, as will be the experiences of any child with a parent with advanced cancer.

Gauging how much and when to tell

The dilemma faced by my two friends and their families in gauging how much information about the mother's cancer to give to their children, and in deciding when to give it and who would relate it were similar to the concerns expressed by the adult participants in the two case-studies presented here. The cases of Richard and Graham indicate that a host of different factors needs to be considered in gauging how much to tell children about their parent's cancer and in deciding when to relate that information so that it is most likely to be understood and absorbed. Parents, guardians or other caregivers standing *in loco parentis* obviously bear the responsibility for deciding how much and when to tell, and for carrying out their decision.

One important factor to consider is the child's chronological age and developmental stage, both at the time of diagnosis and during the critical period immediately after the parent's cancer has been classified as advanced by medical practitioners. This will give some indication of his or her ability to understand parental illness (Lewandowski, 1992; Siegel et al., 1990) and his or her stage in the cognitive development of a concept of death (Adams-Greenly & Moynihan, 1983; Stambrook & Parker, 1987). When Graham's mother was diagnosed when he was 2 1/2 years old, he was cognitively incapable of understanding the major components of a death concept: universality, irreversibility, nonfunctionality (Speece & Brent, 1987) and causality (Lazar & Torney-Purta, 1991). In contrast, Richard, who was 7 years old when his father's cancer was found, would have probably just passed into the Piagetian stage of concrete operations, and would likely have already been in the process of acquiring the major aspects of a death concept (Lazar & Torney-Purta, 1991; Speece & Brent, 1987). His mother's explanation that Richard's father's cancer meant that he might not continue to live would have fit with Richard's understanding of the causality and irreversibility of death.

The conversation Graham had with his friend Ross the day after his mother died gives a clear indication of his grasp of the causality of death. In Jan's words:

> **Jan:** So the first time Ross communicated with Graham about [his mother's death] was after school. And he said, "Oh - I'm sorry about your Mom". And Graham just said, "Well, well it was cancer, it was **cancer**, that's what it was. Yeah".
>
> (Case 2, interview 6)

In the months following Christine's death just after Graham's sixth birthday, he and his father had a series of "death talks" (Case 2, interview 2) in which Graham revealed his belief that his mother was still conscious, but had gone to place that was inaccessible to him. Paul did not argue but simply accepted his son's viewpoint as different from his own. This evidence that Graham had not yet acquired a cognitive understanding of the nonfunctionality of death has been reported for other children his age (Palombo, 1981; Speece & Brent, 1987), and is congruent with the findings of Lazar & Torney-Purta (1991) that different components of a death concept (in this case, causality and nonfunctionality) may be acquired at different times.

It would seem then, that parents, guardians or other primary caregivers need to gauge the explanation of parental cancer they give a child so that it fits with the child's death concept, which is dependent on the child's stage of development (Doka, 1995; Kubler-Ross, 1976). They can also expect the need to revise their explanation as the child grows and develops a more sophisticated death concept (Adams-Greenly & Moynihan, 1983). Developmental stage will also indicate the kind of language that the caregiver might use so that the child can understand what is said to him or her (Adams-Greenly & Moynihan, 1983; Christ et al., 1993; Doka, 1995; Lewandowski, 1992; Siegel et al., 1990). In Chapter 5, Elizabeth gives some outstanding examples of how she spoke to her son about his father's cancer using developmentally appropriate language.

Another factor is congruency: what children are told about their parent's cancer and the way in which they are told needs to be congruent both with how they were treated before the illness occurred and with how their parents themselves regard the cancer. In Case 1, when Elizabeth told her son that his father's survival was not likely, it was an accurate reflection of what she herself believed. In Case 2, what Christine and Paul told Graham was congruent with their conviction that Christine would live.

The child's character or temperament also needs to be considered. If Graham in Case 2 had not been "a worrisome little boy" (Case 2, interview 1), his parents might have decided to tell him more about the possible implications of his mother's illness. Their concern to shield their son is similar to the concerns expressed by the healthy spouse in the study conducted by (Titler et al., 1991) on critical care hospitalization. At the same time that the health of the parent with advanced cancer is deteriorating, children are growing and developing physically, emotionally, cognitively, socially and spiritually (Berger, 1988; Doka, 1995, p. xi). It is incumbent upon parents or other caregivers to ensure that children are told about what is happening to their parent in ways that will allow them to continue to grow and develop.

Whatever the parents, guardians or primary caregivers decide to tell their child about his or her parent's cancer, it is essential that everyone who is in regular contact with the child knows what the child has and has not been told, and upholds that decision even if they might not agree with it. In both cases presented here consistency across caregivers in what the child was told underpinned everything the participants discussed and may have made an important contribution to Richard's and Graham's ability to cope with the ongoing difficulties of their daily lives.

Once the child's primary caregivers have agreed on what information to give their child, they will need to decide when to relay it so that the child is most likely to be receptive. In Case 1, Richard's mother allowed his moods and behaviour to guide her in her choice of an appropriate time to talk to him about Ralph's cancer. She also watched Richard very closely as she was relating the information for signs that he had heard all he could handle for one occasion. It would seem that the adult doing the telling needs to maintain ongoing sensitivity to the child's responses and to be prepared to stop if the child should indicate that enough has been said.

A related issue is who should tell the child. In both case-studies presented here, it was the mother, as the person who was closest to her son and knew him best, who first talked to him about what was happening. The findings in the cases of Richard and Graham affirm what previous researchers have asserted: it is less stressful for children if the person chosen to inform them about their parent's cancer is someone they know and trust (Hymovich, 1993; Lewandowski, 1992). It is also helpful if this person is available to provide support and additional information to the children when and if they may need it at a later date (Christ, 1991a; Siegel et al., 1990). Informing the child about their parent's cancer is not viewed as an appropriate role for professionals unless they have a close, ongoing relationship with the child. Professionals can, however provide information and support to those who will be telling the child (Christ, 1991a; Siegel et al., 1990).

There are no simple answers to the complex question of what to tell the child whose parent has advanced cancer, how and when to tell it, and who should do the telling. Similar concerns have been raised in discussing the provision of information about the illness to the spouses (Northouse, 1993) and children (Hilton, 1993, 1994a) of women with early stage breast cancer. In the two case-studies presented here, a consideration of the above factors was important in assisting each family to arrive at an answer that was right for them and for their particular child.

The child's feelings, thoughts and behaviour

When a parent contracts cancer, the process of debilitation and decline that may eventually result in death is characteristically fairly slow. Children will be making a series of adjustments at each stage of their parent's disease at the same time that they are growing and developing (Corr, 1995; Doka, 1995, p. xi). It is apparent from the two cases investigated here that parental cancer was having an impact on Richard's and Graham's feelings, thoughts and behaviour long before their parent actually died. When Richard's father's cancer reached the advanced stage, his acute reactions occurred immediately after his mother explained to him the significance of what was happening. Graham, on the other hand, who was not told of the seriousness of his mother's illness, seemed instead to be responding to the increased levels of tension in his household. Studies on critical care hospitalization of a parent have documented the intense and shifting emotions experienced by the child (Lewandowski, 1992; Titler et al., 1991). Recent research has reported acute emotional distress in children with a parent with advanced cancer (Christ et al., 1993; Siegel et al., 1990, 1992).

Richard and Graham differed in their specific reactions to very different situations. They were both, however, highly reactive and very easily upset during the period when their parent had advanced cancer. Although Richard was reported displaying anger far more frequently than Graham, both children had occasions when they acted their anger out verbally and/or physically, either against the adults around them or against their peers. The participants in both cases also reported quite a few minor incidents that unexpectedly provoked the two boys into major outbursts of tears. The adults who cared for Richard and Graham found that their behaviour was often unpredictable and difficult to handle.

In Case 1, the participants discussed numerous occasions when Richard refused to discuss his father's illness with them. Elizabeth explained that her son would "just shut the door [to his feelings] completely" (Case 1, interview 3) if she persisted in her attempts to get him to talk. Richard's refusal to dress himself in the morning and his clinging to his mother are similar to the attention seeking behaviours reported by other children whose parent has cancer (Hymovich, 1993). The stomach-aches Graham experienced in Christine's final months are consistent with the increased somatic complaints reported for other children with a parent with advanced cancer (Christ et al., 1993; Siegel et al., 1990, 1992).

Although the specific constellation of feelings, thoughts and behaviours may be different for different children, and will vary depending on specific incidents, it seems that adults caring for children with a parent with advanced cancer need to be prepared for unexpected swings in the children's feelings and thoughts accompanied by unpredictable shifts in their behaviour. This is congruent with the research showing that the initial reactions of children to the death of a parent may be extremely varied, and that caregivers need to exercise both awareness and tolerance in their responses (Kaffman et al., 1987). Children with a parent with advanced cancer may be unaware of or unprepared to examine how their parent's cancer is affecting them. As Elizabeth persisted in doing over and over again with Richard in Case 1, caregivers may want to gently nudge children towards making connections between how they feel, think, and act and what they have been previously told about their parent's illness. They can also expect occasions when the child might flatly refuse to talk about his or her parent's cancer even though it might be quite obvious to them that that is what is bothering the child. Christ (1991a) reported the initial reluctance of children who exhibited anger at either the ill or the healthy parent to discuss their parent's illness with social workers.

Caregivers will need to find a balance in their response to the child between exercising tolerance and restraint, on the one hand, and continuing to set clearly defined limits for acceptable behaviour on the other. Jan, in Case 2, clearly describes this delicate balancing act as she experienced it. As Richard's mother in Case 1 discovered, simply giving in to the child's demands might make a difficult situation temporarily more manageable but might also result in additional difficulties with which caregivers will be forced to deal later. Christine and Paul considered that keeping Graham's environment as steady and predictable as possible under the circumstances was important to maintaining his equanimity. It would seem that the predictability of children's daily routines may assist them to cope with the profound uncertainties engendered by their parent's cancer (Christ et al., 1993; Siegel et al., 1990).

Role for art

Participants in both case-studies indicated that art played a part in assisting the two boys to express their thoughts and feelings about their parent's cancer. Richard in Case 1 drew quite happily at the invitation of the school counsellor. One of his drawings, a red car with teeth, which the counsellor described as "the angriest red car" (Case 1, interview 5) successfully expressed the anger Richard was unprepared to admit to verbally. After Christine's death, Graham in Case 2 spontaneously drew the course of his mother's cancer immediately after his father had explained it to him.

It appears that art, as one of the young child's forms of expression (Garbarino et al., 1992, pp. 154-169; Landreth, 1978) can be useful in assisting children to communicate thoughts and feelings about advanced parental cancer that they may be unable or unwilling to express verbally (Doka, 1995, pp. 37-8). Art has been used extensively with hospitalized children to increase their self-awareness and self-expression, reduce stress and to facilitate coping with their disease and hospitalization (Hodges, 1981; Sourkes, 1991). Art has also been used to assess the psychosocial needs of healthy siblings of ill children (Rollins, 1990). With bereaved children, guided art activities have been used to provide a safe environment for the nonverbal expression of thoughts and feelings about a difficult issue and to facilitate more open and adaptive patterns of grieving (Junge, 1985; McIntyre, 1990; Segal, 1984; Simon, 1981; Zambelli, Clark & Heegaard, 1989).

The child with a parent with advanced cancer may not need or benefit from formal sessions with an art therapist. It may be important to these children that they can draw or paint in an informal, familiar environment, and that they have the support of an adult whom they know and trust as they engage in the art activity. One article included in the literature review recommended that children with a parent with advanced cancer be invited to draw after a hospital visit (Adams-Greenly & Moynihan, 1983). Several of the participants in the second case-study thought that drawing had been helpful to Graham. His father ensured that art materials were available but Graham decided of his own accord to draw his father's explanation for his mother's death. Although Sarah, Graham's teacher, used art activities every day with her class, she did not think that he would have benefitted from formal art therapy sessions. The hospice volunteer and the nanny, however, believed that either art or play therapy might have been helpful to Graham.

Different members of a family's support system, then, may hold very different ideas about what might be useful to a particular child. The actual needs of different children with a parent with advanced cancer may also vary a great deal. Jane, in Case 1, used Richard's angry car as evidence to support her suggestion that he might have benefitted, either before or after his father's death, from working with a skilled art therapist. She was concerned that Richard did not talk to her about his feelings even though he was quite willing to come and see her. Whether or not an art therapist sees the child, it would appear that having art materials readily available and periodically inviting the child to use them could provide an important nonverbal avenue of expression for the child's thoughts and feelings.

Support for the child

During the period when a child's parent has advanced cancer, the demands on adult family members increase and the family's need for additional sources of support may become acute (Call, 1990; Christ et al., 1993; Lewandowski, 1992; Siegel et al., 1990) An overload of responsibilities on the healthy spouse is considered a major factor in the reduced family cohesiveness and increased conflict reported when one parent has a chronic illness (Peters & Esses, 1985). The family's support system may be able to moderate some of these adverse effects on the family environment both before and after the bereavement (Lewandowski, 1992; Peters & Esses, 1985; Silverman & Worden, 1992). Issel et al (1990) asserted that the children's use of their support systems, which the researchers term "tapping into group energy" was an essential component of their ability to cope with parental cancer. If, as hospice personnel and other health care professionals increasingly assert, the family rather than the ill parent is to be considered the unit of care (Buckingham, 1982-83; Corr & Corr, 1983, 1985; Davies et al., 1990, 1995; Hall & Kirschling, 1990; Lewandowski, 1992; Lewis, 1986, 1990; Northouse, 1984; Schwenk & Hughes, 1983; Titler et al., 1991) then it is crucial that the needs of the family's children be included in planning meaningful and effective support for the family unit.

One way in which hospice volunteers, health care professionals and other members of the family's support system might be effective in assisting the family's children is to strengthen and support the people who are already in regular contact with the children (Adams-Greenly & Moynihan, 1983; Christ et al.,1993; Corr & Corr, 1985; Siegel et al., 1990) rather than attempt to form a new relationship with the children themselves. There are two related issues here. One concerns the need members of the family's support system might be experiencing for more information on how to interact effectively with the child. The mother of Graham's friend in Case 2 provides a clear example of this:

> **Jan:** And I would like to have been more equipped . . . Ashley and I said a number of times we would really like access to somebody who could help us - on dealing with the child on the day to day . . . that was the afterwards. Before - I would have liked it the before, too.
>
> (Case 2, interview 6)

The second issue concerns the child him or herself. From the two case-studies presented here, it would seem that the period when the child's parent has advanced cancer is not an opportune time for a child to form a new relationship. Richard in Case 1 consistently turned his head away from the hospice volunteer in an evocative refusal to have anything to do with her. Ashley, the nanny in Case 2, commented that it took a long time for her to form a bond with Graham.

Given the difficulties already occurring in the lives of children with a parent with advanced cancer, these children may be particularly sensitive and reactive to changes in caregivers, should such changes occur. Some children with a parent with advanced cancer, like Richard, may not experience a significant alteration in caregivers. Others, like Graham, may have to contend with a situation in which they are cared for by several different people, some of whom they did not know before their parent became ill. Christ et al. (1993) found that if the relationship with the dying parent was especially close, while that with the well parent more distant, children felt particularly anxious and vulnerable. A negative correlation between the amount of time the surviving parent spent with the child before bereavement and teachers' reports of the level of disturbed behaviour exhibited by the child after bereavement indicates that the child's long-term adjustment is influenced by his or her pre-bereavement relationship to the surviving parent (Krantzler et al., 1990). Health care professionals can assist the family to choose the childcare solution that will be the most acceptable and least disruptive for the child (Black, 1989). Adults who look after these children periodically can assist them by tailoring their approach so that it is congruent with that of the child's primary caregivers (Lewandowski, 1992).

At the same time that the child may be highly reactive to a change in caregivers, the healthy parent may be experiencing the need for respite from his or her childcare responsibilities. It is particularly likely that this will be the case if he or she is shouldering childcare duties that had previously been the responsibility of the ill parent or if childcare needs alter as a result of the ill parent's hospitalization. Elizabeth made recommendations for childcare services on the hospital site to cover the specific difficulties she encountered in attempting to procure childcare for Richard so that she could visit her husband in hospital.

The question to ask when planning support for the family unit is not who is available to spend time with the child, but who does the child want and need to spend time with? What responsibilities can that person relinquish in order to have time to spend with the child? Particularly if it is the healthy parent the child wants to be with, that parent needs to be temporarily divested of some of his or her other duties if he or she is to participate in activities with the child. Given the staggering number of demands experienced by the healthy parent in families with young children when the other parent has advanced cancer (Brown, 1989; Lewandowski, 1992; Lewis et al., 1990; Rolland, 1989; Siegel et al., 1990), this is a necessity. Paul, the father in Case 2, provided an eloquent illustration of his son's experience when he stated that, "three-quarters of the cylinders of the family for that child are gone" (Case 2, interview 2). The next question to ask is: who can temporarily take over some of the parent's other responsibilities? In this way, the people providing secondary support to the family, like hospice volunteers, health care professionals, friends, relatives or neighbours, can include the needs and wishes of the family's children when planning how they can best be of service to the family.

Role of the school

The two case-studies presented here provide evidence for the claim made by DeFrances Van Dexter (1986) that the school is uniquely placed to provide ongoing support to both the child with a parent with a life-threatening illness and to his or her family. Attending school is a normal expectation for most children; children with a parent with advanced cancer can be given assistance during the school day with little or no disruption of their regular routines. The substantial amount of time the child spends in school each week also affords a prime opportunity for respite from the relentless difficulties of his or her home environment. The look of relief which appeared on Richard's face some mornings as he came through the classroom door showed his teacher how much that opportunity meant to him (Case 1, interview 4).

One of the difficulties for school personnel, however, is that teachers only rarely confront the situation in which one of their pupils has a parent with advanced cancer. Neither of the two teachers who participated in this research project had previously taught a child whose parent had advanced cancer; between the two of them, they had had almost fifty years of experience teaching at the elementary level. Given that this situation is uncommon, it would seem more appropriate to have resources available at the district level to assist teachers as and when the need should arise, rather than to provide specialized information and training for all teachers. Richard's and Graham's teachers expressed the wish that they had been to be better equipped to deal with the two boys through their respective parent's final months' of life.

In Case 1, the school counsellor played an instrumental role in providing support to Richard, as well as to his mother and teacher. In Graham's case, the role of the school counsellor was severely limited, given his parents' position that Graham not be told the nature and seriousness of his mother's illness. Paul asserted that the ongoing support that Sarah, Graham's teacher, was able to provide to Graham helped him to adjust to and cope with his situation, both before and after his mother's death. From the two cases presented here, it would seem that teachers of a child whose parent has advanced cancer may need to adjust the demands they make to accommodate his or her reactions to the situation at home. They can also expect that there may be periods when the child exhibits unexpected or uncharacteristic behaviour that is difficult to handle. The child will undoubtedly benefit if the teacher can accept and tolerate these periods.

Normalcy

One of the biases with which I began this research project, that children with a parent with advanced cancer would benefit from some form of specialized counselling, was not confirmed by any of the adult participants in Case 2. In Case 1, only Jane, the school counsellor suggested that formal art therapy sessions, either before or after his father's death, might have been helpful to Richard. When asked about services that they wished had been available to the two boys, none of the participants mentioned group therapy. Instead, the participants emphasized that Richard and Graham derived substantial benefits from the opportunities that were available to them to engage in ordinary, everyday activities for children of their ages. I have entitled this theme "normalcy", defined as the maintenance the patterns of daily living. The participants discussed how the two boys could have used more opportunities to spend time simply doing the things that they liked to do and temporarily putting to one side their worries about their ill parent and their home situation. These opportunities fell into several different categories.

One was engaging in social activities with other children. The school provided the prime opportunity for this to happen. Whatever else was occurring in Richard's and Graham's daily lives, both boys attended school regularly. Playing with their friends and classmates after school, either in their friends' homes or their own provided another opportunity for the two boys to socialize with other children. It took a great deal of energy, however, for either the ill or the healthy parent to ensure that these visits occurred. The first time Christine called her, Jan was aware that it was more difficult for Christine to arrange for Graham and Ross to play together after school than she would ordinarily have expected. As the tremendous number of different demands being made on both the ill and the healthy parent may make it difficult for either of them to arrange these occasions, it may be helpful if another member of the family's support system does so for them.

Attending organized groups like Cubs or Beavers, which Sarah, the school teacher in Case 2 suggested for Graham, could provide a worthwhile opportunity for children with a parent with advanced cancer to socialize with other children in a group setting, and to participate in more structured group activities. Membership on a sports team presents another possibility for participation in a group activity with other children on a regular basis. Again, the deciding factor for the family will be whether anyone is available to deliver the child and pick them up from meetings or practices. Graham started to play on a baseball team after his mother died. His father explains, " we do one thing really well [now] and that is baseball. 'Cause I've figured out how to fit that in . . . I couldn't have got that going before [Christine's death]" (Case 2, interview 2). Whether the child plays with a friend or participates in a group activity, it would seem important for him or her to have a regular period of time away from the home environment. As the teacher in Case 2 put it, at home the difficulties of parental cancer can be "just too close" (Case 2, interview 5).

A second category of activity involved either the healthy or the ill parent taking the child on regular outings (Christine taking Graham to a local park to play ball) or special trips (Elizabeth's presence on Richard's school field trip). Both boys appeared to relish occasions when either their ill or healthy parent could do things with them that they had been accustomed to doing together before the cancer occurred. Efforts that the ill parent made to participate in a special event seemed to be particularly rewarding for both parent and child. Graham's delight at his sixth birthday party was paralled by the joy his mother showed in being able to arrange and participate in it. The determination with which Ralph took Richard on a fishing expedition the last Father's Day that they had together provided Richard with an important memory that he could draw on when Father's Day the following year arrived.

This theme, which I have entitled normalcy - the need of children with a parent with advanced cancer to engage in normal activities both with other children their own age and with their parents - was one I had not anticipated when I began this research project. It is clear from the number of demands with which Elizabeth, in Case 1, and Paul, in Case 2, were contending that they were unable to provide as many of those opportunities for their sons as they would have liked. As has been addressed in the previous section on support, other members of the family's support system could provide opportunities for the children to engage in social activities with other children on a regular basis. Other researchers have also discussed the importance of maintaining a normal environment for the child both at home and at school (Issel et al., 1990), and assisting the child to maintain age-appropriate interests and activities (Adams-Greenly & Moynihan, 1983) including their social life (Nelson et al., 1994). "Business as usual" is how Issel et al (1990) describe the child's use of normal activities as an important strategy for coping with parental cancer.

Effects of the Research Process on the Participants

The inclusion of catalytic validity in this study requires an assessment of the effects of the research process on the participants. Catalytic validity, as discussed in Chapter 3, represents "the degree to which the research process re-orients, focusses and energizes participants toward knowing reality in order to better transform it" (Lather, 1986). It is an ongoing process, one that cannot be wrapped up into a neat parcel as this research project nears completion. In conjunction with the concept of reciprocity between the researcher and the researched, the use of catalytic validity made me pay close attention to the effect that participation in the research project was having on the participants and increased my sense of responsibility to them. This section presents indications that catalytic validity was occurring for the participants both during the initial period of being interviewed, and a year later, when they took part in the process of respondent validation.

Fairly early in the research project it was apparent that the process of participating was having an effect on some of the participants. One participant remarked that, after my initial overture to her, she had called another participant who had already been interviewed. The two women were not in the habit of speaking to each other regularly. They had had a lengthy discussion about their experiences with the family, and one of them had been able to impart information that the other did not know. Their conversation convinced the second participant that she not only wanted to talk to me about her involvement, but also that she might need more time than I had requested in my letter. Another indication for catalytic validity occurred when, at the end of her interview, Ashley, the nanny in Case 2, explained that she planned to volunteer with an organization interested in setting up a live-in hospice. In her words:

> **Ashley:** . . . I'm thinking about getting involved with the research for that, so - . . . it was strange again, after talking to you [initially] and then finding out [about the research], and going, "Oh", and then having been with this family, I would be really interested.
>
> (Case 2, interview 1)

The process of respondent validation contributed to the catalytic validity of this study in several ways. The first was a direct result of the year that had intervened between interview and respondent validation. The passage of time allowed the participants to evaluate their words differently and thereby to assess the progress they had made. A few times as he was reading, Paul, the father in Case 2, remarked, "Did I really say that?" (Fieldnotes, early June, 1995). Checking through the results section allowed him to underscore how far he had come in his process of grieving and to appreciate how much his life had changed as a result.

The participants were also able to reflect on the long-term effects of the interview on them. One participant remarked that after her interview she had been able to put her experiences to rest in a way that she had been unable to countenance before. Ashley said that the interview had encouraged her to reflect on her experiences as the nanny to Graham's family and had helped to confirm her growing interest in hospice and long-term health care. This process had definitely influenced her choice of career. She is currently an administrator for an organization involved in the provision of health care services.

The Hospice Coördinators who participated in respondent validation for Chapter 4 discussed how the dearth of information on the experiences of children with a dying parent seemed to be paralleled by the lack of services available to these children. They expressed the hope that I would make my findings available to a wider audience of health care professionals. One Hospice Coordinator remarked that it had been valuable to learn about the variations in procedures I had encountered at the different hospices I had contacted prior to writing my account of the fictitious "Open Hand Hospice Society". She pointed out that "there is no manual for Hospice Coordinators" (Fieldnotes, late June, 1995) and said that what I had said confirmed for her the importance of holding regular meetings with other Hospice Coordinators in the region in order to exchange information and ideas about hospice services.

Respondent validation also provided useful feedback to some of the participants about their effectiveness in helping others. Jane, the counsellor in Case 1, explained that it is rare for a school counsellor to receive the detailed feedback I had been able to provide about how Richard's mother and his teacher had experienced her interventions. She reiterated that the process of learning what others had said about her work had been extremely valuable to her.

During the process of respondent validation, most of the participants requested a copy of the entire thesis once completed. It is not possible to discuss at this point future courses of action that they might take as a result. The indications thus far, however, give me confidence that reading the work will have an effect. The use of catalytic validity in this study underscores the ongoing nature of the research process and the artificiality of cutting it off at any particular point. Haig-Brown (1994) states this succinctly: "an ethnography is never complete, just finished".

Directions for Future Research

Several directions for further research present themselves now this research project is finished. The first is to use a similar framework to conduct a prospective study. The participants in the two case-studies presented here were interviewed between nine months and 1 1/2 years after the death. The acute stages of grieving their loss were, for the most part, behind them and they had had considerable time to reflect on their experiences during the deceased's final months. If they had been interviewed while the parent with cancer was still alive and they were actively contending with the profound stresses and uncertainties of that time, their responses might have been quite different. Researchers investigating the responses of bereaved children have also recognized the need for prospective studies that occur immediately after the parent's death rather than months or years later (Silverman & Silverman, 1992; Van Eerdewegh et al., 1985).

The second direction is to talk with the children themselves. For the reasons given in Chapter 3, this thesis did not directly address the question: what are the experiences of children living with a parent with advanced cancer? An initial approach to those experiences has been made through the filter imposed by the perceptions of the adult participants. The children, therefore, still need to be interviewed, preferably during the period when their parent with advanced cancer is alive. Both Rosenheim and Reicher (1986) and Siegel et al (1992) have indicated that parents might not possess an accurate picture of their children's level of distress; children might try to hide their feelings in an effort to protect both the ill and the healthy parent. The ability of parents to recognize subtle changes in their children's behaviour indicative of the children's feelings might be impaired by the many other demands with which they are contending (Siegel et al, 1992).

Gender-based studies need to be conducted that will establish if the impact of parental cancer differs depending on whether the child is male or female. Research also needs to investigate if the responses of children to advanced parental cancer are connected to whether the ill parent is the same or the opposite sex to that of the child. Studies that examine the impact of advanced parental cancer on children from different cultural groups are required if differences and similarities between children drawn from a diversity of cultures that accurately reflect Canadian society are to be clearly established. The possibility that class-based differences in children's responses to advanced parental cancer exist should be explored through studies specifically designed to target children from different socioeconomic classes.

In both case-studies presented here, the two adults with whom the child lived were the child's biological parents. Although at least one of the child's parents had been previously married and had had other children, those children were much older and did not live in the home. The experience of advanced parental cancer for children living in blended and single-parent families might be quite different, and needs to be investigated.

Combining qualitative and quantitative methodologies into a single research design would seem to offer unique research opportunities. It makes possible the discovery of factors common to all children while ensuring that those influencing a single child or just a few children will not be lost. This is particularly important given the exploratory nature of research in this area and the extreme sensitivity required in obtaining access to participants. Using the two methodologies in tandem can be extremely powerful. Hilton at U.B.C. School of Nursing (Hilton, 1988, 1993, 1994a, 1994b, 1994c), the research team at the University of Washington (Lewis 1986, 1990; Lewis et al, 1985, 1989) and the one at the Memorial Sloan Kettering Cancer Centre in New York (Christ & Siegel, 1991a; Christ et al, 1993; Siegel et al., 1990, 1992) have all consistently built both methodologies into their research designs.

Conclusion

"A child is still a child", a hospice volunteer said to me when I remarked on the child's ability to take pleasure in playing baseball with other children at the same time that his parent's life was threatened by metastasizing cancer. Her empathic words encapsulated the child's experience; they reflected an insider's understanding of the child that my remark completely lacked. I was struck by the simple fact that these children continue to grow and develop, as other children do, even though their families dwell in the blatant shadows cast by an uncertain future. Children like Graham, whose mother was diagnosed when he was very small, may never remember having a fully healthy parent. Shooting a hoop, kicking a soccer ball, having a birthday party, going on a fishing trip, walking to school, visiting the aquarium, seeing a movie are essential components of these children's daily lives. Providing opportunities for them to continue to engage in activities they enjoy presents a dilemma for the family that needs to be addressed. Children with a parent with advanced cancer may enhance their abilities to cope with the profound difficulties of their situation when they participate in ordinary, everyday activities with their peers, the parents of their peers and their own parents.

Cancer is an illness that affects all family members; living with parental cancer is an ongoing, dynamic process that requires a series of adaptations from children and adults alike. The thoughts, feelings and behaviour of children with a parent with advanced cancer do not arise in isolation, but are firmly embedded in the difficulties that confront the entire family. It is hoped that this research project, by exploring multiple perceptions of the child held by participants both within and outside the family, will contribute to our understanding of children with a parent with advanced cancer seen within the interactive and dynamic framework of both the family system and the larger community.

Appendix I

Literature search

The following data bases have been searched for relevant current theoretical, review and research articles:

1) Psycinfo (1980 to March,1994)
2) Current Index to Journals in Education (1969 to March,1994)
3) Medline - 1990-1994
4) H.W.Wilson Social Science and Humanties Index
   (copyright 1983)
5) Nursing and Allied Health (to 1993)
6) Sociological Abstracts (to 1993)
7) Infotrac (1980-1994)

Appendix II

This appendix contains copies of the following:

- Information Letter for Hospice Volunteer
- Consent to Participate for Hospice Volunteer
- Information Letter for Families - from Hospice Volunteer
- Family's Authorization for the Release of Information by the Hospice Volunteer
- Information Letter for Participating Families
- Consent to Participate for Family Member
- Participant Feedback Form

The letters of information sent to a nanny, a mother of a friend of the child, a school counsellor and two school teachers are not included here. These were suitably modified versions of the one for the hospice volunteer. These letters named the child and the family concerned and explained specifically why I thought that the perspective each prospective participant might decide to contribute would be of value. The forms giving consent to participate were included with the information letters. For the interviews with each of these participants, authorization for release of information by them was obtained from the surviving spouse, using a modified version of the form authorizing release of information by the hospice volunteer.

Information Letter for Hospice Volunteer

March, 1994

Dear: ________________________

My name is Sheila Lindfield. I am a Master's student in Counselling Psychology in the Faculty of Education at Simon Fraser University, and work part-time as a school counsellor in a school for hearing impaired children.

In the last five years, I have had two friends die of cancer after long, hard battles: both were women in their mid-thirties, both had children. As my friends grew more and more ill, I saw how difficult it was for the healthy adults in the family to meet the children's needs, while at the same time caring for the children's mother, and undergoing intense emotional reactions themselves. This research project is a direct result of my concerns about the experiences of the children of these two families during the period when their mother was terminally ill, but before she had died.

When I examined the research literature, I found that there has been almost no formal investigation of the experiences of children after it is apparent that their parent is unlikely to recover, but before the parent dies. It is unclear whether or not these children are in need of assistance, and if they are, what form that assistance should take. If effective health care services are to be provided for the children during the difficult final months of their parent's life, then their experiences need to be more thoroughly understood.

As a hospice volunteer, your involvement with the client during his or her final months gives you firsthand knowledge of the family's situation. I think that your understanding of the experiences of the family's children, whether it is gained through other family members, or directly from the children themselves, has a valuable contribution to make to our knowledge of the children's needs and concerns.

If you have worked within the last two years with a family with at least one child between the ages of 7 and 11, whose mother or father was or is terminally ill with cancer, I would be interested in interviewing you about your perceptions of the family's, and the child's situation. Before proceeding with the interview, I will ask you to contact the family to explain the research project to them directly, and to obtain from them a signed release form giving you their permission to discuss their situation with me.

The interview will last approximately one hour, and can take place either in the office of a colleague, or, if you prefer, in your own home. I would like your permission to audiotape the interview so that I do not need to make notes while we are talking. You will be given the opportunity to meet with me a second time after the interviews with all hospice workers have been completed, in order to discuss what I have found, and to check through the part of the thesis dealing with your interview. I will at this time be prepared to make any modifications that you request. Every effort will be made to protect your anonymity, and that of the family you discuss, both in the written transcripts of the interviews and in the final document.

Your position as a hospice volunteer with ______________________ Hospice does not place you under any obligation to participate in this study. If you do agree to participate, you can refuse to answer particular questions and are free to terminate the interview at any time. These actions on your part will not in any way affect your position at ________________________ Hospice, nor your relationship to the Hospice staff.

If you are interested in learning more about the study, and/or wish to participate, please contact me at *(phone number given).* I am enclosing a copy of the consent form that I will be asking you to sign in my presence before the actual interview starts.

I want to thank you for your time, and for considering my request.

Yours sincerely,

Sheila Lindfield, M.A. candidate
Counselling Psychology

Consent to Participate for Hospice Volunteer

Title: The Hospice Volunteer's Perceptions of Children with a Parent with Advanced Cancer

Investigator: Sheila Lindfield, M.A. candidate
Dept. of Counselling Psychology
Faculty of Education, Simon Fraser University

Mailing address:
(home address given)

I, ________________________________ agree to participate in the research study on the hospice volunteer's perceptions of children with a parent with advanced cancer. I have read the description of the study given in the information letter and have had the purpose of the research explained to me.

I understand that:

- I may refuse to comment or answer any particular question at any time
- I may terminate the interview at any time

These actions will not affect my position as a hospice volunteer with ____________________ Hospice, nor my relationship to ____________________ Hospice staff.

I further expect that:

- The interview will last approximately one hour
- The interview will be audiotaped and transcribed and the tapes erased after completion of the study.
- The tapes will be listened to only by the researcher and her faculty advisors
- The transcriptions will be kept in a locked drawer and destroyed within three years of completion of the study. The signed consent forms will be kept in a separate locked drawer.
- Every attempt will be made to obtain a signed release form from the family to be discussed prior to the interview.
- Every effort will be made to protect my anonymity and that of the family I discuss. Transcripts will be identified only by code number; my name and the name of the family I discuss will not appear in any research report, published or unpublished.
- The content of my discussions with the researcher will be kept strictly confidential by the researcher and her thesis committee.
- Once all interviews are completed, I will be given the opportunity to discuss the collective findings, and to check through and modify the part of the thesis dealing with my interview.
- Through the subject feedback form I will be given once my participation in the research project is completed, I may choose to direct comments on my involvement to the Chair of Simon Fraser University's Ethics Review Committee.

I have been able to ask whatever questions I have about the research and have had all questions answered to my satisfaction by the researcher. I understand that I can ask for additional information at any time. I will be given a copy of this consent form once I have signed it and a summary of the research findings will be sent to me once the thesis is completed. A copy of the completed thesis will be available from Sheila Lindfield on request.

Any complaints about the study may be directed to:

Senior Supervisor:
Dr. Celia Haig-Brown
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

or to

Director of Research and Development:
Dr. Phil Winne
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

____
Hospice Volunteer

____
Researcher

____
Date

Information Letter for Families - from Hospice Volunteer

Dear:________________________

Sheila Lindfield, a Master's student in Counselling Psychology in the Faculty of Education at Simon Fraser University, has asked me to participate in the research project described below. In order to do this, I need your permission to discuss your situation and that of your family with her. Please read through the enclosed material before deciding whether or not you wish to grant your permission. Your decision will not in any way affect your relationship with me, or with other members of ________________ Hospice.

Sheila Lindfield has found through an examination of the existing research literature that there have been very few investigations of the experiences of children who have a parent with advanced cancer. It is unclear whether or not these children are in need of assistance and if they are, what form that assistance should take. She is planning to interview a small group of hospice volunteers who have worked with families like yours, in order to investigate the hospice volunteer's perceptions of the children. It is hoped that an increased understanding of the children's experiences will result, and that this will contribute to the provision of more effective health care services for them.

For these reasons, I would like your permission to discuss the experiences of your family with her. You will not be asked to participate directly yourself. Every effort will be made to protect your anonymity, and whatever information I impart will be kept strictly confidential by Sheila Lindfield and her thesis committee. The details of how that information will be treated are outlined on the authorization form that I have enclosed.

If you have any questions or concerns, you can either let me know what they are and I will relay them to Sheila, or if you prefer, you can contact her directly. Her address and phone number are:

Thank you for taking the time to consider this request.

Yours sincerely,

____
Hospice Volunteer
________________ Hospice

Family's Authorization for the Release of Information by the Hospice Volunteer

I hereby give my permission to ____________________ to discuss me and my family's experiences and concerns with Sheila Lindfield, Master's candidate in Counselling Psychology in the Faculty of Education at Simon Fraser University, for the purposes of the research described in the letter of information.

I understand that:

- The interview Sheila Lindfield conducts with ____________________will be audiotaped and transcribed and the tapes erased after completion of the study.
- The tapes will be listened to only by the researcher and her faculty advisors
- The transcriptions will be kept in a locked drawer and destroyed within three years of completion of the study. This signed release form will be kept in a separate locked drawer.
- Every effort will be made to protect my anonymity and that of my family. Transcripts will be identified only by code number; my name and the names of other family members will not appear in any research report, published or unpublished.
- The content of the interview between __________________ and the researcher will be kept strictly confidential by the researcher and her thesis committee.

I have been able to ask whatever questions I have about the research and have had them answered to my satisfaction. I understand that I can ask for additional information at any time. I will be given a copy of this form authorizing the release of information once I have signed it. A summary of the research findings will be sent to me once the thesis is completed. A copy of the completed thesis will be available on request from:

(address given)

Any complaints about the study may be directed either to:

Senior Supervisor: Dr. Celia Haig-Brown
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

or to
Director of Research and Development:
Dr. Phil Winne
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

Family member who is next of kin to deceased client	Date

Relationship to deceased client

Guardian of children (if different from above)	Date

Information letter for Participating Families

March, 1994

Dear _______________________:

My name is Sheila Lindfield. I am a Master's student in counselling psychology in the Faculty of Education at Simon Fraser University, and work part-time as a school counsellor in a school for children with impaired hearing.

In the past five years, I have had two friends die of cancer after long, hard battles: both were women in their mid-thirties, both had children. As my friends grew increasingly incapacitated, I saw how difficult it was for the healthy adults in the family to meet the children's needs, while at the same time caring for the children's mother, and undergoing intense emotional reactions themselves. This research project is a direct result of my concerns about the experiences of the children of these two families during the period when their mother was terminally ill, but before she had died.

When I examined the research literature, I found that there have been very few investigations of the experiences of children after it is apparent that their parent is unlikely to recover, but before the parent dies. It is unclear whether or not these children are in need of assistance, and if they are, what form that assistance should take. If effective health care services are to be provided for the children during the difficult final months of their parent's life, then their experiences need to be more thoroughly understood.

As the surviving parent, your firsthand knowledge of your children's experiences in the period that preceded your spouse's death can make an extremely valuable contribution to our understanding of the children's needs and concerns.

The interview will last approximately one hour, and can take place either in your own home, or, if you prefer, in the office of a colleague. I would like your permission to audiotape the interview so that I do not need to take notes while we are talking. You will be given the opportunity to meet with me a second time after all the interviews have been completed, in order to discuss what I have found, and to check through the part of the thesis dealing with your interview. I will at this time be prepared to make any modifications that you request. Every effort will be made to protect your anonymity and that of your family, both in the written transcripts of the interviews and in the final document.

Your position as the family member of a former client of ______________ Hospice does not place you under any obligation to participate in this study. If you do agree to participate, you can refuse to answer particular questions and are free to terminate the interview at any time. These actions on your part will not in any way affect your relationship to the Hospice staff or hospice volunteers.

If you are interested in learning more about the study, and/or wish to participate, please contact me at *(phone number given)*. I am enclosing a copy of the consent form that I will be asking you to sign in my presence before the actual interview starts.

Thank you for your time, and for considering my request.

Yours sincerely,

Sheila Lindfield, M.A. candidate
Counselling Psychology

Consent to Participate for Family Member

Title: Adult Perceptions of Children with a Parent with Advanced Cancer.

Researcher:
Sheila Lindfield, M.A. candidate
Dept. of Counselling Psychology
Faculty of Education, Simon Fraser University

Mailing address:
(home address given)

I, ______________________________, agree to participate in the research study on adult perceptions of children with a parent with advanced cancer. I have read the description of the study given in the information letter and have had the purpose of the research explained to me.

I understand that:

- I may refuse to comment or answer any particular question at any time
- I may terminate the interview at any time

These actions will not affect my relationship to ________________________ Hospice staff or hospice volunteers.

I further expect that:

- The interview will last approximately one hour
- The interview will be audiotaped and transcribed and the tapes erased after completion of the study.
- The tapes will be listened to only by the researcher and her faculty advisors.
- The transcriptions will be kept in a locked drawer and destroyed within three years of completion of the study. The signed consent forms will be kept in a separate locked drawer.
- Every effort will be made to protect my anonymity and that of my family. Transcripts will be identified only by code number; my name will not appear in any research report, published or unpublished.
- The content of my discussions with the researcher will be kept strictly confidential by the researcher and her thesis committee.
- Once all interviews are completed, I will be given the opportunity to discuss the collective findings, and to check through and modify the part of the thesis dealing with my interview.
- Through the subject feedback form I will be given once my participation in the research project is completed, I may choose to direct comments on my involvement to the Chair of Simon Fraser University's Ethics Review Committee.

I have been able to ask whatever questions I have about the research and have had all questions answered to my satisfaction by the researcher. I understand that I can ask for additional information at any time. I will be given a copy of this consent form once I have signed it and a summary of the research findings will be sent to me once the thesis is completed. A copy of the completed thesis will be available from Sheila Lindfield on request.

Any complaints about the study may be directed to:

Senior Supervisor:
Dr. Celia Haig-Brown
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

or to:

Director of Research and Development:
Dr. Phil Winne
Faculty of Education
Simon Fraser University
Burnaby, B.C. V5A 1S6

____
Family member

____
Researcher

____
Date

Simon Fraser University
University Research Ethics Review Committee

Participant Feedback Form

Completion of this form is **optional,** and is not a requirement of participation in the research project. However, if you have been a participant in the project and would care to comment on any aspect of the way the project was conducted (how you were interviewed, for example), you are invited to complete this form and sent it to the Chair, University Research Ethics Review Committee. All information received from you will be treated in a strictly confidential manner.

Principal Investigator: Sheila Lindfield

Title of the Project: Adult Perceptions of Children with Parent with Advanced Cancer

Dept./Faculty: Dept. of Counselling Psychology
Faculty of Education

Were you given an Information Letter before agreeing to participate in the project?

Did you sign a Consent to Participate Form before participating in the project?

Did what you were asked to do differ in any way from what the Information Letter had explained?

I wish to comment on my involvement in the above project which took place:

(Date) (Place) (Time)

Comments:

Completion of this section is optional

Your name: ____

Address: ____

Phone: (w) ____________________ (h) ____________________

This form should be sent to:

Chair
University Ethics Review Committee
c/o Vice Preseident, Research
Simon Fraser University
Burnaby, B.C. V5A 1S6

Appendix III

This appendix contains copies of the following:

- Questionnaire for Hospice Volunteers
- Interview Guidelines:
  - Semi-Structured Interview with Hospice Volunteers
- Interview Guidelines
  - Semi-Structured Interview with School Personnel

Interviews with the nanny, the mother of the friend of the child, and the two surviving spouses used interview guidelines similar to the two formally prepared ones that are reproduced here.

Questionnaire for Hospice Volunteers

This questionnaire has been designed to acquire background information on the client and the client's family before the interview occurs. It is not expected that you will be able to provide all the information requested. You can just put "unknown" in response to those questions to which you do not have an answer. Thank you for whatever information you are able to provide - it will be of benefit.

In order to ensure that the family's identity remains confidential, please identify family members only by their first initial.

Background on the client and his or her family

Approximate date of client's initial diagnosis: ______________________

Age of client when diagnosed: ______________________________

Client was ***mother*** ***father*** (please circle one) of:

1st initial of child	***Age***	***Sex***	***Grade***
_______________	_______	_______	_______
_______________	_______	_______	_______
_______________	_______	_______	_______

List any health problems or disabilities any of the children had:

____

____

____

Were the parents living together? (please circle one) **Yes** **No**

If not, were they (please circle as appropriate):

separated **divorced** **remarried**

List the other members of the household, their age, and sex (use their first initial only):

____

____

____

Describe the cultural and religious background of the client's family:

____

____

List the level of education and employment of each adult in the household:

1st initial of adult	**Education**	**Employment**
____________________	____________	________________
____________________	____________	________________
____________________	____________	________________
____________________	____________	________________

List any health problems that you know of in other adult family members:

____

____

List (by first initial) any relatives, family friends or neighbours living outside the household that spent time with the family during the period when you were working with the client:

____

____

____

Do you know if the family had had previous experiences with death and what they were? Please describe:

____

____

____

Background on the hospice volunteer's experiences with the client and his or her family

When did you start working with the client?

____

How long did you work with the client?

____

What sorts of things did you do with the client?

____

____

What sorts of things did you do for the client?

____

How many visits in an average week would you make to see the client?

About how long would you be there each time?

Would you talk on the phone? **Yes** **No**
How many times a week? ________________________________
About how long would an average call be? ____________________

Is there anything else about the client or the client's family that you think it would be helpful for me to know before the interview? Please describe here.

Interview Guidelines:

Semi-Structured Interview with Hospice Volunteers

Background information on the hospice volunteer:

Education/employment
Experience and motivation - hospice work
Previous experience with families dealing with cancer
Previous experience with client's culture and religion

(Ask hospice volunteer to stand back from their own opinions for a while and try to paint the scenes for me so that I could almost be there myself. "Help me to see it as it was when you were there". Focus on what is said/done, what is observable. Reiterate that the hospice volunteer's opinions are important and there will be a special place for them towards the end)

Family context: "Paint me a picture of this family ..."

Important people and their roles in the family
Part played by culture/religion/rituals - beliefs about death
Strengths - support system
Problems - finances, health, alcohol, etc.
Issues of time, energy and money
Previous family experiences with death

Lifestyle changes as a result of parent's illness:

"Tell me about the changes that happened in the children's lives as their parent was dying."

Caregiving arrangements
Schooling changes
Activities with the family
Changes in seeing friends; outside social activities
Chores, routines

Emotional reactions to the situation: "I'm interested in what you observed of the children's reactions to ..."

First hearing the news
Later reactions, when it became clear parent would not get better.
Was child directly told that parent was likely to die? *Set scene etc.*
Reactions to the death.

Hospice volunteer's experience: *(stop acting as impartial observer and be the expert advisor)* "Tell me what it was like for you to go through this time with the family ..."

Coping of the surviving parent and of child - how surviving parent perceived and dealt with the child's needs.
Given your experience as a hospice volunteer over y years - were the experiences of this family typical? Atypical? In what ways?

How do you see the needs of children who are experiencing a parent's illness and death? How do you believe those needs can best be met?

What do you see is the role of the hospice volunteer with the children of terminally ill parents?

Finish:

Is there anything you'd like to add about the family that we haven't discussed? Anything else?

Anything that's not specifically about this family?

Debrief (tape recorder off):

What has it been like for you to do this interview?

Is there anything that you'd like to ask me?

Discuss:

Once all interviews are completed, the hospice volunteer will be offered the opportunity to discuss the collective findings and to read a first draft of the portion of the thesis dealing with his or her interview. Modifications that he or she requests will be incorporated into succeeding drafts.

Interview Guidelines:

Semi-Structured Interview with School Personnel

Background information on the participant

Education/employment

Previous experience with children whose families are dealing with advanced disease, especially cancer

Nature of contact with the child.

How long have you known the child?

In what capacity - teacher, counselor?

How much time per week did you spend with the child during the period when their parent had advanced cancer?

Do you see the child currently? In what capacity?

The child in the school environment: "What kind of child was this?"

Strengths shown in the school environment

Any areas of difficulty - academically, socially

Behaviour

Were there any marked changes in the child's behaviour 4-6 months before the parent's death? What were they?

Were there any additional changes 1-2 months before?

At the time of death?

After the death?

Social Interaction

Were there any changes in the child's interactions with other children 4-6 months before the parent's death?

Were there any additional changes 1-2 months before?

At the time of death?

After the death?

Gather details of the changes.

Preparation for parental death

In what ways was the child prepared for his or her parent's death?

Were any events planned with the child which could provide material for commemoration after the death? *If so, gather details.*

Was the child involved in caring for the dying parent? In what ways?

How did the child discuss what was happening at home?

(Be cautious not to breach confidentiality with school counselor here).

Conclusion:

What forms of assistance was the school able to provide for the child?

Was the child referred for other services? *If so, gather details.*

Were there any services that you would have liked to have been able to offer the child, that were not available? *(If yes, gather details of services)*

During what period do you think these services could have been helpful?

Is there anything you'd like to add about the family that we haven't discussed? Anything else?
What was it like for you to live through this time with the child and his or her family?
Is there anything you'd like to discuss on this issue that's not specifically about this family?

Debrief (tape recorder off):

What has it been like for you to do this interview?
Is there anything you'd like to ask me?

Discuss:

Once all interviews are completed, school personnel will be offered the opportunity to discuss the collective findings and to read a first draft of the portion of the thesis dealing with their nterview. Modifications that they request will be incorporated into succeeding drafts.

Appendix IV

Individual letters of thanks were sent to each participant within five days of the interview. A generic letter follows, but each was written to be appropriate specifically to the person for whom it was written. Details of the participant's relationship to the family, certain aspects of the interview, or specific qualities that the participant had brought to it might be included.

Dear Participant:

I want to extend my heartfelt thanks to you for your participation last week in the research project I am conducting on Adult Perceptions of Children with A Parent with Advanced Cancer. Your firsthand experience with and detailed knowledge of *(name of client)* and her two children over the year that you visited her will add an important dimension to the project. *(One or two sentences were usually added here that were specific to the individual participants.)*

After all the interviews have been completed, and I have written an initial draft of the thesis, I will ensure that you have the opportunity to check through the section that deals with your interview, so that you may make any modifications that you judge are necessary. It is important that the interpretation I place on your words fits with what you had originally meant.

I am very appreciative of the time you gave me, and the thoroughness and thoughtfulness with which you answered my questions. Thank you, once again.

Yours sincerely,

Sheila Lindfield

Appendix V

Case 1

Relevant Codes & Frequency Count

F1 = Ralph, the father in Case 1
HV1 = Anna, the hospice volunteer in Case 1
M1 = Elizabeth, the mother in Case
OB1 = Richard, the older boy in Case 1
R = myself, the researcher
SC1 = Jane, the school counsellor in Case 1
ST1 = Jessie, the school teacher in Case 1
YB1 = Robin, the younger boy in Case 1

Table 1: Case 1

Code	Freq	Code	Freq
Childcare	10	Diagnosis	04
Financial problems	12	Normalcy	10
F1 before ill inconsistent with OB1	03	F1 before ill occupation	02
F1 before ill spirit post accident	02	F1 could not stand noise	02
F1 drank heavily	06	F1 end shuts M1 out	03
F1 outlived prognosis	02	F1 wanted to be at home	07
F1: OB1 wanted hate, yelled at him	04		
HV1: M1 freq'y & location of visits	07	HV1: M1 role	04
HV1: M1 didn't agree buying drink	02	HV1: M1 picked her up after death	03
HV1: M1 how experienced visiting	02	HV1 background & previous work	07
HV1 philosophy	04	HV1 thinks OB1 would refuse services	01
M1: F1 background & relationship	14	M1: F1 hurt by drinking	02
M1: OB1 angry at him	02	M1: OB1 decided not at F1's death	02
M1: OB1 gives in to son	09	M1: OB1 knows encourages feelings	09
M1: OB1 major parenting responsibility	03	M1: OB1 prepares, paces & respects	18
M1: OB1 protective of son	04	M1: OB1 religious teaching	06
M1: OB1 shows her feelings	02	M1 end dedicated F1	06
M1 end hated shut out by F1	05	M1 end last moments with F1	02
M1 end puts F1 in hospital	02	M1 end surgery conflicts F1 cancer	06
M1 accommodating	09	M1 coped	09
M1 demands on self	43	M1 feels did all could	02
M1 friendly sweet & honest	04	M1 lacked support system	06
M1 philosophy	08	M1 support system	38
OB1 background	02	OB1 end last visits F1	08
OB1: F1 Father's Day outing	02	OB1: F1 feelings re cancer	04
OB1: F1 helpful & accepting	04	OB1: F1 wants visits alone	03
OB1: HV1 didn't like her	01	OB1: M1 demanding of her	13

OB1: M1 disliked her showing feelings	02	OB1 academic issues	04
OB1 classmates loyal & tolerant	05	OB1 previous exp'ce with death	01
OB1 problems	09	OB1 reluctant to talk at school & home	14
OB1 shows anger at school & home	22	OB1 support system	15
OB1 upset & sad at school & home	06	OB1 weight problem	05

SC1: M1 concerns re OB1	03	SC1 : M1 initial contact	02
SC1: M1 provides support	06	SC1: OB1 early contact	06
SC1: OB1 - he takes charge	02	SC1: OB1 not open re feelings	07
SC1: OB1 offers support	09	SC1: OB1 opened up a bit	05
SC1: OB1 tense & stubborn	02	SC1 professional background	04
SC1 philosophy	04		

ST1: M1 field trip	02	ST1: M1 regards highly	02
ST1: M1 & OB1 reflects on exp'ce	04	ST1: OB1 background	04
ST1: OB1 didn't know how to help	02	ST1: OB1 field trip	02
ST1: OB1 prepares classmates	02	ST1: OB1 puts self in his shoes	03
ST1 information and support	10	ST1 philosophy	05
ST1 professional background	01		

Mechanics of interview	23	Mechanics of transcription	02
Participation	07	R impressions participants & OB1	13
R journey	10	R on topic	04
R possible avenues extra interviews	04	Recommendations for OB1	07

Case 2

Relevant Codes and Frequency Count

F2 = Paul, the father in Case 2
FOB2 = Ross, Jan's son, the friend of the older boy in Case 2,
HV2 = Sue, the hospice volunteer in Case 2
M2 = Christine, the mother in Case 2
MFOB2 = Jan, the mother of a friend of the older boy in Case 2
N2 = Ashley, the nanny in Case 2
OB2 = Graham, the older boy in Case 2
R = myself, the researcher
ST2 = Sarah, the school teacher in Case 2
YB2 = Lawren, the younger boy in Case 2

Table 2: Case 2

Code	Freq.	Code	Freq.
Catalytic Validity	06	Diagnosis	06
Financial issues	02	Normalcy	27
F2 & M2 background	14	F2 & M2: OB2 impart values	04
F2 demands on self	12	F2 on cancer	07
F2 on parenting	06	F2 philosophy	05
FOB2 character	16	FOB2: OB2 wanted time away	06
HV2: M2 relationship	03	HV2: M2 received referral	02
HV2: M2 responsibilities & freq'y visits	13	HV2: OB2 & F2 limited contact	02
HV2 background & future	07	HV2 info & support	03
HV2 motivation & philosophy	08		
M2 concern for HW2 N2 & MFOB2	07	M2 end last days and death	14
M2 & F2 didn't want OB2 told	24	M2 & F2 hope and work together	15
M2 & F2 relationship	06	M2 & F2 support system	30
M2: HV2 discuss OB2	02	M2: N2 looked after children well	02
M2: OB2's birthday party	06	M2: OB2 cancer affects playing	10
M2: OB2 firm and strict	09	M2: OB2 gauges & tells	08
M2: OB2 tolerant knows stressed	01	M2: OB2 needs nannies	03
M2: OB2 separates herself	02	M2: OB2 & YB2 background	02
M2: OB2 & YB2 concern and sadness	18	M2: OB2 & YB2 loving	02
M2 demands on self	11	M2 effects of cancer	22
M2 fights to live & be normal	32	M2 possesses irony & humour	03
M2 private person	12		
MFOB2: F2 contact & relationship	10	MFOB2: M2 available and supportive	18
MFOB2: M2 1st meetings	14	MFOB2: M2 friendship	27
MFOB2: M2 last visit	05	MFOB2: M2 learns cancer & serious	09

MFOB2: M2 parenting differences	06	MFOB2: M2 parenting similarities	03
MFOB2: M2 spends time away	06	MFOB2: M2 reflects on experience	08
MFOB2: N2 mutual support	10	MFOB2: OB2 careful & considerate	07
MFOB2: OB2 demanding relationship	15	MFOB2: OB2 & FOB2 limits on telling	09
MFOB2: OB2 & FOB2 visit M2 hospital	04	MFOB2: OB2's friendship with FOB2	34
MFOB2 background	01	MFOB2 demands on self	45
MFOB2 information & support	12		

N2: F2 relationship	03	N2: M2 affected by cancer	05
N2: M2 encourages support	02	N2: M2 hiring & start	02
N2: M2 takes over responsibilities	03	N2: M2 talk character & commitment	03
N2: OB2 difficulties re not knowing	04	N2: OB2 responsibilities hrs & duration	07
N2 background	07	N2 demands on self	04
N2 information & support	02	N2: YB2 role & relationship	03

OB2 character	26	OB2: M2 day of death	02
OB2: M2 knew had owwie	05	OB2: M2 didn't know cancer & serious	20
OB2: M2 observant of rules	05	OB2: M2 visits in hospital	06
OB2: MFOB2 trusting	07	OB2: N2 needs time attention to bond	03
OB2 angry & upset	13	OB2 bright intellectual & proud	22
OB2 copes through learning	04	OB2 fearful & anxious	15
OB2 long term effects cancer & YB2	06	OB2 misses out	05
OB2 physical dev't & confidence	03	OB2 physically sick	01
OB2 previous exp'ce with death	02	OB2 support system	20

ST2: M2 & F2 regards highly	02	ST2: M2 knew cancer & serious	02
ST2: OB2 difficulties re not knowing	09	ST2: OB2 duration in class	06
ST2 previous exp'ce kids losing parent	02	ST2 professional background	01

Mechanics of interview	32	Mechanics of transcription	02
Mechanics of respondent validation	04	Participation	19
R impressions participants & OB2	09	R on topic	05
R possible avenues, extra interviews	10		

Recommendations for OB2	17

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