

THE EXPERIENCE OF TEENAGERS LIVING WITH A PARENT
WITH ADVANCED CANCER

By

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Abstract

The purpose of this study was to examine the experience of teenagers living with a parent with advanced cancer, and to determine whether the conceptualization of "fading away", as described by Davies, Chekryn-Reimer, & Martens (1990), reflects the teenagers' experience as it does the experience of children over the age of 18 years in the same situation. The grounded theory approach to qualitative research was the method used in this study.

Data were collected through a series of interviews with eleven teenagers who were living with a parent with advanced cancer. Initial interviews were loosely guided by a set of questions derived by Davies et al. (1990), from their previous research on the conceptualization of "fading away". Data were analyzed according to the constant comparative method of Strauss & Corbin (1990), in order to uncover core categories. The data were then in a format which could be, first, discussed within the conceptualization of "fading away", and second, compared to data from children over 18 years from the research of Davies et al. (1990).

Findings revealed that living with a terminally ill parent undoubtedly had a profound emotional and physical impact on the teenagers in this study. The teenagers described the phenomenon of shielding which was a useful strategy they adopted in order to pursue the developmental tasks of adolescence, and to get on with their own lives despite the worsening situation at home. Four of the seven phenomena of the conceptualization of "fading away" reflected the experience of the teenagers and three did not. The differences between the two age groups of children could be accounted for by developmental stage.

The findings from this study provide nurses with a better understanding of the experience of teenagers living with a parent with advanced cancer. It provides direction for assessing, teaching and supporting teenagers living in this type of family

situation, and offers guidance for working with the parents of these teenagers.

Implications for future research include further exploration of different aspects of the teenagers' experience, in-depth examination of the phenomenon of shielding with different populations of teenagers, and a recommendation for intervention studies.

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CHAPTER 1

Introduction

Background to the Problem

There are approximately 100,000 new cases of cancer diagnosed in Canada every year. About 26,000 of these cases are women under the age of 54 years and about 18,000 are men in the same age group (National Institute of Canada, 1989). Over half of these individuals will die from their disease. Many in this age group have young or teenage children who experience living with cancer in their family and who face the possibility, and at times the inevitability, of their parent's death.

In the few months preceding death, the individual with advanced cancer is cared for either at home or in hospital. With a trend toward cuts in hospital funding, bed shortages, greater acuity of illness in hospitals, and nursing shortages, more and more people with advanced cancer will be cared for at home by family and friends, rather than in hospital. According to Brown, Davies and Martens (1990), many families also prefer to care for their dying family member at home rather than hospital. Day to day living, however, for these families can lead to feelings of social isolation, a sense of being tied down, role overload, and physical fatigue (Brown et al., 1990). All family members, not just the person with advanced cancer, feel the impact of the cancer experience on their daily lives.

One predictor of success of the palliative home care experience is the accessibility and availability of home care services, including visiting nurses (Brown et al., 1990). Nurses are often responsible for assisting the terminally ill cancer patient and family in planning and providing care, and in coping with the demands of life-threatening illness. Many home care and hospital nurses consider the whole family as the unit of care rather than just the individual patient (Giacquinta, 1977). This viewpoint reflects the belief that an illness experience in one family member has an impact on every other member and on the family as a whole. Care of the entire

family at home may in many instances prevent hospitalization of the terminally ill family member as nurses support and educate caregivers, while ensuring symptoms in the patient are prevented or, at the least, well managed. If nursing interventions are to be appropriate and effective in the home care palliative situation, it would seem imperative that nurses have a clear understanding of the impact upon all family members of having one of its members dying from cancer at home.

Most of the emphasis in the published literature on the impact of terminal illness on the family has focused either on the patient's response to illness or on the spouse's needs or adjustment to the situation. We therefore know very little about how the advanced cancer experience affects other family members such as the children. The only systematic investigation into the nature of this impact on the family as a whole, during the terminal stage of illness, has been done by Davies, Chekryn-Reimer and Martens (1990). In this study, the family's experience is conceptualized as a transition of "fading away", incorporating three phases: The Ending, the Neutral Zone and the Beginning. Families with children over the age of 18 participated in the study but not families with children younger than 18 years. There is no published research to date on the impact of advanced cancer in a parent on the family which consists of one or more adult members and at least one child under the age of 18 years.

It may be anticipated that families with teenagers might perceive the advanced cancer experience quite differently from other families. There are well-documented conflicts that frequently occur in the well family with teenage children (Grinder, 1973). Most teenagers emotionally withdraw from the family unit and intensify relationships outside of it in order to master the developmental task of emotional and physical separation from parents. Having a sick parent at home creates conflict because the process of separation is reversed. Teenagers are pulled in the opposite direction from the natural course of emotional separation and

brought into reintensified contact with parents (Wellisch, 1979). They may feel their freedom has been restricted because of this pull toward being at home more, which may then lead to feelings of isolation from their friends (Berman, Cragg, & Kuenzig, 1988). There is also documented evidence of the difficulties adolescents experience when a parent is fatally ill, such as acting-out behaviour, extreme anxiety and poor scholastic achievements (Rosenheim & Ichilov, 1981; Wellisch, 1979). The feelings and behaviour changes experienced by these teenagers will undoubtedly have ramifications on the functioning of the family as a whole. At the present time, however, there is no documented research on the family with teenager's perceptions of caring for a parent with advanced cancer at home.

The topic of this research project therefore was the experience of families with teenagers caring for a parent with advanced cancer at home. The data obtained were compared to the findings of Davies et al. (1990) to ascertain whether the conceptualization of "fading away" was verifiable as a theoretical abstraction for families with teenage children as it was for those with children over the age of 18 years. The data from the proposed study has the potential to generate additional information to expand or broaden the conceptualization. This expansion may then afford the conceptualization more general application as well as greater explanatory and predictive power (Glaser & Strauss, 1967).

Statement of the Problem and Purpose

Little is known about the experience of families with teenagers caring for a parent with advanced cancer. It is unclear how family members perceive the impact of the advanced cancer experience on their daily lives. It is also unknown whether the conceptualization of "fading away" is as applicable to families with teenagers, as it is to families with an adult child over the age of 18 years.

The overall purpose of this research project was to explore and describe the experience of families with teenagers caring for a parent with advanced cancer at

home, and to determine whether the conceptualization of "fading away" reflected that experience.

This research project was instigated in two stages. The first was the focus of this study and its purpose was to explore and describe the teenagers' experience, and to determine whether the conceptualization of "fading away" reflected their experience, as it did the experience of children over the age of 18 years caring for a parent with advanced cancer. The teenagers' experience was compared to the experience of children over the age of 18 years, using the data collected by Davies et al. (1990). The second stage will be to analyze the data collected from the patients and spouses of those families with teenagers, so that conclusions may be drawn about the whole family's experience caring for a member with advanced cancer, and about whether the conceptualization of "fading away" reflects that experience. The second stage of the project will be initiated on completion of the first, although data for the second stage (from the patients and spouses in the families with teenagers) were collected during the first stage of the project.

Research Questions

1. What is the experience of teenagers living with a parent with advanced cancer at home?
2. Does the conceptualization of "fading away" reflect the experience of teenagers when a parent with advanced cancer is cared for at home, as it does for children over the age of 18 years who are also caring for a parent with advanced cancer (Davies et al., 1990)?

Definition of Terms

The terms contained in the research questions were defined as follows:

Fading away - A transition that occurs for a family during the final stage of life of one of its members, as described by Davies et al. (1990)

Advanced Cancer - Cancer for which it is no longer medically appropriate to treat the patient with the intent to cure the disease

Teenager - 13 to 19 year old child residing in the same household as their parent who has advanced cancer

Experience - The personal meaning that the teenager constructs around living on a day-to-day basis with a parent with advanced cancer.

Significance of the Study

Each year more and more individuals are affected by cancer at a younger age (National Institute of Canada, 1989). This fact, along with the recent trend away from hospitalization at the end stage of life, dictates an increased demand for nursing care of the whole family, as the family takes on the prime responsibility of caring for their dying family member at home. A description and conceptualization of the teenager's experience living with a parent with advanced cancer will provide nurses with an increased understanding of that experience so that appropriate and effective interventions can be designed for those teenagers who are an integral part of the family unit requiring care. This increased understanding will assist nurses to anticipate problems and design appropriate interventions to address existing problems and prevent future problems. It will also help to prevent nurses from planning care based on their own assumptions and biases about the experience of the teenagers caring for a parent with advanced cancer at home.

This study adds to existing knowledge about families living with advanced cancer in one of its members by examining the teenager's experience within the family. It also comments on the relevance of the conceptualization of "fading away" for those teenagers who are living with a parent with advanced cancer. By building theory from the ground up in an inductive manner, as opposed to a deductive one, the meaning of the experience and its context for the family as a whole is preserved.

Assumptions and Limitations

The following two assumptions are inherent in the proposed study:

1. Living with a family member with advanced cancer has an impact on the day-to-day lives of all family members, including the teenagers;
2. Families can be viewed as open systems, with each member's response affecting every other member's response, all members being interdependent.

A limitation of the study was recognized at the outset. The quantity and hence the overall quality of data was somewhat compromised due to the limited time available to the researcher. However, the researcher has had considerable recent experience interviewing families as a research assistant for a family breast cancer study. This experience was expected to aid in the richness and quality of the data collected.

Summary

In this chapter, the problem and purpose of the overall project were outlined as well as the purpose of each of the two stages of the larger project. The research questions of Stage I of the study were stated and the terms defined. The significance of the study, the assumptions inherent in the study design, and the one limitation that was recognizable from the outset were all made explicit.

Chapter 2 reviews available literature on the impact of advanced cancer on the family, and specifically, the impact on teenagers of living with a parent with cancer. The research method used in this study is described in Chapter 3, and the findings from the interviews with the teenagers are outlined in Chapter 4. In Chapter 5, the findings are discussed in relation to existing literature on the topic. Finally, implications for nursing practice and research are examined.

CHAPTER 2

Critical Review of the Literature

In this chapter, pertinent theoretical perspectives and research studies will be examined in order to place this study into the context of current literature. The following four areas of literature will be explored:

1. The Impact of Advanced Cancer on the Family;
2. Family-Oriented Research and the Cancer Experience;
3. Family-Oriented Research and Advanced Cancer;
4. The Impact on Teenagers of Cancer in a Parent.

The Impact of Advanced Cancer on the Family

Cancer in one individual undoubtedly impacts upon the family in which that person resides (Lewis, 1986) as all family members, not just the patient, share the strain and demands of the illness (Olsen, 1970). Understanding all family members' responses to cancer then is crucial if nurses are to effectively target support to the whole family.

However, most of the research studies to date which profess to examine the impact of advanced cancer on the family have only investigated the impact on individual family members, usually the spouse or primary caregiver, and not the impact on the family as a whole. In fact, only five studies in total were found which included the cancer patient when investigating the impact of advanced cancer on the family (Chekryn, 1984; Googe & Varricchio, 1981; Grobe, Ilstrup & Ahmann 1981; Hinton, 1980; Putnam, McDonald, Dugan, & Logue, 1980). Similarly, only one study included teenagers in the interviews of family members of a terminally ill adult (Krant & Johnston, 1977-78). Ideally, when investigating issues such as the impact of cancer on the family, all members of the family unit should be included in the study design: the cancer patient, their spouse or partner, and any children or other family members residing in the family home. All members of the family should be

interviewed. This wholistic approach would reflect the belief that the family, not just the individual with cancer, is the unit of care for nursing.

Despite the lack of evidence for this wholistic approach to research in the area of advanced cancer, the studies in the area do reveal some useful information. Northouse (1984) reviewed a total of 24 studies of which 15 investigated family members in the terminal phase of cancer. Similarly, Lewis (1986) reviewed 15 studies, of which six focused on the impact of advanced cancer on the family. These studies and several more recent ones comprise the extent of documented reports on the topic of the impact of advanced cancer on family members. The findings will be discussed under three headings: 1. Emotional impact of advanced cancer; 2. Physical impact and demands of advanced cancer; and 3. Alterations in communication, roles and responsibilities.

Emotional Impact of Advanced Cancer

The person with advanced cancer is liable to experience a variety of emotions at different times, such as anxiety, depression, fear of dying, uncertainty about the future, anger, and sadness (Clark, 1990). Kubler-Ross (1969) states the natural grieving process which occurs for all dying persons is usually accompanied by a wide variety of emotional responses.

Family members are most often the primary source of emotional and physical support for the individual who is dying at home (Hinds, 1985; Parsons, 1977; Rose, 1976). There is evidence that providing such support often has a negative impact on family members, particularly on the primary caregivers. The patient's changing health state creates a great deal of uncertainty and stress for the caregivers (Chekryn, 1984; Gotay, 1984; Hinds, 1985; Lovejoy, 1986; Wright & Dyck, 1984), as well as a fear of the future (Krant & Johnston, 1977-78; Welch, 1981; Wright & Dyck, 1984), and fear of the person dying (Gotay, 1984; Krant & Johnston, 1977-78; Welch 1981). Some family members experience feelings of helplessness and guilt

(Chekryn, 1984; Giacquinta, 1977; Holing, 1986; Krant & Johnston, 1977-78), and several described existential concerns (Chekryn, 1984; Gotay, 1984; Krant & Johnston, 1977-78).

Vachon, Freedman, Formo, Rogers, Lyall & Freeman (1977) interviewed 73 widows, 81% of whom rated the period of final illness as extremely or very stressful. Comparing a control group of widows of chronic cardiovascular disease patients and widows of cancer patients, Vachon et al. (1977) found that the final illness was much more stressful for the cancer wives than for the other group. The cancer wives described feelings of helplessness and frustration at not being able to relieve their husbands' suffering. In contrast, the wives of the cardiovascular patients did not describe feeling helpless but saw their role as active and useful in relieving their husbands' suffering. Similarly, Rose (1976) interviewed 26 spouses of deceased cancer patients who overwhelmingly supported the claim that caring for a cancer patient at home is a profound emotional burden. They described a sense of hopelessness about the situation and indicated that the stress was created from the wide range of demands placed upon them in caring for their ill spouses while trying to maintain usual family functions. Likewise, Grobe, Ilstrup, and Ahmann (1981) supported this conclusion as 46% of 28 family members of advanced cancer patients, and 52% of 29 family members of deceased patients, expressed a need for emotional support during the terminal care period. The above studies undoubtedly support the idea that caring for a family member with advanced cancer at home often has a great emotional impact on family members.

Physical Impact and Demands of Advanced Cancer

Caring for a terminally ill member at home often requires intense physical work for family members (Martens & Davies, 1990). The greatest concerns are often about the best ways to handle the patient's physical needs and personal care (Grobe, Ilstrup, & Ahmann, 1981; Holing, 1986; Skorupka & Bohnet, 1982; Welch, 1981).

Holing (1986) interviewed 14 primary caregivers of terminally ill family members. The subjects identified 66 critical events in total during the terminal phase, 69.7% of which were perceived as stressful and 30.3% perceived as joyful. Almost half of the caregivers identified some physical difficulty in providing care for the terminally ill person, primarily problems in lifting or moving the person. Stetz (1987) also found that 69% of 65 caregivers of advanced cancer patients at home reported that the greatest demand was assisting the ill spouse with activities of daily living and treatment regimens, as well as coping with changes in the physical and/or emotional state of the ill spouse.

Caring for a family member with advanced cancer is not only physically challenging for family members but also often causes ill health and fatigue (Googe & Varricchio, 1981; Vachon et al., 1977; Welch, 1981). Googe and Varricchio (1981) interviewed 15 primary caregivers of terminal cancer patients being cared for at home and found that 53% lost sleep because of patient care demands. Such statements as "too worried to sleep", "having to provide care during the night", and "afraid the patient might die" were cited as examples of family members' statements. Stetz (1987) also reported that 22% of 65 spouses of terminal patients suffered excessive fatigue or illness as a direct result of caregiving. The above studies clearly indicate that caring for a terminally ill family member at home has a physical as well as an emotional impact on the primary caregivers.

Altered Communication, Roles and Responsibilities

Communication within families is viewed as the cornerstone of healthy family functioning and serves to bind together all the subsystems of the larger family system (Friedman, 1986). In the family where one member is terminally ill, communication is often strained and talking about death itself may be particularly difficult. Three studies found that limited discussion about death takes place in families. Krant and Johnston (1977-78) found that 78% of the 126 family members

interviewed had not discussed death with the dying family member. Similarly Vachon et al. (1977) found that 61% of the couples in their study never discussed death with one another, and Hinton (1981) reported that 65% of the couples had either very limited or no discussion of death. However, both Vachon et al. (1977) and Hinton (1981) suggested that non-discussion may be an effective coping strategy for some individuals. Non-discussion made no difference to the widow's adjustment (Vachon et al., 1977), nor to the anxiety or depression level of the patient (Hinton, 1981). In contrast, other studies showed that open communication aids adjustment in the bereavement phase (Cohen, Dizenhuz, & Winget, 1977) and affects the level of closeness in the couple prior to death (Hinton, 1981).

As with alterations in communication, there is substantial evidence that household roles and lifestyle are impacted as a result of cancer. Caring for a terminally ill family member at home requires that there be reorganization of the usual family roles and responsibilities. Several studies suggested that family members found changes in roles and relationships to be of some concern (Chekryn, 1984; Giacquinta, 1977; Gotay, 1984; Stetz, 1987). However, in Lovejoy's sample (1986) of 105 family members, 45% described changes in family responsibilities and priorities in a more positive light, with many carving out new purposeful roles in relation to caring for family members. Many found that role change aided in coping with the situation. Some family members however, found the responsibility of managing the household and finances to be a demand (Lovejoy, 1986; Stetz, 1987) and others commented on the financial difficulties of the family since their family member became ill (Googe & Varricchio, 1981; Hinds, 1985). Stetz (1987) interviewed 65 spouses of advanced cancer patients in order to describe the caregiving demands. She found that the second most frequently reported demand (39%) was coping with additional role responsibilities and economic demands.

Limitations of the Impact Studies

Although the studies described above provide valuable information about the emotional and physical impact of advanced cancer on family members and alterations in family communication, roles and responsibilities, only one study included teenagers in the interviews with family members (10 out of the 126 family members interviewed were teenagers in the study by Krant & Johnston, 1977-78). Very little therefore is known from these studies about the experience of caring for a family member with advanced cancer in a family with children or teenagers. One might expect the experience and perceptions of family members in this family type to be quite different from those in families without children or teenagers. For example, teenagers may have a need to talk about death within the family because of their preoccupation with death at their particular stage in development (Grinder, 1973). Alternatively, teenagers may not feel comfortable talking about death-related issues because of a typical pattern of deterioration in adolescent/parent communication at this developmental stage (Hunter, 1985). At the present time then, there is little information available about teenagers' experience living with a parent with advanced cancer at home from which to derive family level nursing interventions.

As well as discounting the experience of children, the majority of the studies described above are retrospective in nature, interviewing family members about the impact of the terminal phase of cancer on them after the family member has actually died. This retrospective approach assumes accuracy of recall of past events as well as assuming that retrospective accounts actually represent the experience as it is lived. More data on the current experience, that is, using prospective rather than retrospective designs, are required in this area and particularly from the perspective of the family with children and teenagers.

Family Oriented Research and the Cancer Experience

As mentioned above, research studies which are allegedly aimed at assessing the impact of cancer on the family have almost always interviewed only individuals with cancer and/or their spouse or primary caregiver, and have generally not examined the perceptions of all family members, especially the children. Lewis, Woods, Hough and Bensley (1989) describe chronic illness in a family as a multidimensional experience which create demands or stresses on individuals which then have an impact upon the emotional and physical resources of the family as a unit. Thus, if chronic illness has an impact upon the entire unit, family research should reflect this by collecting data on family functioning, with all family members being interviewed individually and as a group.

Only one research team was found, headed by Lewis, (Lewis, Ellison & Woods, 1985; Lewis et al., 1989; Stetz, Lewis & Primomo, 1986) which consistently interviewed all family members including young children and teenagers. Their research focused on families living with non-metastatic cancer in the mother. One hundred and twenty-six families were interviewed (Lewis et al., 1985). Children were divided into three age groups: 7-10 years, 10-13 years, and 14-19 years. Different responses to "The Child's Perception of the Mother's Illness" interview schedule were found for each age group. Adolescent interviews illustrated teenagers' conflict between wanting to spend time with their mother and wanting to "do their own thing". The authors clearly state that there is a great need to consider the impact of cancer in the mother on family functioning and particularly on the children and teenagers, so that psychosocial problems will not occur (Lewis, Ellison & Woods, 1985). Data from this longitudinal study are still being collected and are obviously yielding interesting and useful information for nurses caring for families with cancer. No research has been initiated, however, investigating the family with teenagers in

which the parent has advanced cancer, rather than cancer in the earlier diagnostic or treatment phases.

Family-Oriented Research and Advanced Cancer in a Parent

The only research study which 1. expands the definition of the family to include the individual with cancer, the spouse and an adult child, and 2. explores the impact of advanced cancer rather than non-metastatic cancer, is the one which is still in progress by Davies, Chekryn-Reimer, & Martens (1990). Eighteen families participated in the first phase of the study and patients, spouses and children over 18 years were interviewed using semi-structured interview guides. All patients were deemed palliative; that is, they were no longer receiving curative therapies. The purpose of the first phase of the study was to examine the experience of families having a member with advanced cancer who was receiving palliative care either at home or in hospital. Conceptual analysis of the data revealed that families were in transition: a transition from living with cancer to dying with cancer. The authors described the transition as one of "fading away". Fading away is characterized by three phases, each one describing aspects of the experience and tasks to be accomplished by the patient and the family members as they come to terms with inevitable death.

The first phase, "The Ending", was signalled by a decline in the patient's physical condition as the patient was no longer seen as maintaining a plateau of health. Unrecoverable weakness, inability to mobilize, loss of independence in personal care, and loss of mental clarity were the four major symptoms which signalled this decline. During the Ending phase, families faced two tasks: redefining and dealing with burden. Redefining occurred as the patients and family members accommodated to changes in the patients' health status and began to let go of the old view, seeing the patient in a different way. In redefining themselves, patients perceived themselves to be a burden to their families and desired to relieve that

burden. Family members did not, however, indicate that they felt the patients were burdens to them and, in fact, adult children often tried to relieve the patient's feelings of burden by concealing their own sad feelings.

The second phase, "The Neutral Zone", was one of emptiness characterized by feelings of fear, loneliness, confusion, and uncertainty. The three tasks of this phase were: struggling with paradox, contending with change, and searching for meaning. The main struggle had to do with the paradox of living and dying at the same time. Patients struggled with the paradox of wanting to fight to keep going but also wanting to give up. Family members struggled with carrying on the normal business of living while caring for someone who is dying. Contending with change occurred at both individual and family levels. Changes included alterations in roles and responsibilities within the family, socializing patterns, values or health status. Searching for meaning was one way of enduring the discomfort of the Neutral Zone.

The third phase, "The Beginning", reflected subtle shifts toward reorientation and realignment. Those families who had entered this phase had reoriented to life as it is now, and had a perspective of living from day to day. Family members were preparing for the patient's death. Both patients and family members entering this phase could describe aspects of personal growth.

The way in which these families faced the tasks of the transition was related to style and past experience, particularly past experience with loss and death. Individuals and families had different styles and these were reflected in how they managed the current transition. The first phase of the Davies et al. (1990) study therefore provided a detailed description of the experience of families living with a family member with advanced cancer.

The second phase of the study was instigated using a broader definition of family, to include a spouse and/or an adult child and sometimes other relatives such as a sibling, niece, nephew, aunt, uncle or good friend. The more traditional

definition of "family" selected in phase I of the study was often found to preclude families with other combinations of individuals. Data were collected on eight families in order to verify whether the beginning conceptual analysis of the transition of "fading away" accurately reflected the experience of terminally ill patients and their families. Findings from phase II of the study have not yet been published but data elicited from the children in their study are used for comparison with the teenager data in this study.

With an understanding of the issues families face, nurses can more effectively assist them "to acknowledge the ending of their life with cancer and to define a new way of living out their final days together as the patient and the family as they have known it fades away" (Davies, Chekryn-Reimer, & Martens, 1990, p. 19).

The Impact on Teenagers of Cancer in a Parent

Although there is a dearth of research on families with teenagers caring for a parent with advanced cancer at home, there has been some individual-focused research on teenagers and the impact of cancer in a parent. However, adolescents' responses to death of a parent have been of more interest to researchers than their responses to living with and caring for a parent with advanced cancer prior to death.

For example, Furman (1985) describes three tasks in the grieving process that bereaved children and adolescents face: 1. to understand and accept the reality and circumstances of the death; 2. to mourn effectively; and 3. to resume and continue the course of living. Furman (1985) and other researchers have identified several variables that influence the outcome of this grieving process, including the parents' attitudes toward death (Furman, 1985); adolescent's preparation for, and involvement in, the mourning process (Adams-Greenly, Beldoch, & Moynihan, 1986; Furman, 1985); subsequent changes in the home and family roles, cultural and religious beliefs, availability of support systems before, during and after death (Elizur & Kaffman, 1983; Gray, 1987; Hilgard, Newman, & Fisk, 1960); good relations with

the surviving parent prior to loss, and a balanced personality style (Gray, 1987). Although these studies yield interesting data, it is important to note once again that the results are based on retrospective accounts in all studies. Hilgard et al. (1960) interviewed adults who had lost a parent as a child; Gray (1987) interviewed individuals who had lost a parent six months to five years previously when they were between 12 and 19 years old; and, Elizur et al. (1983) based their conclusions on parents and teachers' accounts of bereaved childrens' reactions to their fathers' deaths 6 to 42 months previously. There has been no consideration of children or teenagers' perceptions of the experience of living with advanced cancer in a parent.

Other researchers report depression and emotional disturbances in adults who, as children, experienced the death of a parent (Adam, Lorenz, Harper, & Steiner, 1982; Beck, Sethi & Tuthill, 1963; Brown, 1966; Dennehy, 1966). Conclusions from these four studies however may not be generalizable to the larger population as the samples were selected from inpatient psychiatric populations. Three out of the four studies were also conducted almost 30 years ago, thereby not reflecting the growth of the thanatology field since that time.

Death of a parent for a child or teenager is always traumatic no matter the family environment and external circumstances (Furman, 1985). However, the young people may cope more effectively with this trauma if assistance and support are made available to them during the final few months of living with their ill parent. Intervention with teenagers and children during the period before death may play a part in preventing difficulties in adulthood (Rosenheim & Ichilov, 1981). It would therefore be useful to have an understanding of teenagers' experience living day to day with a parent with advanced cancer.

Only seven published studies were found which addressed the impact of cancer on children or teenagers as they experienced it on a day-to-day basis. Four of these studies investigated childrens' responses to a parent's cancer at an early stage

in the disease trajectory, usually at the diagnosis/treatment phase (Grandstaff, 1976; Lewis, Ellison, & Woods, 1985; Rosenfeld, Caplan, Yaroslavsky, Jacobitz, Yuval & Lebow, 1983; Wellisch, 1979). Only three were found which examined childrens' responses to advanced cancer in a parent (Adams-Greenly & Moynihan, 1983; Berman, Cragg & Kuenzig, 1988; Rosenheim & Ichilov, 1981). All studies describe the emotional response of the children/teenagers with feelings expressed such as sadness, fear, anxiety, anger, self-doubt and shock. Rosenheim and Ichilov (1981) describe a short-term preventive therapy program which aided in decreasing levels of anxiety in children of fatally ill parents and improving levels of scholastic and social functioning.

All of the studies also discussed the impact on roles and responsibilities for these children, who often take over more household tasks than they had done before the parent's illness. Berman et al. (1988) found that some of the adolescents interviewed felt their freedom to be restricted, which created difficulties with peer relationships. Similarly Lewis, Ellison and Woods (1985) reported that some adolescents felt torn between wanting to spend time with their parent and wanting "to do their own thing". They also complained about increased household responsibilities and restrictions on the use of the car. However, the same teenagers also commented on the positive effects of the cancer diagnosis such as bringing the family closer together or more time being spent on family activities.

Drawing from his clinical experience, Wellisch (1979) reported that the adolescent living with a parent with cancer has difficulty with what he calls the covert rather than overt role shifts. The covert role shifts, such as the conversion of the adolescent into a pseudo partner or confidante for the well parent, may promote acting-out behaviour. This has been contradicted, however, by Rosenfeld et al. (1983), who did not find adolescents acting out although they did find that teenagers often suffered from psychosomatic or mood disturbances.

Limitations of the Studies with Teenagers

Although these few studies reported some interesting findings, most of the data emerged from clinical practice rather than from a foundation of research. The data collected in the study by Grandstaff (1976), for example, were anecdotal and based on her clinical practice over a two-year period. Similarly, Wellisch's data (1979) were based on six case studies from his psychology practice. Greenly-Adams et al. (1983) reported anecdotal data collected from work with families in the social work department at Memorial Sloan-Kettering Cancer Center.

Only the studies by Lewis et al. (1985) and Berman et al. (1988) demonstrate commitment to scientific rigour. This suggests that few of the above conclusions can be generalized to a larger population of adolescents. There is an indisputable need, therefore, for more research studies on the impact of advanced cancer in a parent on the day-to-day lives of children and teenagers within the family context, so that interventions designed by nurses can reflect an understanding of the true nature of the experience for all family members.

Summary of Literature Review

Although several researchers have investigated the impact of advanced cancer on the family, most have focused on either the patient or the spouse/primary caregiver. Very few studies have focused on all family members within one family including young children or teenagers. Usually, therefore, only the perspectives of selected family members are considered rather than the entire family context. This technique fails to recognize that the impact of advanced cancer affects all family members and hence the family unit as a whole. Very little is known about the teenager's day-to-day experience of living with advanced cancer in a parent and even less about their responses within the context of the family unit.

The population targeted for this study therefore was teenagers who were living with advanced cancer in the family. A qualitative research method guided by

the grounded theory approach (Strauss & Corbin, 1990) was used to elicit a description of the experience in the words of the teenagers themselves. This description was then examined in relation to the conceptualization of "fading away" as described by Davies et al. (1990). The experience of the teenagers was then compared to data from children over the age of 18 years from the Davies et al. (1990) study. The research methods will be outlined in detail in the next chapter.

CHAPTER 3

Methods

Study Design

The study design should be determined by the research question (Goodwin & Goodwin, 1984; Morse, 1986). In areas where little knowledge exists, qualitative designs are appropriate in order to systematically document the issues, concepts, ideas or phenomena under study (Haberman & Lewis, 1990). A conceptualization or theoretical framework emerges from the empirical data whereby the critical properties and dimensions of each concept, along with their relationship with other variables, are described. This framework is then tested for verification of the proposed theory. From the detailed description of relevant concepts might follow an intervention study which calls for manipulation of these concepts.

Qualitative research designs are more than designs. They also represent how human beings interact within themselves and with their social environment; they are guided by a "world view". At the core of this view is the assumption that human beings create personal and social meanings as they transact with their surrounding (Haberman & Lewis, 1990).

The method of qualitative inquiry used in this study was the grounded theory approach (Glaser & Strauss, 1967). The term "grounded" refers to the discovery of theory from data that are anchored in empirical evidence. With this approach, data are not just organized according to themes but are also interpreted creatively using conceptual labels. Statements of relationship between the concepts are then elucidated to bring new insights into the phenomena being described (Strauss & Corbin, 1990).

The conceptualization emerging from empirical evidence in phase I of the study by Davies et al. (1990), provided a detailed description of the context in which families find themselves during the terminal phase of advanced cancer. According to

Glaser and Strauss (1967), verification of theory is crucial in order to establish "major uniformities and universals, strategic variations of theory under different conditions and grounded modifications of the theory" (p. 27). The purpose of phase II of the study by Davies et al. (1990) was to verify the conceptualization of "fading away" with additional families. One aspect of the current study was to verify the application of the conceptualization of "fading away" to the experience of teenagers within families, and to elaborate on certain dimensions of that conceptualization because of the different conditions.

The grounded theory approach in the current study, therefore, was utilized in three ways: 1. it inspired the development of a conceptualization of the experience of teenagers living with a parent with advanced cancer at home; 2. it assisted in potential verification of the conceptualization of "fading away" with a different age group of children of parents with advanced cancer; and 3. it allowed the potential generation of new dimensions to that conceptualization of "fading away".

Issues of Reliability and Validity

Research conducted using qualitative methods requires different criteria to assess reliability and validity of the results than those applied to quantitative methods.

Sandelowski (1986) suggested that auditability replace the criterion of reliability. Auditability exists when another reader can clearly follow the decision trail used by the researcher. The decision trail in this study is described in the presentation of findings, exemplified by excerpts from the data, in Chapter 4. The ease with which the decision trail can be followed was discussed with the chairperson of the thesis committee.

Validity refers to the degree to which researchers are actually observing what they believe they are observing. Sandelowski (1986) suggested that the criteria of fittingness and credibility be used instead of external and internal validity. Direct

observation of the participants during the interviews assisted in validating the data in the audiotaped interviews. Detailed descriptive field notes of subjects, settings, events, activities and behaviours, and reflective field notes of ideas, impressions and hunches were therefore written after each interview to assure fittingness. Credibility was addressed by ensuring the participants of the study could immediately recognize the descriptions generated from the data. As the analysis progressed, the emerging themes were validated by several of the teenagers, as being descriptive of their experience.

Other strategies were also used to help assure auditability, fittingness and credibility. Prior to the interviews, the researcher bracketed her beliefs about the experience of teenagers, by listing them and acknowledging how they might influence the interview process. Interviews were tape recorded in order to achieve accurate and precise accounts of the participants' perceptions and reactions to their situation. The thesis committee Chair reviewed several transcribed interviews and was consulted during data analysis to ensure that the conclusions could be recognized as emerging from the data.

Ethical Considerations

Ethical approval for this study was obtained from the Behavioural Sciences Screening Committee at the University of British Columbia, and the Nursing Research Committee of the institution from which participants were obtained.

All potential participants received an "Information Letter to Family Members" (Appendix A) that clearly outlined the nature and purpose of the study and the expectations of the participants. Written consent was obtained from each person who agreed to be interviewed and a written consent with two signatures (one from the teenager and one from the parent on his/her behalf) was obtained from the teenagers (Appendix B). A copy of the signed consent was given to each participant.

Great care was taken to safeguard the teenager's right to refuse to participate. Teenagers may have felt obligated to participate if their ill parent had wished them to. This issue of the teenager's right of refusal was discussed with the parent(s) prior to their discussing participation with their teenage children. Parents were told that the information from the individual interviews would be kept strictly confidential, and that any information that the teenagers or any family member shared in the individual interviews would not be shared with any other family member. The parents were encouraged to share this information with the teenagers when discussing participation with them, and the teenagers were also informed of this by the researcher prior to their final consent. The researcher also ascertained from the teenagers that the decision to participate was their own, and that they had not been coerced to participate in any way by their parents or any other family member.

Every effort was made by the researcher to protect the rights of the participants. They were assured of confidentiality of information at all times: any information that could identify the participant was omitted from the transcripts; audiotapes would be erased after reports were written; audiotapes and transcripts were stored in a locked drawer separate from the consent forms; and only the researcher, the transcriber and the thesis committee members had access to the transcripts. The right to withdraw from the interview or the study at any time was articulated to the participants at the beginning of each interview, with the assurance that withdrawal would not jeopardize care or treatment that the patient would receive. Before each interview participants were informed that they may choose not to answer any question, and that they may request a break from the interview or to leave the interview at any time.

The researcher was prepared for the fact that the participants might become distressed during the interviews and that in some cases a referral to an outside

resource person would be required. Many of the participants did become emotionally upset during the interviews but, when asked, none wished to discontinue the interview. Following one interview, the researcher decided an outside referral was required and, with the teenager's permission, a call was made to a medical social worker for the teenager to have follow-up counselling.

Selection of Participants

Sample Selection

Participants were selected for this study using theoretical sampling because of its appropriateness to the grounded theory approach. The participants were selected according to the theoretical needs and direction of the research (Morse, 1986). Because the needs and direction of the overall project were to understand the subjective meaning of the experience to all family members, the object was therefore to obtain detailed, relevant and comprehensive information. The sample was therefore selected by the researcher based on the participants' ability to provide such information. Data were collected from all members of the family with teenagers so as to follow the design of the study by Davies et al., 1990. Moreover, all family members were willing to participate, and it was thought that collecting data from all members in Stage I would also significantly hasten the completion of the whole project. The size of the sample was not predetermined because the completeness of the theory directed the selection and the size of the sample. The final sample was six families with a total of eleven teenagers. Effort was made to include both male and female teenagers of varying age groups within the range of 13 to 19 years. The reason for this was that it was appreciated that experiences of teenagers are often both gender and age related. For example, one might expect that the experience of a 13-year-old female living with a terminally ill parent would be significantly different from the experience of a 19-year-old male in the same situation. Despite this effort the majority of teenagers recruited happened to be female. It was decided to extend

the age range to 19 years because all but one of the adult children in the Davies et al. (1990) study were over 19 years.

Selection Criteria

Prior to the recruitment of participants, certain criteria were developed to guide the selection:

1. The family includes a member who:
 - a) has advanced cancer, that is, who no longer receives curative therapies and who has been identified by his/her physician as no longer an appropriate recipient of aggressive cancer therapy;
 - b) is a patient registered at the institution where recruitment is being carried out;
 - c) is judged by the clinical personnel and the researcher not to be significantly burdened by participation in the study, such as those whose physical or emotional symptoms are unmanaged;
 - d) may reside with spouse/partner or other primary caregiver such as niece, nephew, sibling, mother, father or good friend.
2. The family includes the patient, and at least one teenage child (13-19 years old) who lives at home. A spouse/partner or primary caregiver may be identified.
3. The family members are able to communicate in English.
4. The family members are willing to participate in the study and will all be available for interview.
5. The family will reside in the Lower Mainland of British Columbia and be accessible to the researcher.

Selection Procedure

The participants were selected from a cancer treatment facility in a Canadian city. The expertise of nurses, physicians and medical social workers was used to

identify potential families for recruitment. These intermediaries were given copies of the "Information Letter to Family Members (Appendix A) to distribute to potential families. Prior to distribution, the intermediary was asked to speak with the researcher to ensure that the family satisfied all selection criteria, and to ensure that the intermediary fully understood the purpose of the study prior to discussing the study with the potential participants.

When a family member expressed interest in participating or learning more about the study the intermediary asked permission for the researcher to contact them by telephone. Over the telephone, the purpose of the study was reviewed, questions answered, and encouragement given for any of the other family members to speak with the researcher prior to consenting to participate. The family member was then asked to speak with the rest of the family and, on agreement from all participants, an appointment for interview was arranged.

At the first interview each family member was given the chance to ask further questions prior to signing the consent form (Appendix B). A copy of the signed consent and a copy of the "Information Letter for Family Members" was given to each family member.

Recruitment of participants and completion of the interviews took three months. Following the individual interviews it had been the intention of the researcher to conduct a family group interview with all family members present. It was thought that data generated within a group would be somewhat different from data generated in the individual interviews and hence would add to the overall richness of the information received. However, it was suspected that the teenagers did not feel comfortable talking in a family group. In the first family, the teenager refused to participate in a group interview because she was "too busy". One of the teenagers in the second family backed out of the arranged family interview because of exams, and then decided just prior to the second arranged time that because of

limits on her time she did not wish to participate in a group interview. After these three unsuccessful attempts at arranging the group interviews, the researcher decided to discontinue the family group interviews.

Characteristics of the Participants

Eighteen family members from six different families were interviewed. Eleven of those participants were teenagers, nine females between 15 and 19 years, and two males 15 and 19 years old. The researcher had hoped to recruit equal numbers of male and female teenagers but by chance the first six families who were deemed suitable for the study happened to consist mostly of female teenagers. All members from four families were interviewed: four patients, three spouses and nine teenagers. The other two teenagers were interviewed to validate the themes that emerged from the data of the first nine teenagers and to add to the richness of the data.

Three of the seven adults had post secondary education, two had a high school diploma and two had completed grade ten. Three of the four patients were unable to work because of the illness and one worked two or three days a week when he felt able to. One spouse worked full time, one part time and one described herself as a housewife. Six of the eleven teenagers were in high school, two had dropped out of school and were looking for jobs, one was finished school and trying to decide on a career, and two were in post-secondary education.

All four of the patients interviewed were males between 45 and 58 years old; of the two families from which only the teenagers were interviewed, the patients were both female. Two of the patients interviewed had lung cancer, one had lymphoma and one had colon cancer. Three had been diagnosed less than two years previously and one had been diagnosed eight years before. All had been treated in the past with radiotherapy or chemotherapy and only one was presently receiving palliative chemotherapy.

Data Collection

Interviews were conducted with all family members in the first four families, in order to collect data on their experiences living with a member with advanced cancer at home. The question guide for the semi-structured interviews was compiled by Davies et al. (1990) for phase II of their study, and was based on the conceptualization of "fading away" (Appendix C). Two further interviews were conducted with different teenagers to validate the themes that emerged from the analysis of the teenager data from the first nine interviews, although themes were also validated as they emerged through the first nine interviews and in second interviews with four of the nine teenagers. A total of twenty-two interviews was conducted.

All interviews were audiotaped and transcribed verbatim. Descriptive and reflective field notes were recorded for all interviews. The participants were given the choice of being interviewed either in their own home or in the office of the researcher. Six of the eleven teenagers chose to be interviewed in the researcher's office and the rest of the interviews took place at the homes of the families. The fact that the majority of the teenagers chose the researcher's office as the location for interview may reflect that the teenagers felt that they could share more openly in a neutral space, away from their family. Prior to data collection, the researcher had some concern about how openly communicative the teenagers would be when interviewed about their personal lives. This reservation was unfounded however, because after the interviews many of the teenagers expressed how helpful it had been to talk about their situation at home.

Data Analysis

Although data were collected from all family members in Stage I of the project, only data from the teenagers were analyzed in this stage. The data from the patients and spouses will be analyzed in Stage II of the study.

An interview guide was used (Appendix C) to guide the interview although the interview was not confined by the questions in the guide. The researcher encouraged the family members to describe their experience using their own words and probes were used to encourage the participant to explore issues in more detail. The researcher allowed the interview to flow like a conversation so that the experience of the family member could be fully explored.

The interviews and field notes were transcribed following each interview. The researcher then listened to the audiotape of each interview while reading the transcript, to ensure accuracy of transcription and to derive a sense of the interview as a whole.

Data collected from the teenagers were analyzed after each interview. This enabled the addition of new questions as necessary for the following interviews and provided the researcher with an opportunity to present the analysis to participants for validation of the meaning intended.

The researcher used the grounded theory method of Strauss and Corbin (1990) to analyze the teenager data. Open coding was the first step of analysis whereby the data were conceptualized and categorized (Strauss & Corbin, 1990). Each observation, sentence or paragraph in each interview was viewed line by line as a discrete incident, idea or event and given a name which represented the phenomenon being described. As the coding proceeded, incidents, ideas or events were compared with one another and similar phenomena were given the same name. This process led to an initial list of conceptual labels which were then grouped into categories, with concepts which pertained to the same phenomena being grouped under the same category. The phenomenon represented by the category was then given a conceptual name which was more abstract than the concepts grouped under it. The list of categories generated in open coding is presented in Appendix D. In

addition to analyzing the content of participants' responses in the interviews, the transcribed notes and field notes were analyzed using the same procedure.

Following the procedure of open coding, which allowed the identification of categories, the data were then subjected to axial coding whereby connections were made between categories by using the coding paradigm of Strauss and Corbin (1990). Data that were broken down in open coding were then put back together in a relational form whereby certain conditions that gave rise to a category were explored. This procedure allowed the researcher to think systematically about the data and to relate them in complex ways (Strauss & Corbin, 1990).

Following the analysis of the teenager data and the drawing up of a list of categories, the data were then in a format which could easily be compared to the conceptualization of "fading away" with its seven major phenomena (Appendix E). This comparison served to ascertain whether "fading away" was verifiable as a theoretical abstraction for teenagers, and to generate additional information to expand or broaden the conceptualization. In Chapter 4, the categories that emerged from the teenager data are first discussed within the structure of the conceptualization of "fading away" and compared to data from children over 18 years. Second, conclusions about the essence of the teenagers' experience are presented.

Summary

This qualitative research study subscribed to the grounded theory approach. A total of eighteen family members from six different families were interviewed. All interviews and field notes were transcribed. Analysis of the data from the eleven teenagers resulted in a description of their experience living with a parent with advanced cancer, which was then compared to the conceptualization of "fading away" as described by Davies et al. (1990). The following chapter outlines the results from this analysis and comparison.

CHAPTER 4:

Findings

This chapter presents the findings from interviews with the eleven teenagers who participated in this study. Data collected from interviews with the other family members will be analyzed in Stage II of this research project.

Findings from the interviews with teenagers in this study will first of all be described within the context of the conceptualization of the transition of "fading away" as described by Davies et al. (1990). Findings from this study will also be compared to the findings of Davies et al. (1990) from their interviews with children of persons with cancer. All but one of the children in the Davies et al. (1990) study were over 19 years and will be referred to here as adult children. Similarities and differences in the experiences of the two age groups of children will be discussed. Second, certain elements that describe the uniqueness of the teenagers' experience will be highlighted and third, certain factors which influenced the teenagers' experience will be elucidated prior to discussion of the findings in relation to existing literature in Chapter 5.

Using data from their interviews with families, Davies et al. (1990) described the transition of "fading away" as having three phases: The Ending, The Neutral Zone and The Beginning. Within each phase families faced certain major tasks or phenomena: 1) redefining and 2) burdening, in the Ending phase; 3) struggling with paradox, 4) contending with change, and 5) finding meaning, in the Neutral Zone; and 6) living day to day and 7) preparing for death, in the Beginning phase. Findings from this study will be described utilizing these seven major phenomena as a framework for analysis.

The Ending

A sudden realization by the patient and/or family member that the patient was not going to recover marked the beginning of the Ending phase. The realization

that death was inevitable was triggered by a change in the patient's physical appearance such as increased weakness, decreased mobility or diminishing mental abilities. Although the realization was sudden, "fading away" was considered by patients and family members to be a process which occurred over time, as the patient slowly deteriorated.

Although the teenagers in this study acknowledged that their parent would most likely die from cancer, they viewed their parent's physical condition as a series of illness events, rather than as a process of slow decline. Each time the parent's physical condition worsened it triggered the realization in the teenager that their parent was going to die. The physical decline signified that the death could happen at any moment rather than signifying the beginning of a slow decline to death:

The only time I am deathly afraid he will die is when I see him bunched up over the toilet, or deathly pale and lost 25 pounds and not eating anything, when he is physically sick.

The teenagers reacted to what they saw physically or externally, so that when their parent's condition stabilized, the teenagers did not perceive this stable period as part of an overall decline but as a time to be hopeful that their parent would recover. The more physically well the parent appeared to be during the stable periods the less afraid the teenagers were that their parent was going to die:

I was worried when he was in the hospital. Compared to that he is better so I don't think anything is wrong. But you know I could be totally wrong. It could be more inside of him that I don't see on the outside. It's hard sometimes because he is really sick sometimes. Then it seems like there is no hope.

Because of the meaning attached to physical symptoms as signifying the imminence of death, there was extreme distress for the teenagers each time their parent's physical condition declined. Each time physical symptoms worsened, they reacted as though it was a new realization that death could happen in that moment:

I was terrified when he threw up that he was going to die right then and there. I didn't want to be there. I couldn't help. I just ran out of the room.

The teenagers had little understanding of the expected course of the dying process as one comprised of periods of decline alternating with periods of stability. The actual time of death therefore was unpredictable to the teenagers who became extremely fearful each time their parent's physical condition visibly worsened.

Location of care also affected the level of distress for the teenager. If their parent was in hospital for a period of time, it often signified something more serious than if the parent was at home, even though the parent was in a terminal stage of illness at home:

It was pretty horrible going in there and seeing him the first day, seeing him in a hospital bed. L. [sister] wasn't there. She couldn't handle it.

When the parent was at home the teenager was more likely to view their parent as they always had, as being well.

In contrast to the teenagers, the adult children in the Davies et al. (1990) study saw the slow decline of "fading away" as a process that happened over time and one which would ultimately lead to their parent's death. They described a sudden realization that death was inevitable when they acknowledged the decline in their parent's physical condition. They found it distressing to face the fact that their parent was no longer the vital and capable person they had always known him or her to be. Even during periods of relative stability in their parent's health, the adult children understood that death was inevitable.

Redefining

Davies et al. (1990) described the phenomenon of "redefining" as one which required a shift in how individuals viewed themselves and others if families were to successfully adjust to the reality that death was inevitable. Redefining occurred as the patient and family members accommodated to changes in the patient's health status and began to let go of the old view of the patient, seeing him or her in a different way. This readjustment helped both the patient and the family to cope with

the losses and to identify any gains they had acquired or anticipated acquiring in the future (Davies et al., 1990).

The teenagers in this study demonstrated a reluctance to redefine their parent, despite obvious deterioration in the parent's physical condition and despite the degree to which the ill parent had redefined themselves. They held on to the old view of their parent as much as they could by trying not to think about the fact that their parent was seriously ill:

When I look at him I don't see that he has cancer really. I just see him normally, like I always see him. That's the whole point I never think about it. I try not to think about it.

This strategy of not thinking about it helped the teenagers to quell their fears about living in the future without their parent. This was especially true for the younger teenagers (15 and 16-year olds) who did not want to redefine the future without their parent. As one 15-year old daughter said,

She keeps saying she isn't going to be around for long, that she doesn't know when she is going to go and that really hit me hard, right. I didn't want to hear these things. "No Mum, you're going to stick around. You're going to be here for a long time".

Accepting that their parent was going to die would force the teenager to think of the future without their parent and to think of themselves as independent and alone in the world:

I always feel that my parents are there for me. If he died then I guess I'd really understand what it's like to be alone, like kind of having to do all this stuff myself and not having them to always be there for me. And that's the thing that always screws me up when I think about that. Because what happens like if you change your mind, you don't have a job or whatever, you need some help and your parents are always there and just the thought of them not being there. Whoa! Gotta go out and get everything done right now, just so I can get on while everything's still good...So I'm basically just living my life normally and doing everything the same as I would otherwise. I don't want to think ahead about what it could be.

By maintaining the old view of the parent and not redefining him or her, the teenagers did not need to redefine themselves as living in the future without their parents, and hence need not face their fears of independence. In contrast to the

teenagers, the adult children in the Davies et al. (1990) study did not articulate the same fears about the future in terms of being alone and not having their parents there to depend upon for security. The adult children had already established themselves independently with family units of their own.

The teenagers' hesitation in redefining their parent was most apparent during periods of stability when the parent had fewer obvious physical symptoms. At these times, the teenagers often felt that their parents could do more for themselves and that they were using their illness to take advantage of the teenagers' willingness to help:

Sometimes I don't know if he really is tired or whether he is taking advantage of the situation, so I get mad sometimes. Like he walks all over me because he knows I feel sorry for him, feel bad for him. So he's taking advantage of that.

Another daughter said of her father,

He was sitting on the couch and said to my sister "Can you bring me the phone dear?", like as if he couldn't. He was feeling fine and walking around.

The teenagers based their assessments of the seriousness of their parent's illness on the physical symptoms and when these were not present the teenagers had difficulty comprehending that their parent was any different than before the illness. They held on to the old view of their parent and resented them when they did not behave as they always had.

Redefining requires an adjustment to the fact that the ill person is vulnerable to death (Davies et al., 1990). For the adult children, this acknowledgement precipitated them to redefine themselves as also being vulnerable to death and to reevaluate their priorities and values in their own lives. They often resolved to take better care of themselves and their health (Davies et al., 1990). In contrast, the teenagers did not redefine themselves as being vulnerable to death as a consequence of realizing that their parent was going to die. In fact, their behaviour indicated that they believed they were invincible. Several of the teenagers described risk-taking or

self-destructive behaviours such as smoking, taking drugs, overeating and engaging in unprotected sexual intercourse. One 19-year old said,

Well what could be worse than my Dad dying. I don't really care if I am pregnant. One life ends and another begins. I'd be doing it for my Dad.

The teenagers did not question their own mortality, but challenged it by engaging in self-destructive, as opposed to self-caring, behaviours.

In summary, the teenagers tried to maintain the old view of their parent rather than to redefine them. Redefining would force the teenagers to confront the future without their parent and hence would bring them face to face with their fears of independence before they were prepared for this transition. Maintaining the old view allowed them to get on with their own lives but also prevented them from coming to terms with the losses and from perceiving any gains from the experience. Viewing their parent's illness experience as a series of events, rather than as a process of decline over time, also allowed the teenagers to believe that perhaps death was not inevitable and that their own lives could go on uninterrupted.

Burdening

When patients became unable to take care of their own personal needs or to fulfill their former roles and responsibilities, they relied on family members to become involved (Davies et al., 1990). The patient often felt that this was burdensome for the family although the family did not often concur that this was in fact the case. The degree to which the patients felt themselves to be a burden depended on how much they had redefined themselves. Accepting a new view of themselves allowed them to use what limited energy they had, to offer emotional support and encouragement to the family. When the old view was retained, energy was used to defend this view and the patient could not comprehend the extent of the burden they were to others nor offer support to their families (Davies et al., 1990).

The teenagers in this study felt significantly burdened by living with a seriously ill parent, regardless of whether the ill parents had redefined themselves or not.

Spending more time at home

The teenagers spent a lot more time at home than they did before their parent became ill. Many thought that they should be spending even more time with family than they already were. Although most of the teenagers acknowledged that they wanted to be there for their parent, they also tended to view staying at home as an obligation or duty:

I am spending more time at home. I'm a bit more conscious of when I should be home and if no one is home I feel it's a bit more of a duty to stay at home.

Some felt more burdened than others at having to stay home more and expressed the need to take breaks away from the situation at home. One 16-year old who was providing most of the care for her father said tearfully,

I don't like it. I feel kind of trapped. Like why is this happening to me? You can't leave it. You always know you have to come home to it...I like spending time at my friends at the weekend. It's a nice break.

The degree of resentment and burden felt by the teenagers, depended on how much was expected of them in terms of providing care to the ill parent. It also depended on how much the parent encouraged or discouraged the teenager from going out with friends and from getting on with their own lives.

As well as needing to take breaks away from the situation, feeling they had to be there for their ill parent often prevented the teenagers from seriously considering moving out of the family home to live independently:

I was going to move in with one of my friends, me and her and I thought "What about my Mum? She's going to need me. If I move out it's going to put more stress on her". But every once in a while I just want to get out.

One daughter who had been away from home for two years commented on how hard it had been to leave:

When I left home when I was 17, I wanted to get out of there so badly. One of the reasons was because of my father and I just felt so awful for leaving.

Taking on more responsibilities at home

As well as spending more time at home, the teenagers commented on the added responsibilities they had at home:

You feel bad if he does anything. Like if he cooks dinner, I think "Oh, I should have been home to cook dinner". I have lots of extra things to do. Like take the dog out which he usually does or put the garbage out which he usually does. I'm not used to doing those.

Some of the teenagers resented the increase in household chores as it interfered with their own activities:

The housework and grocery shopping. We all have to do quite a bit more. I find it frustrating because this is my summer. I'm probably just being selfish though.

Some teenagers became defiant about having to stay home and do more chores:

Because every once in a while I'll say "No" and she'll say, "Well you know what I'm going through" and I'll say "I know but I don't want to always be in the house and doing work and all this. I want to be out sometimes too".

Expressing feelings/repressing feelings

The increase in household chores often led to arguments between siblings:

I've had lots of arguments with my sister over who's doing more. Cos you say "Well can't you do this? I did this, this and this". And she'll be like "I loaded the dishwasher, blah, blah, blah".

One strategy for dealing with the arguments over chores was to divide them up fairly among siblings:

We had to sit down yesterday J. and I and figure out what had to happen. "OK relax. Start a little list and we will get time to do it all".

Although the teenagers spoke of arguments and tension at home, they also felt the burden of keeping the peace at home, as they tried to protect themselves and the ill parent by repressing their own feelings:

You've got to be careful what you say, because if you say something wrong, she's going to explode. You've got to be more helpful and more understanding because you don't want to say "No" and then she's "OK then I'll do it myself". So it's "Yes I'll do this" and "Yes I'll do that". Before it was easier, you could just say whatever or do whatever. Now you just kind of watch what you say.

The teenagers felt responsible for not adding more stress to an already tense situation at home:

I don't ever let it surface as anger, and I think that's where my headaches, stress and fatigue comes from. I don't want to cause any more ripples, I don't want to cause any more problems. There are already enough. I just want to keep everything as calm as possible.

Trying to keep a lid on feelings, however, often led to outbursts of anger or arguments:

Sometimes I just get really, really grumpy for no reason. I get really mad for no reason.

They talked of how stressful the situation was at home and how "edgy and moody" they often felt. One 18-year old daughter said,

I get depressed fairly easily sometimes. You just feel like you are alone. You just start digging yourself in deeper and then you just start thinking of all the negative possibilities that can happen.

As well as repressing feelings, the teenagers seldom spoke about their fears with other family members or friends. As one daughter said,

I just don't want to talk about it. It's hard because they can't experience it in the same sense. I think I'm scared of my emotions. I don't know how to go about it at a very controlled level so that I don't get overwhelmed.

Another said,

I know I totally keep all my feelings inside. I don't like getting the feelings out. I don't feel I could just dig them up any time and open them out. I can't do that. I don't have the control or strength to do that.

They felt that friends could not really understand what it was like to be living with a parent who was very ill and so the teenagers chose not to share feelings with those friends. Repressing feelings and not talking about their fears and concerns was a major burden for these teenagers.

In summary, burdening was a major phenomenon for teenagers who were living at home with a parent in the terminal stages of cancer. Unlike the adult children, a major reason for this was because the teenagers were living in the same household as their ill parent. They felt the burden of having to stay at home more and of having to take on more of the household chores which often led to animosity between siblings. They also felt restricted when considering a move away from home to live independently, because of feelings of obligation to be there for their ill parent. They felt the burden of having to keep the peace at home by watching what they did and said, for fear of upsetting their parent. They repressed their feelings which precipitated angry emotional outbursts and arguments, and they found it very difficult to communicate their fears with anyone.

The parent's attitude toward the teenager's need for independence significantly affected the teenager's feeling of burden or of being trapped at home. The teenagers whose parents encouraged them to stay at home with them felt the most resentful and the most trapped:

Like he doesn't even want me to go to university because I won't be close to home. He can't do that to me. I'm too selfish. He's holding on I think as much as he can. I just get so fed up with him 'cos he's just totally hounding me to do things for him.

The teenagers whose parents encouraged them to get on with their own lives felt the least burdened:

When I went away for three months Dad said "I'm going to be OK, we will keep you informed...It's not the end of the world. You are just somewhere else and you have to deal with that because we can't hold you back, we can't keep you here".

Adult children in the Davies et al. (1990) study had mixed feelings about assuming extra work and responsibilities. They felt exhausted from having added work on top of their own responsibilities of their careers, their own children and their homes. However, they also felt satisfied that they were contributing to the family situation. Although the adult children experienced burdening because of their

multiple conflicting responsibilities, most did not live at home with their ill parent. This protected them from some of the burden that was directly linked with living in the same household as their ill parent. The teenagers were protected from some of the burden that the adult children felt of having families or homes of their own to take care of.

While the adult children in the Davies et al. (1990) study felt burdened by the conflicting responsibilities of having to care for their sick parent while also having to care for their own children, home and careers, the teenagers felt more of a burden with conflict between what they wanted to do and what they felt they should do: their sense of duty or obligation to be at home more and their desire to meet their own needs for independence.

One strategy that both the adult children and the teenagers adopted to handle burdening was to take time out from the situation. The teenagers spent time with friends as did the adults. However, the adults used that time with friends to elicit support from them by talking and sharing their feelings, and the teenagers spent time with friends to take their minds off the situation:

I don't want to talk about it with friends. I just want to go out and have a good time and not worry about it. So I don't want to talk about it.

Another strategy the adult children used was to reorganize their priorities by decreasing their recreation and social time as a way of handling the burden. The teenagers also spent less time with friends than they did before their parent became so ill, but this added to their burden because,

I feel guilty when I go out with friends and then I feel guilty when I stay at home.

The teenagers' sense of obligation to both their families and their friends compounded the feeling of burden.

The Neutral Zone

The Neutral Zone was described by family members as being a time when they felt lonely, confused, fearful and uncertain. It was an uncomfortable time when they felt their lives were on hold, that there was no moving forward or backward. There were three major tasks which characterized the Neutral Zone: struggling with paradox, contending with change and searching for meaning (Davies et al., 1990).

Struggling with Paradox

The central paradox for the patients in the Davies et al. (1990) study was the struggle of living and dying at the same time, wanting to fight yet also wanting to give up. The adult children struggled with wanting their parent to live and yet not wanting their parent to suffer. They wanted to spend as much time with their parent as they could and yet they also needed to get on with their own lives and spend time with their own children.

There were many paradoxes for the teenagers as they struggled with the developmental need to move away from family to independence, and yet at the same time also feeling compelled to stay at home to be there for their ill parent. Unlike the adult children, the teenagers did not express the need to spend as much time with their parent as possible before they died. They did not have the same ability to look into the future and see the outcome of the inevitability of death and hence did not feel the need to make the most of the time left with their parent.

Wanting their parent to live/wishing it were all over

Like the adult children, the teenagers struggled with the paradox of wanting their parent to live and wishing the cancer would go away, as well as wishing it would all be over. Unlike some of the adult children though who wished it would be over to relieve their parent's suffering, the teenagers wished it would be over to relieve their own suffering:

Sometimes I wish he would get better and sometimes I wish he wouldn't get better. I know it's mean to say but that's just the way I feel. I don't want to feel like this forever. I just want it to be over. Of course I would really like him to get over this, to quit smoking and once again live a healthy, happy life. I just want some normalcy again, some stability in my life.

The teenagers were concerned with the disruption to their lives which prevented them from getting on with establishing their own identity and independence from family.

Wanting to be at home/wanting to be with friends

Although the teenagers wanted to be at home to help out, there was more of a sense of obligation or duty attached to being there than there was for the adult children. Many felt guilty about not being at home more and also felt guilty about not spending more time with friends:

I asked to go out with my friend and she was really shaky and it was like "Go and lay down, do you want me to stay?" And she's "No, no". Then you worry about her when you're out with your friends. Is she going to be OK? I should be at home. Because you feel guilty when you go out with your friends and then you feel guilty when you stay at home.

Some teenagers just preferred the company of their friends to their family:

Sometimes I feel I should be home spending more time with my Dad and my family. My Mum and Dad always get mad because I go out too much, but I don't like spending a lot of time with my family. Maybe it's because I am a teenager and like spending time with my friends and I get along really well with my friends and there is no hassle like asking me questions, prodding me or whatever, what are you doing? What are you going to do next? It's yourself and it doesn't matter in front of your friends. In front of your parents you have to kind of confine yourself and don't let anything you feel come out. You just have to see through it first and then let it come out so that it's appropriate.

The pull towards being a normal adolescent was intense, their own needs for independence coming to the fore to vie with the obligation they felt to be at home with family.

Pushing thoughts of death away/dwelling on death

The teenagers had a tendency to try and push away the reality that their parents were going to die, which the adult children tended not to do. Many teenagers talked of trying not to think about it and yet they also commented on the

fact that they dwelled upon the fact that their parent might die. Some adamantly claimed that not much had changed for them, and yet later comments suggested that there had been some major changes for them in their lives:

No nothing has changed that much actually. It's just like it hasn't really hit me in an overall way. I just don't think about it really...You just start thinking, it makes you think about what things would be like, what you would do, what would happen to the family?

The teenagers were able to get on with their own lives by perceiving things at home as being relatively unchanged and yet they often found themselves thinking about the situation and worrying about the future.

Caring about their parent/resenting their parent

There was a paradox for the teenagers of feeling empathy for their sick parent and wanting to do things for them, and yet also feeling resentful toward them for using their illness to take advantage of their willingness to help:

It's kind of like brought us together because something has happened and you feel more for her, like not pity but you want to help her. But sometimes I don't like it because she uses it more like a weapon sometimes. That kind of bothers me.

Feelings of empathy alternated with feelings of resentment at being taken advantage of. Although the adult children in the Davies et al. (1990) study expressed empathy toward their parent they did not articulate perceiving that their parent was taking advantage of them in any way.

Longing to be closer/not knowing how to get closer

Although the older teenagers acknowledged an increasing level of closeness between themselves and their parent, the younger teenagers felt a longing to draw closer to their parent. However, they did not know how to do this nor did they particularly want to. These teenagers tended to view themselves as outsiders to the family not wanting to do "family stuff". They were more interested in spending time with friends than with family but felt there was something missing in their

relationship with their parent. They described themselves as not needing to be close to family and yet, paradoxically, they expressed a desire to be closer:

I wish that we were all closer, but that's the way I have always been, always off doing my own thing, always off doing whatever, never been around doing things with the family. So I've thought about that, doing regular home life things but how would I go about doing it? It's something that I've never really done.

The teenagers explained the difficulty they had with this paradox of wanting to be closer but also not wanting to be closer:

I want to talk with him more but it's not something that's going to come easy to me, the wanting is there logically, but emotionally it isn't. I want to share more with him but it's so hard. Like 'cos from staying clammed up for so long it's just so hard to bare my soul to him, just all at once, it takes so long, so hard. I want to be able to but feelings-wise I don't want to, like I couldn't really care less really. I have a strong sense that I don't want to, but I do want to because I do love him and I don't want him to die thinking that maybe I don't love him or whatever.

This clearly illustrates the paradox of wanting to share and be close with the ill parent and yet emotionally not having the means to do this.

Having questions to ask/not wanting to know the answers

Most of the teenagers felt that they had all the information they wished about the disease itself but often had unanswered questions that were not related to the illness. The questions had more to do with the future in relation to themselves. None of the parents had discussed with their children specific plans for the family after the ill parent had passed away. The teenagers had questions such as,

What's going to happen around the house? Will my Dad go with someone else or is he going to stay with us or what's going to happen with us? What would happen if he dies from cancer? What would it be like around the house, how would our lives change?

Although the teenagers had questions about the future, they were also uncertain about whether they really wished to have answers to those questions:

I think I'd rather have them more as questions than to find out. Because if they get answered I may not like them. I'd rather just think about the good things. Yeah, cos I thought about getting them answered. I thought well should I ask? I thought No, I'll just leave those questions.

Like these teenagers, the younger adult children in the Davies et al. (1990) study commented on the paradox of wanting to know the details of the parent's illness and prognosis and yet not wanting to ask. In some families the parents wanted to protect their children by not giving them full details. This withholding of information created a feeling of uncertainty about how they should communicate with their parents (Davies et al., 1990).

In summary, there were many paradoxes for the teenagers in this study. The central struggle was between getting on with their own lives and yet feeling an obligation to spend more time at home than they necessarily wanted to. The teenagers also struggled with trying not to think about the situation at home and yet found themselves dwelling on it. They had a longing to establish a closer relationship with their ill parent and yet emotionally did not have the means to initiate this. They had many questions about what the future would hold for them but they did not necessarily want answers to those questions. The main strategy that the teenagers used to be able to get on with their own lives was to try not to think about the fact that their parent was going to die. This conscious repression of feelings acted like a shield protecting them from fear and allowing them relative freedom to focus on their own lives.

Contending with Change

Changes in relationships

The teenagers felt a shift in dependency between themselves and their ill parent:

I suddenly realized that I could no longer depend on my Mum as a mother anymore. She has become more of a friend to me or I am more like a mother to her. That feels kind of strange.

They also commented on other aspects of their relationships with family members that had changed. The older teenagers felt that they had become closer to the ill parent:

My Dad has been willing to give out more, not necessarily materially, but emotionally, and I have been able to take from that what I need and what I want. I just think my father's and my relationship has improved a lot.

The younger teenagers thought that they could be closer to their ill parent and wanted to, but often did not know how to go about changing the relationship:

I'd like to be closer to my Dad but I never seem to do it. I've thought about that but how would I go about doing it?

Although the teenagers argued more with their siblings particularly over doing household chores, most of them also felt that they had become closer to their siblings through their parents' illness:

After this happened we did get a bit more open. We didn't talk a lot about Dad but we talked about weird things like clothes and I'm happy about that, to be more open with each other. [My brother] is not good at telling anybody the way he feels.

Like the teenagers, the adult children in the Davies et al. (1990) study described changes in their relationships. They described major changes in their relationships with both their parents as they now felt they were expected to parent their parents. Like the teenagers, they experienced a shift in dependency roles which they often perceived to be a burden.

Changes in roles

As well as changes in relationships, both groups of children experienced changes in their roles within the family. Although most of the teenagers were not expected to assume legal or financial responsibility for the family, one teenager was expected to take on the responsibility of caring for his mother after his father passed away:

He's putting a lot of trust in me to take care of the family if it doesn't all work out. He's looking at me to be in charge of the household. I'm going to have to look after my Mum too. That's the thing he's concerned about most. He's really concerned about how well she'll handle it, and he wants me to be there for her.

Unlike the teenagers, the adult children were expected to assume responsibility for financial, legal and emotional support, as well as for some of the physical care of their parents (Davies et al., (1990). Only one teenager was responsible for providing the majority of the emotional support and physical care for her father. This was a major role change which the daughter found to be overwhelming:

He said, "All I have is you. You are my strength". That took a lot out of me him saying "You're my strength". I didn't think that was fair of him to say that. It's like, "Why me?"

In the other families with teenagers, the spouse took on the majority of the responsibility for the emotional support and physical care of the ill parent.

Most of the teenagers did however assist with some aspects of the physical care of the sick parent:

When he gets sick I always stay by him and offer him a glass of water and rub his back if he is throwing up or whatever. Get him a cold towel or a hot water bottle.

Some teenagers were more comfortable than others with providing personal care to their sick parent, but all teenagers offered assistance in ways that they felt able to. Physical symptoms often created fear that the parent was going to die suddenly and the teenagers often expressed a need to have someone else close by in case "the worst happened":

Well he gets really sick at night and I can hear him up. I can hear him coughing all the time and getting out of breath and sometimes throwing up in the bathroom and stuff. And if you needed help it's kind of nice to have someone else with you even if just to know someone's there.

It was not only caring for their parent while at home but the teenagers also kept vigil over their parent when they themselves were out with friends. They checked in at regular intervals to make sure everything was alright at home:

Well I better go and check on my Mum if I'm out with friends, just to make sure she's fine and everything".

The teenagers were genuinely concerned for the well-being of the parent when they were not at home:

It's always there in the back of your mind. It doesn't matter where I am or what I am doing, alone or with friends around me I have to call my Dad, let him know that I love him.

The adult children spoke about emotionally supporting the well parent whom they perceived as being very stressed and to not be taking good care of themselves (Davies et al., 1990). In contrast, the teenagers rarely mentioned the well parent's need for support nor often commented on their own relationship with the well parent. They occasionally acknowledged how hard it would be for the well parent when their spouse died but made no mention of providing support to that parent. The exception to this was the 19-year old son who had specifically been asked by his father to take care of his mother after he died.

Changes in socialization with friends

Both the teenagers and the adult children noted changes in socialization with friends. Both groups spent less time with friends although the adult children put their social life more on hold than the teenagers did. The teenagers felt the need "to get away" so that they could stop thinking about things at home for a while. They also felt the urge to get on with their own lives and not to put everything on hold:

I just have to get on with my own life. I can't let everything else fall because of this.

The teenagers commented on the changes they had noticed in their relationships with their friends. They felt they had less in common to talk about with their friends since the situation at home had changed:

My friends gossiping "You know what so and so did to me?" I just look at them. I said "How can you waste your time on that? There's so many more important things in life. There's so much more to life. Why are you looking at this? It's nothing".

Many of the teenagers commented on the distance they felt had grown between themselves and their friends. They attributed this to the fact that they had had to take on more responsibility than their friends and had had to mature faster:

I think I had to grow up quite quickly, by choice I think. I could have turned inward and become more of a kid. As a result, in some ways it's negative, in a lot of ways positive. I've been given a lot more responsibility which complements at certain times, but sometimes it's too much to handle so it becomes a really stress relating factor.

The teenagers also spoke of the experience in terms of making them stronger:

I think a lot about this stuff. I have looked at it more from my own side. Why is this happening? I just tell myself "Well this will make you a stronger person". I am stronger this time than last time. I have to learn to handle this curved ball. I feel I am a long way further though.

Change in home atmosphere

As well as the changes in roles, relationships and social life, the teenagers emphasized the changes at home in terms of the escalating tension and the increasing number of arguments. Unlike the adult children who consciously avoided arguments and discussions that would add to an already stressful situation, the teenagers commented on how stressful the atmosphere was at home since their parent had become so ill. The arguments appeared to be unrelated to the illness situation but were related to mood swings or issues of independence:

Well, me and my sister we'll have our days when we are really, really grumpy and then that will set my Mum off and then my Dad gets in on it. I'm much more stressed out and I get mad for no reason.

One teenager spoke of the arguments related to being treated like a child:

Last night I blew up at my Mum and I don't often blow up. I just said I am fed up and I started screaming and it was just like I am fed up being treated like a child yet people want me to act like an adult but they still want me to listen like I'm a child and I just said I'm so frustrated, I just don't want to listen to you.

Emotional outbursts were common, and yet the teenagers felt that often repressed their feelings to keep the peace at home:

I don't ever let it surface as anger, and I think that's where my headaches, stress and fatigue comes from. I don't want to cause any more ripples. I don't want to cause any more problems. There are already enough. I just want to keep everything as calm as possible.

The teenagers felt responsible for not adding to the tension at home and hence kept many of their own feelings inside. This repression of feelings led to stress-related health concerns for some of the teenagers.

Changes in own health

The teenagers explained that their own health had suffered over the last few months since their parent had become so ill. They described stress-related illnesses such as headaches, fatigue, exhaustion, stomach problems, colds, coughs and flu.

As one teenager said,

I have had chronic headaches. Every day I would wake up and go to bed with them and I started going to a doctor and eventually to a specialist who told me that I would just have to learn to live with it because it was stress.

The adult children complained of exhaustion but not of other stress-related illnesses (Davies et al., 1990).

Changes in schoolwork

The teenagers also described how their school work had suffered as they found it hard to sustain their level of concentration. One teenager had to drop two courses:

I just couldn't keep my train of thought. I felt I should be spending my time with Dad rather than studying. I guess I was just really exhausted, wiped mentally and physically.

Another teenager said she had dropped her marks significantly over the last term.

The teenagers who had left school acknowledged that they were having difficulty deciding what direction to follow career-wise. They talked about having little motivation or direction, of feeling "up in the air":

It's always there hanging over you and all the decisions you make you have to think about him in those. It's hard this distraction. I don't feel I deserve it because he's not quite on his death bed. Is he sick enough for me to feel this way?

It was distressing for the teenagers to feel the sense of urgency to get on with their lives and yet to have difficulty deciding which direction to follow.

In summary, the teenagers living with a seriously ill parent had to contend with many changes in themselves and their behaviour, changes in their relationships with family members and friends, and changes in their roles and responsibilities. As they acknowledged the extent to which the situation promoted such changes in their lives, the teenagers tried to find some meaning in the situation.

Searching for Meaning

Searching for meaning involved making sense of the situation and putting the experience into some context (Davies et al., 1990). The teenagers also searched for meaning in their situation and often asked the question "Why me?". They wondered why serious illness had struck their family. Their questions centred around worrying about the future rather than around resolving to change their values or behaviours like the adult children did. The teenagers came face to face with vulnerability related to facing their aloneness in the world unlike the adult children who faced the vulnerability of their own death.

As a result of the reality of impending autonomy sinking in, the teenagers experienced fear of the future which the adult children did not express. They also experienced a sense of urgency to get on and establish themselves in the world "while the going was good". As one son said,

My parents are always there for me. I feel like if something like that happened it would really screw me up. Then I guess I'd really understand how it felt to be alone, having to do all this stuff myself and not having them there to always be there for me. Just the thought of them not being there Whoa! Got to go out and get everything done now while everything's still good.

There was a significant threat to the teenagers' security as they tried to comprehend the meaning of their parent's death in terms of its effect on their future.

As they searched for meaning and acknowledged their own vulnerability, the teenagers did not resolve to take better care of themselves as the adults did, to participate in maintaining their own health. The teenagers believed that getting cancer was based purely on chance and that one's own health behaviours had little bearing on the development of illness:

Just happening to get cancer, or happening to get hit by lightning, or happening to win the Lotto 649. Those are so much due to luck.

Rather than engage in health-promoting behaviours like the adult children did, the teenagers often engaged in self-destructive behaviours.

Although the teenagers believed that getting cancer was due to chance, they also felt that their parent had a responsibility to get well. The teenagers were often extremely judgemental if their parent continued to smoke in spite of their poor state of health:

I don't really have hope that he'll get better because he still continues to smoke and he drinks alcohol with his pills so I mean he's not taking care of himself, and if he really wanted to, or at least help, he would stop.

Unlike the adult children, the teenagers did not demonstrate much reflective thinking about the illness in relation to their values or attitudes. The teenagers' thinking was more concrete and revolved around a basic survival need for security for themselves. They felt a sense of urgency to get on with their own lives while still having a base from which to launch. The teenagers had to struggle with many paradoxes, contend with a multitude of changes and throughout the uncertainty of the Neutral Zone try to make some sense out of the whole experience in relation to their own lives and futures.

The Beginning

Living Day to Day

The Beginning phase occurred after the families had been able to find some meaning in their situation. After the turmoil of the Neutral Zone, the situation was

put into perspective and it became clear that living day to day and preparing for death was what needed to be done. Living day to day was characterized by making the most of the time left and accepting the way things were rather than worrying about the future (Davies et al., 1990). The adult children tried to live from one day to the next as they coped with their many conflicting responsibilities, caring for the ill parent, their own families and their careers.

The teenagers in this study, however, were too caught up with needing to get on with their own lives to be able to live day to day. They consciously tried not to think about things at home so that they could get on with their lives:

I live for tomorrow. I always look forward to things in the future. I can't wait till the weekend or I can't wait till next summer. I always try and push this out of my head so it's not something I think about every day. I have lots of things to do like homework, talking on the phone and other things.

The teenagers alluded to feeling trapped by their obligations at home and felt a sense of commitment to get on with their own lives:

You just have to keep your chin up and keep focused on your other things and realize that life's going to go on and what's going to happen is going to happen. I can't let my school suffer any more because of this.

Living day to day would force the teenagers to face the reality of the impending death of their parent. The teenagers in this study had either not reached this phase in the transition, or because of the nature of their developmental drive for independence, could not afford to focus only on the day at hand but had to continue to move ahead with their own lives as best they could. Their focus away from the present to the future and their own lives made it difficult for the teenagers to make preparations for their parent's death.

Preparing for Death

Because the teenagers did not live in the present moment, nor thought or talked much about the situation with their parent, they could not be fully prepared for the death of their parent. They experienced intense moments of fear that their

parent was going to die suddenly during periods of exacerbation of physical symptoms. The lack of understanding of how to gauge the seriousness of each situation prevented the teenagers from realistically predicting the actual time of death:

About nine months ago now they gave him two to six months to live. So he's basically living on borrowed time. That's why I never know what's going to happen. Like half the time, he'll be sleeping and usually when he sleeps he snores, right? And I'll walk into the living room or something and he won't snore and I'll look at his chest to see if he's breathing and I can't see it moving so I'll turn on all the lights and he'll wake up. "What are you doing?" I'm not going to say, "Oh I'm just checking to see if you're breathing Dad". Then he'll be mad.

In this family the ill parent and spouse were prepared for death, all the plans were made, the patient reminisced about his life and the spouse talked about how hard it would be for her after he died. The teenager, like all the other teenagers, wanted to get on with her own life, although she had made a recent decision "to put family before friends". Although she had accepted he was going to die, she made such comments as,

I hope he is around to see me graduate [which would be two years]...I don't even think that he's going to die sometimes, if it happens, well everybody dies sometime.

At times, the teenager acknowledged that death was imminent and at other times she maintained hope that her father was in fact going to pull through.

In contrast to the teenagers, the adult children prepared for death by making practical preparations such as making legal arrangements as well anticipating the actual time of the death and funeral. They thought about their own future without their parent and their well parent's future without their spouse (Davies et al., 1990).

The Beginning phase signified a time when families lived from day to day as they prepared for imminent death (Davies et al., 1990). The teenagers however, focused on getting on with their own lives, looking into the future and trying not to

dwell on the fact that death was imminent. Looking at death closely filled them with fear for their own future.

Summary of the Similarities and Differences Between the Experiences of the Teenagers and the Adult Children

Examination of the teenagers' experience living with a parent with advanced cancer within the conceptualization of "fading away" reveals that there are several similarities and some significant differences between their experience and the experience of adult children in the same situation.

Both the teenagers and the adult children felt the burden of taking on the added responsibilities of caring for their ill parent. The teenagers felt trapped by what they perceived to be a hindrance to getting on with their own lives and cultivating their independence from family. Both groups of children struggled with many paradoxes, as they tried to meet the needs of their parents as well as meet their own needs. The adult children were exhausted by trying to juggle their many conflicting responsibilities of caring for their parent as well as administering to their own families, homes and careers. Both also had many changes to contend with in their relationships with others, in their roles and in their socialization with friends. Searching for meaning in the situation was one way that both groups of children tried to make some sense out of the situation. Living with a parent with advanced cancer undoubtedly affected the lives of both groups of children in many ways.

One of the most striking differences between the two groups of children was the fact that the adult children redefined their parents as being different from the parents they once knew, as they adjusted to the inevitability of their parents' deaths, and yet the teenagers persisted in holding on to the old view of their parents as they had always known them. Maintaining the old view allowed the teenagers to believe that their lives were not going to change and that they could continue to pursue their

own goals. Redefining their parent as being seriously ill would have forced the teenager to confront their fears of their parent dying and hence their future alone.

Another interesting difference between the two groups of children was that the adults were able to comprehend the process of dying as being one of exacerbation of symptoms followed by periods of relative stability, with an overall gradual decline to death. The teenagers however did not understand this process and hence became extremely afraid of death at times when the parent's symptoms worsened. During the stable periods, the teenager felt the parent could be doing more for themselves and felt hopeful that their parent might recover. This lack of understanding prevented the teenagers from preparing for death as the actual time of death was completely unpredictable to them.

There were some differences between the two groups as a result of the fact that the teenagers lived in the same household as their ill parent whereas the adult children did not. The teenagers described a worsening atmosphere of tension and arguments at home and the need to change their behaviour to keep the peace. They argued with siblings about household chores and fought with parents about issues of independence.

The teenagers expressed a longing to become closer with the ill parent but had difficulty knowing how to go about doing that. They had a particular view about themselves that they did not know how to change, nor knew if they wanted to. They looked to the future with questions about their own security whereas most of the adult children had already established their own homes, families and independence and did not need to worry about their own security in the future. Adult children expressed empathy for and offered emotional support to the well parent, whereas the teenager viewed the death of their parent only in relation to themselves and their own future.

Adult children found it helpful to talk with friends about the situation, whereas teenagers spent time with friends to get away from the situation and preferred not to talk about it. The teenagers often engaged in self-destructive behaviours as they tested their own vulnerability, whereas the adults tended toward taking better care of themselves because of realizing that, like their parents, they too were vulnerable to death.

The adult children were able to acknowledge the imminence of their parent's death and hence could make preparations for the death, making the most of each day left. The teenagers, however, did not acknowledge that death was a reality and could therefore not prepare themselves nor make the most of the time left with their parent.

The experiences of each group of children were similar in ways and yet unique in others. The implications of these findings will be discussed in Chapter 5, within the context of existing literature.

The Essence of the Teenagers' Experience

The conceptualization of fading away as described by Davies et al., (1990) provided a useful framework within which the experience of teenagers living with a parent with advanced cancer could be described and compared to the experience of adult children in the same situation.

The essence of the teenagers' experience became clear, however, through the initial coding of the data using the method described by Strauss and Corbin (1990). Findings from this initial analysis provided the key to understanding the meaning of this experience for these teenagers.

The underlying theme pervading all the interviews with the teenagers was their intense drive to put their own lives ahead of others and to get on with doing the work of adolescence. Although the teenagers made an effort to be there for their ill parent by spending more time at home, assisting with some aspects of physical care,

reassuring their parent and checking in on them when they were out with friends, they viewed the situation as a hindrance to getting on with their own lives.

Encountering this hindrance in their lives brought on a host of emotional reactions for the teenagers as they perceived themselves as being held back in their lives. Fear was a major emotion underlying many of the actions and behaviours of the teenagers. One useful way of ensuring continuance on their developmental path and to protect themselves from fear, was to shield themselves from the reality that death of their parent was inevitable. They shielded themselves not by denying reality but by choosing not to think about the situation, by staying positive and by trying to view their parents as they had before they became ill. When the shield was lowered at times, for example when their parent's physical symptoms worsened, the teenagers became overwhelmingly afraid of their parent dying because of the implications this had for the security of their own future. The shield protected the teenagers from facing a reality for which they were not yet ready.

Shielding describes the essence of the teenagers' experience living with a parent with advanced cancer. As the hindrance of living with a seriously ill parent was encountered and the emotions experienced, teenagers created a protective shield which allowed them to get on with their own lives and to continue to strive for mastery of the developmental tasks of adolescence.

Factors Influencing the Teenagers' Experience

Strauss & Corbin (1990) describe Intervening Variables as factors influencing the actions taken within a specific context (Appendix D). They are the broader structural context pertaining to the phenomenon. There are several factors which affected the actions of the teenagers living with a parent with advanced cancer, both of a personal and a situational nature.

Although the researcher had hoped to select an equal ratio of male to female participants, the sample of teenagers actually consisted of only two males and nine

females. By chance the first six families who fit the selection criteria happened to be comprised mostly of female teenagers. Because of the fact that only two males were interviewed, it was not possible to draw any conclusions about whether gender influenced the actions of the teenagers or not. One would expect that gender might affect the experience for these teenagers.

The 15 and 16-year old teenagers often reacted differently from the 17 to 19-year olds. The younger teenagers tended to be even more intent than the older ones on not thinking about the fact that their parent was going to die. The younger teenagers had developed less independence from parents than their older siblings, and hence one would expect that the threat to their security, and the need to get on with establishing themselves in the world would be greater. The younger teenagers also tended to feel more trapped and more resentful than their older siblings and often spent more time with friends than family.

Sibling order affected the amount of responsibility the teenagers perceived themselves to have within the family. The eldest teenagers in two families perceived themselves as having more responsibilities at home than their younger siblings. One of the two eldest teenagers, a male, was the only teenager who was specifically asked by his dying father to take care of his mother after he had passed away.

The unique personality of each teenager was also a personal factor that influenced behaviour. For example, one teenager described herself as the caretaker of the family. She made a particular effort to keep her feelings of anger to herself at all times so as not to upset other family members any more than they already were. Thus, the personal factors of age, gender, sibling order and personality all appeared to play a part in influencing the actions of these teenagers.

There were also several situational factors that played a part in shaping the experiences of these teenagers. The relationships with both parents prior to the illness and the length of the illness itself affected the family situation. For example,

the teenagers whose father had had cancer for eight years found it difficult to discern how many of the changes in their lives were due to the fact that their father was ill or to the fact that they were growing older. One teenager felt she had become much closer to her father in recent months but did not know whether this was because she was older or because he had become sicker.

None of the teenagers had talked about the impending death in a family group. Some had talked one on one with their ill or their well parent about the situation and others had not. The ill parent's attitude toward their death and toward the teenager's need for independence also affected the teenagers' actions. For example, the teenagers who were encouraged by their parents to get on with their own lives felt less trapped and less resentful about spending time at home than the ones whose independence was discouraged.

The amount of care provided by the well parent and hence the degree to which the teenagers were expected to provide care also affected the behaviour of the teenagers. The more physical care that the teenagers had to provide, the more resentful they became about not being able to get on with their own lives. The teenagers found it more frightening when their parent spent time in the hospital. It became more difficult for them to maintain the old view of their parent as being well, and the reality of the seriousness of the illness was less avoidable.

There were many situational and personal factors then which played a part in influencing the actions and behaviours of these teenagers who were living with a parent with advanced cancer. Having an awareness of the context surrounding the experience for these teenagers assisted in enriching the understanding of what that experience was actually like for them.

Summary

This chapter described the experience of teenagers living with a parent with advanced cancer within the context of the conceptualization of "fading away" as

described by Davies et al. (1990). Living day to day with a terminally ill parent undoubtedly significantly hindered the teenager from getting on with the work of adolescence. The experience of the teenagers was compared and contrasted with the experience of adult children in a similar situation, from the study by Davies et al. (1990). The emerging phenomenon of shielding was discussed as being the essence of the teenagers' experience and several factors, of a personal and situational nature, which influenced the teenagers' experience, were emphasized. The following chapter discusses the findings in light of existing research.

CHAPTER 5

Discussion and Implications

In this chapter, the findings of this study are discussed in relation to the findings and theories of other researchers. The literature reviewed in Chapter 2 will be revisited in light of the findings from this study, and other pertinent theories and literature will be used to bring the findings into a context whereby implications for nursing practice and further research may be extracted. The discussion will illustrate how understanding the perspective of teenagers living within the context of a family in which a parent has advanced cancer enhances what is already known about the impact of cancer on families in general.

The Conceptualization of Fading Away: The Fit

"Fading away" as a theoretical construct, comprised of seven major phenomena, provided a useful framework within which the experience of teenagers living with a terminally ill parent could be described. It became clear through the analysis that the experience of teenagers is similar in some ways and yet different in others from the experience of adult children in a similar situation.

The phenomena of burdening, struggling with paradox, contending with change and finding meaning were useful categories within which the experience of both the teenagers and the adult children could be described. Although these conceptual labels certainly described the essence of the experience for both groups, there were also some major differences in the experiences of the two groups which can best be described within a developmental context.

Havighurst (1972) pioneered work in the area of defining the developmental stages which an individual encounters throughout the life span, from birth to old age. In 1952, he defined ten developmental tasks of adolescence which, in 1972, were revised to a set of eight tasks. One of the eight tasks of adolescence is to achieve emotional and physical independence from parents and other adults. As

teenagers begin the process of breaking away from parents, they also need to feel the security that their parents will be there for them if needed (Gravelle & Haskins, 1989). Most adolescents face the process of separation-individuation with great ambivalence (Daniels, 1990). They are given new freedoms that carry adult responsibilities but which also elicit mixed feelings about becoming independent. Adolescents vacillate between the desire for independence and the security afforded by childhood (Daniels, 1990). The security of parents and home is a necessary prerequisite to healthy separation from parents and hence any threat to that security is liable to create difficulty in separation for the teenager. Having a parent who is seriously ill disrupts the normal process of breaking away for teenagers, as their security is shattered and they feel pulled back into the family.

Adult children have different developmental tasks to master at their stage in the life cycle. Most expend time and energy on maintaining a career to assure financial and emotional security for later years; most maintain a stable home and bond with another person; they guide their childrens' development and often care for aging family members; and many participate in community life beyond the family (Duvall, 1971). Unlike the teenagers, most adult children have already gained independence and hence do not experience insecurity about their future without their parent. They do however have many conflicting responsibilities which in themselves create a whole different set of issues and concerns when caring for a terminally ill parent.

Acknowledging the developmental context for these two groups of children then assists in further explaining the main differences in the experiences of the two groups. The teenagers often felt trapped and held back in their lives as they were expected to assume more responsibilities at home. The fact that they, unlike the adult children, were still dependent on their parents and living at home was paramount in compounding their feeling of burden. The teenagers struggled with

many paradoxes which were all connected to their fundamental need to establish autonomy and independence from family. In contrast, the adult children struggled with the conflicting demands of their own families, homes and careers with the demands of caring for a terminally ill parent. The changes that the teenagers had to contend with in their relationships, roles, home atmosphere, and school were often perceived as a hindrance interfering with their developmental drive to get on with their own lives. Changes for the adult children, however, centered around providing physical, emotional, legal and financial support to both parents while also having to attend to their own responsibilities of being young adults. The teenagers searched for meaning in the situation as they contemplated their own insecure future, not yet ready for complete independence. Unlike the teenagers, having a terminally ill parent challenged the adult children to reconsider their values and priorities in life, at a time when developmentally this type of life review is expected (Murray & Zentner, 1985). Developmental stage is undoubtedly a crucial factor influencing the experiences of the two age groups of children caring for a terminally ill parent.

The phenomena of redefining, living day to day and planning for death were not as useful in describing the teenagers' experience, as they were for the adult children's experience. The reasons for this are also most clearly understood within a developmental context. The teenagers did not redefine their parent as being any different than before the illness because by retaining the old view they could shield themselves from the reality that their parent would die, which in turn freed them up to get on with the work of adolescence. As the teenagers focused their energies on their own lives and futures they did not describe living from one day to the next, making the most of the time left with their ill parent. Similarly, no matter how close the parent was to death the teenagers were not fully prepared for the event because they had shielded themselves from the reality of the situation and did not have an

adequate enough understanding of the dying process to fully gauge the seriousness of the situation.

Analysis of the data from the teenagers in this study, using the conceptualization of "fading away" as a framework for discussion, has undoubtedly generated new information. The analysis verifies of four of the seven phenomena of the framework for this population of teenagers, and has added new dimensions to all seven phenomena thereby broadening the understanding of the experiences of living with a terminally ill member to include the teenager's experience. The analysis has also generated the new phenomenon of shielding which is unique to the teenagers' experience.

Shielding Versus Denial

Some authors suggest that the protective mechanism of denial comes into play when a young person is faced with the impending death of a loved one (Adams & Deveau, 1987; Gravelle & Haskins, 1989; Raphael, 1986). Denial may serve to allow the teenagers to behave as normal teenagers and push away from family instead of drawing back into the family circle. Denial, according to Kalish (1985) is an unconscious avoidance to insulate the self from the emotional impact that death is a reality. Although the teenagers in this study made efforts to protect themselves from fear and the reality of imminent death of their parent, they consciously chose to push thoughts away in order to carry on with their own lives, rather than to unconsciously avoid the issue. The teenagers clearly articulated that they knew that their parent was going to die and they just as clearly spoke of not wishing to think about it because it interfered with their daily lives. The term shielding, rather than denial, is proposed then as a more accurate descriptor of the strategy used by teenagers to cope with the impending death of a parent from cancer. Shielding was used by the teenagers to alleviate fear about their future, and to allow them to get on

with mastering the developmental tasks of separating from family and moving toward autonomy and independence.

The Impact of Advanced Cancer in a Parent on Teenagers

The findings from this study clearly illustrate that living with a parent with advanced cancer has a profound impact on the day to day lives of teenagers. It affects them emotionally and physically as they experience changes in themselves, their relationships, their roles and responsibilities, and their perceptions about their own futures.

Emotional Impact of Advanced Cancer

Researchers have found that although some caregivers of terminally ill family members expressed fear about the future (Krant & Johnston, 1977-78; Welch, 1981; Wright & Dyck, 1984), and of the person dying (Gotay, 1984; Krant & Johnstone, 1977-78; Welch, 1981), other emotions such as anxiety, stress, uncertainty, guilt and helplessness (Giaquinta, 1985; Gotay, 1984; Hinde, 1984; Holing, 1983; Krant & Johnston, 1978; Lovejoy, 1986; Rose, 1977; Vachon et al., 1977; Wright & Dyck, 1984), were the more commonly experienced emotions as the caregivers felt the burden of providing both the physical and emotional support to their dying family member.

Like these caregivers, the teenagers in this study experienced many different emotions. They described emotions such as guilt, resentment, sadness, anger, anxiety, and hopelessness. They often found it difficult to comprehend the reason for the mood swings, not necessarily attributing them to the fact that their parent was dying. They perceived themselves to be repressing feelings to minimize the stress at home and yet they also described arguments with siblings and increasing tension at home. They were often resentful of their feelings of obligation to stay at home more and to take on more responsibilities. They felt guilty when not at home and guilty when not out with friends.

Unlike the caregivers in the other studies, however, fear was the predominant emotion underlying many of the feelings, actions and behaviours of the teenagers. Fear was triggered for the teenagers in two main areas. First, the teenagers became very afraid when their ill parent's physical condition visibly deteriorated. They became fearful that their parent would die at any moment and were horrified at the thought of being present at the time of death. Second, the teenagers became scared when they anticipated their own future without their parent. They feared the insecurity of not having basic needs met such as having a stable home and having at least one parent there for them. These two areas concerning the profound emotional impact that fear had on the experience of these teenagers warrants further discussion in light of developmental and other theories.

Fear of worsening physical symptoms

Unlike the adult children in the study by Davies et al. (1990), the teenagers in this study became fearful and distressed when their parent's external, visible condition deteriorated. The teenagers did not appear to have an understanding of the process of dying, as being one of alternating periods of deterioration and stabilization, with an overall decline to death. Without this knowledge, the teenagers had no means by which to anticipate the likely time of death, and hence fear of death could be triggered at any time.

Being unable to gauge the seriousness of their parent's condition and hence being unprepared for the death itself, one would expect the teenagers to be very shocked when in fact the death did occur. Berman et al. (1988) support this supposition. Despite having information about the diagnosis, prognosis and changes in their parent's condition, the parent's death came as a shock to the teenagers in their study. Other authors have also commented on the severity of the shock reactions of teenagers at the death of their parent, even though the death had been expected and even though the teenagers knew the prognosis (Gravelle & Haskins,

1989; Raphael, 1986). These findings suggest that nurses should not assume that teenagers have absorbed information they have received about the imminence of their parent's death. Nurses should be prepared to support the teenager who may experience a severe shock reaction at the actual time of death.

Teenagers may also be unprepared for death because of the general lack of knowledge and open discussion about death and dying which pervades western civilization, as death in our society is still a taboo subject (Munley, 1983). Today's youth has been called a deathless generation as children and adolescents have rarely experienced or witnessed the death of a close family member or friend, and hence are mystified by the process of dying (Bernstein, 1983). Most youngsters have two parents throughout childhood, and the deaths of older relatives can appear as remote incidents, particularly as many children are separated from their grandparents by some distance. If there should be a death within the immediate family, technical advances are such that the person is more likely to die in hospital than die at home and children are often prohibited from full access to visiting in hospital. Death education in the classroom is not yet commonplace and hence childrens' knowledge and experience with death is limited (Cassini & Rogers, 1989).

Several of the teenagers in this study had experienced the death of a grandparent and one teenager had experienced the death of a schoolfriend. None of the teenagers, however, felt that these experiences had had much of an emotional impact on them, nor did they think that these past experiences with death had prepared them in any way for the present experience with their parent. It is not surprising, therefore, that the teenagers in this study experienced fear as they faced death close at hand for the first time, with little past experience and little knowledge about the process of dying.

According to Murray & Zentner (1985), adolescence is a time when attention is focused on body surface as the development of body image and self concept is

realized. Teenagers are very conscious of creating an image and of manipulating external cues to create a socially-acceptable physical appearance. It is not surprising therefore that the teenagers focused on the physical cues of illness to determine the seriousness of their parent's condition. Having more information about the significance of certain physical symptoms may well be of benefit to the teenager whose fear is often triggered by such factors.

With this understanding about the teenagers' lack of knowledge about the dying process, as evidenced by the intensity of fear each time their parent's physical condition worsened, along with the understanding that adolescents tend to focus externally rather than internally, nurses are directed to ensure teenagers are more fully educated in attempt to alleviate some of that fear.

Fear of the future without the parent

Looking into the future and facing the reality that their parent was going to die triggered intense fear for the teenagers in this study. The reality shook their foundation of security so much so that they adopted certain strategies to prevent facing the inevitability of their parent's death. They shielded themselves by not redefining their parent, by deliberately not thinking about the situation at home, by taking breaks away from home to be with friends, and by trying to maintain their old view of their parent, hoping that the parent would recover, and maintaining a positive attitude that recovery could in fact happen. The teenagers often had questions about their future which they were afraid to ask because they were afraid to hear the answers. The questions related directly to the security of their home and assurance of the presence of the well parent in their lives. The adult children in the Davies et al. (1990) study, in contrast to the teenagers in this study, did not express fear of the future in relation to their own security.

Alleviating fear: Communication

Understanding that living with a parent with advanced cancer has a profound emotional impact upon teenagers, particularly in relation to the fear that the situation triggers in them, offers guidance to nurses to develop interventions specifically geared toward alleviation of that fear. Nurses can assist parents to anticipate questions teenagers may have about security issues for their future, so that as much reassurance as possible can be given to the teenagers to minimize their fear about insecurities. Nurses can also provide information to teenagers about the process of dying so that they can better gauge the seriousness of the situation and be more prepared for the death. Nurses can also be available to talk with teenagers or their parents to provide emotional support and counselling in the area of death and dying.

Debate is needed however, as to whether talking about the situation is helpful or unhelpful in alleviating fear for teenagers living with a parent who is dying. In this study, one strategy used by the teenagers to reduce fear was to shield themselves from the reality of death by not thinking or talking about the situation and by repressing feelings. They chose not to talk much with family or friends. They commented that friends could not really understand what it was like to have a seriously ill parent and that their friends talked about trivial rather than important things in life. They also commented that when they did spend time with friends they wanted to go out and have a good time and forget about things at home for a while. Not talking about the situation for the teenagers may have been adopted as a useful strategy to enable them to get on with their own lives.

Literature on communication in families caring for a terminally ill member reveals some controversy about the value of open discussion in families on death and dying. Studies by Krant and Johnston (1977-78), Vachon et al. (1977) and Hinton (1981) all found that limited discussion about death takes place in families. These

researchers conclude that non-discussion makes no difference to the widow's adjustment after death nor to the anxiety or depression level of the patient.

Other studies suggest however, that open communication aids adjustment in the bereavement phase (Cohen, Dizenhuz, & Winget, 1977), and affects the level of closeness in the couple prior to death. Berman et al. (1988) are the only researchers to date who have commented on communication about death in the family with teenagers. They stated that all ten of the teenagers they interviewed had had the opportunity to talk about death within the family prior to the death itself, and seven out of the ten had spoken with the dying parent before the death. They also commented that teenagers turned to siblings and friends for support, although some of the teenagers reported that it was difficult to turn to peers who had not experienced the loss of a parent. Two of the ten teenagers found it helpful to talk to other adolescents who had lost a parent. Although this study reports interesting findings, there was no comment on whether talking about death within the family significantly assisted the teenagers in reducing fears and anxiety.

Data from the current study concur with the findings of the researchers who found that limited discussion about death takes place in families. Although little discussion occurred, the teenagers in this study perceived that the dying parent was open and available for discussion about death and dying but the teenagers themselves chose not to initiate discussion. When their parents initiated conversation about death and dying, the teenagers tended to reassure their parent that everything was going to be fine rather than to express their own fears and concerns. The teenagers often had questions about the future but were hesitant about having those questions answered. As with the teenagers in the study of Berman et al. (1988), the teenagers in this study found it difficult to turn to friends for support. They found that friends could not understand what it was like to live with a parent who was dying.

Perhaps, as Berman et al. (1988) suggest, it would be helpful for teenagers to speak with other teenagers who are going through the same situation as themselves. Two of the teenagers in their study found it helpful when they spoke with other adolescents who had lost a parent. Five teenagers from the current study suggested that getting together with other teenagers in the same situation may be helpful to them. The younger ones were more hesitant about the usefulness of getting together with other teenagers because of how difficult they found it to open up to others to talk about their feelings. Since data were collected for this study, three of the teenagers have organized a support group for other teenagers who are living with a parent with cancer, so that they can meet to talk and offer support to each other. This action suggests that some teenagers do want to discuss their feelings, fears and concerns about living with a parent who is dying. Perhaps their need is to talk to people their own age, who are also going through the experience, and who are unknown to themselves and their family.

There is also some evidence to support the value of professional counselling for teenagers living with a terminally-ill parent. Rosenheim and Ichilov (1981) are the only authors who have documented findings of the benefits of a goal-oriented psychotherapy program for children of fatally-ill parents. They describe a decrease in teenagers' anxiety levels, and an improvement in both their scholastic achievements and their social behaviour at school, as a result of ten to twelve consecutive weekly meetings with a therapist. The meetings revolved around three main issues for the teenagers: the perception of the illness and their reaction to it; the factual life situation at home; and the feelings towards the parents and self-concept. Ten out of the twelve teenagers expressed their interest in keeping up with the meetings.

Based on the fact that living with a parent with advanced cancer has a profound emotional effect on teenagers, and the limited evidence that some teenagers

have expressed an interest in meeting informally with other teenagers or formally with a therapist, more research is needed to confirm that this need exists and that interventions of a formal or informal nature would in fact be helpful in alleviating some of the the teenagers' fear, freeing them to get on with their lives.

The Physical Impact of Advanced Cancer

Other studies have documented that caretakers of persons with advanced cancer perceived the situation to have a physical as well as an emotional impact on them, with complaints of excessive fatigue, unsatisfactory health, and psychosomatic disturbances (Googe & Varricchio, 1981; Stetz, 1987; Vachon et al., 1977; Welch, 1981). The only documentation of negative effects on the teenagers' health of living with a parent with cancer was from the clinical observations of Grandstaff (1976). She commented on the fact that teenage boys, unlike girls, showed a continuous pattern of various illnesses since their mother's surgery for breast cancer. Neither the spouses nor the children in the study by Davies et al. (1990) complained about their own health suffering as a consequence of caregiving demands. They did, however, resolve to take better care of themselves as a result of realizing their own vulnerability to death. In contrast, most of the teenagers in this study complained of a deterioration in their own health since their parent had become so ill. They complained of chronic headaches, fatigue, exhaustion, stomach problems, and unshakable colds, coughs and flus. They also described themselves as becoming more involved in risk-taking behaviour "to escape from the situation". This behaviour included the use of alcohol and drugs, engaging in unprotected intercourse and overeating.

Of the seven published studies on the impact of cancer on teenagers, only Wellisch (1979) described acting out behaviour when a parent had cancer. Wellisch (1979) stated that acting out behaviour was the result of subtle role shifts between the teenager and both parents which reintensified emotional contact between

adolescent and parent at a time when the teenager was in the midst of separating from parents. Rebellious, self-destructive behaviour is not uncommon during adolescence as teenagers test the limits of their feelings of omnipotence and deal with the anxieties associated with adulthood (Thornburg, 1982). Teenagers who use drugs and alcohol typically do so to reduce levels of anxiety and fear, and eating disorders are often associated with a lack of establishing an identity separate from parents (Conger & Peterson, 1984). In most cases these behaviours do not persist past adolescence (Conger & Peterson, 1984).

Teenagers who are living with a parent with advanced cancer may be at greater risk therefore of harming themselves because of their high level of anxiety and fear, and because of the emotional stress of trying to continue the process of separating from parents to develop their independence, while at the same time being pulled back into the family. More research in this area is needed in order to assess the level of risk for these teenagers who are living with a dying parent, and to assess the effectiveness of interventions put in place to assist in the relief of anxiety and fear in less self-destructive ways.

Conclusions of the Study

The first conclusion that arises from this study is that living with a parent with advanced cancer undoubtedly has a profound emotional and physical impact upon the day-to-day lives of teenagers. Fear is the predominant emotion underlying many of the actions and behaviours of teenagers living in this type of family situation.

A second conclusion is that unlike adults in the same situation, teenagers shield themselves from the reality of the imminent death of their parent so that they can continue to pursue the developmental tasks of adolescence, and to get on with their own lives. Shielding describes the essence of the experience for teenagers living with a terminally ill parent.

The final conclusion is that only four of the seven phenomena described in the conceptualization of "fading away" (Davies et al., 1990) accurately reflect aspects of the teenagers' experience. Unlike adults in the same situation, teenagers do not redefine their ill parent in order to adjust to the changing situation at home, nor do they describe themselves living from day to day or making preparations for their parent's death. The differences are explainable within a developmental context.

Nursing Implications

The findings from this study provide direction for nursing practice and further research with families with teenagers who are dealing with advanced cancer in a parent.

Implications for Nursing Practice

The lack of research to date on the effects on teenagers of living day to day with a terminally ill parent has left nurses ill-equipped to deal with this particular group of individuals. If nurses are, in fact, committed to caring for the whole family as a unit when one member has cancer, then understanding all family members' responses to such a situation is essential. The findings from Stage I of this research study provide a contribution to understanding the effects on teenagers of living with a terminally ill parent, and hence assist in activating that commitment to wholistic nursing care.

Assessing the teenagers

The findings from this study strongly support the fact that teenagers whose parents are dying must be included in the plan of nursing care. The fact that six out of the eleven teenagers in this study chose to be interviewed in the researcher's office rather than in the family home suggests that nurses should offer the option of conducting the initial nursing assessment, and possibly follow-up sessions, in a neutral space. Teenagers in the study often expressed how much they repressed their feelings at home, how little they talked with other family members and how

they tried to keep the peace. Bearing this in mind, therefore, it is more likely that teenagers would express their fears and concerns in an environment away from home.

The personal and situational factors which affect the teenagers' experience, (Appendix D), may be used as a helpful guide when collecting initial assessment data. Of particular note are age, sibling order, relationship with the ill parent prior to the illness, family communication and coping style, length of illness, ill parent's attitude toward death and dying, level of independence encouraged by parents, and amount of care provided by the well parent. These factors appear to influence the severity of the emotional and physical impact upon the teenagers and hence the degree to which they are able to get on with their own lives. The nurse might then use the categories from the conceptualization of "fading away": burdening, struggling with paradox, contending with change and finding meaning, as a guide to building a more complete picture of the teenagers' present situation. The nurse might also assess the degree to which the teenager is using the protective mechanism of shielding as an indicator of how intent the teenager is on continuing with mastery of the developmental tasks of adolescence.

Assessment of risk is an important role for the nurse caring for teenagers whose parents are dying. The findings from this study suggest that some teenagers respond to such a crisis in the family by becoming involved in, or exaggerating existing, self-destructive behaviour patterns. An exploration of such types of behaviours and an assessment of the level of risk to the teenager must be considered. Assistance with developing health-promoting, rather than self-destructive strategies for stress management should be emphasized. Assessment of the teenagers' own health status is also important and appropriate referrals made if any health concerns become evident through the interview.

Teaching and supporting the teenagers

The findings from this study suggest that teenagers living with a parent with advanced cancer lack an adequate understanding of the process of dying and hence become very fearful at their parent's worsening physical symptoms. Because of this lack of knowledge, they cannot discern the seriousness of the situation nor predict when their parent is likely to die.

Nurses are in a prime position to assess the teenagers' level of knowledge about the physical condition of their parent and to then educate the teenagers about the likely course of decline and about what to realistically expect within a certain time frame. This intervention may help to alleviate some of the extreme fear that the teenagers often experience when their parents' condition worsens. The nurse may also learn that the teenagers are fully aware of the situation but have chosen to shield themselves from the reality that their parent is going to die. Understanding the phenomenon of shielding, the nurse can then respect that the teenagers have consciously chosen to protect themselves in order to get on with their own lives.

An important role for the nurse is to support the teenagers who wish to discuss feelings of guilt and resentment, of being used, of being trapped, of blaming the ill parent for not assisting in their recovery or of feeling their friends do not understand. From the data it is clear that few teenagers talk openly with family members or friends about the situation at home. Based on the willingness of the teenagers to talk openly in the interviews however, it appears that teenagers may be more open to talking with individuals who are unknown to them. The nurse who ascertains that the teenager would benefit from this type of support then has an obligation to refer the teenager to an appropriate person for ongoing counselling and support.

From the findings of this study, there is also preliminary evidence to suggest that teenagers who are living with a dying parent might benefit from talking with

other teenagers in the same situation. The fact that several teenagers from this study have already instigated a peer support group implies the need for this type of intervention. Nurses could be of assistance to teenagers who have expressed an interest in setting up such a group by: 1) helping to find a suitable, neutral space for meetings; 2) securing funding for posters, advertising, photocopying etc.; 3) suggesting speakers who could educate the teenagers in such areas as death, dying, grief, loss, bereavement, and anxiety management; 4) being available as a resource for the group organizers; 5) informing other health care professionals in hospitals and the community, school counsellors, and community agencies about the group.

Teaching and supporting the parents

The findings from this study suggest that little communication goes on in families with teenagers about death and dying when a parent is terminally ill. The teenagers often find it difficult to talk about the situation at home and/or choose not to do so. The nurse has a role in teaching parents therefore about common responses of teenagers in this type of home situation because the parents may be unaware of how the teenagers are feeling. Parents should be encouraged to support the teenagers to carry on with their usual activities, and to refrain from expecting too much of the teenagers in terms of responsibilities at home, particularly in relation to providing physical care to the ill parent. The more the teenagers can be encouraged to pursue the normal tasks of adolescence the less likely they will feel burdened and held back in their own lives.

Parents should be encouraged to anticipate the teenagers' questions about the future in terms of security such as: Where will we live? Who will be there with me after the death? Will you remarry? The teenagers require much reassurance during this period particularly from the well parent that they will still be provided with some security and a home after the ill parent dies.

Many of the teenagers expressed a longing to become closer to the ill parent but they did not know how to initiate that type of change in their relationship with their parent. In this type of situation, where the teenager has expressed the desire to get closer, the nurse could help the ill parents to identify some strategies which might enhance closeness between themselves and their teenage children.

Teaching the community

With the incidence of cancer increasing annually, the numbers of teenagers living with a parent with advanced cancer can only increase. Health care professionals, school counsellors, social workers, police officers and other community workers will therefore encounter more and more of these teenagers in their daily practice. The study findings emphasize the profound impact that living with a terminally ill parent has on teenagers. Once nurses have this knowledge, therefore, they should take on the responsibility of educating professionals in the community, to enhance their knowledge base and offer them some guidance for designing helpful interventions for these teenagers.

This study provides direction to nurses as they care for teenagers who are living with a terminally ill parent. The study is however just a beginning contribution to this area of family nursing research which still requires much more exploration.

Implications for Nursing Research

Data analysis of Stage 1 of this project has been useful in demonstrating those phenomena of the conceptualization of "fading away" which reflect the experience of teenagers living with a terminally ill parent and those phenomena which do not. The study has also generated the new phenomenon of shielding hence broadening the application of the conceptualization of "fading away" to other populations or conditions. The analysis of Stage II of the project will serve to refine

this existing theory further as the experiences of all members of families with teenagers will be described in relation to "fading away".

The findings from this study raises several questions for future research which would help to further build theory in this area where so little research has so far been conducted:

- 1) What are the differences between the experiences of male versus female teenagers who are living with a parent with advanced cancer?
- 2) What effect does gender of the parent with advanced cancer have on the experience of teenagers?
- 3) What are the differences between the experiences of teenagers of varying ages: 13-15 year olds; 16-17 year olds; 18-19 year olds?
- 4) How does length of illness of the parent with advanced cancer affect the experience of teenagers?
- 5) What are the differences in the experiences of teenagers living with a single parent with advanced cancer versus teenagers living with two parents?
- 6) How does ethnicity affect the experience of teenagers living with a parent with advanced cancer?

The findings of this study also imply that further research is needed to verify the phenomenon of shielding as a strategy unique to teenagers living in this type of family situation. Teenagers may in fact use this coping strategy in other crisis situations such as impending divorce or separation of parents, illness in a sibling or close friend, or illness in themselves. More research is needed therefore to further delineate the properties and dimensions of this phenomenon.

Research is also needed to examine the effect of interventions with teenagers during the period prior to the death of a parent, first, on physical and emotional parameters; second, on grieving after the death of their parent; and third on the long term effects on adults who have lost a parent during adolescence. Evaluation

studies of interventions such as individual counselling or peer support groups would be helpful for nurses when proposing to promote such interventions.

Summary

This chapter discussed the findings of Stage I of this research project in light of other research and theoretical perspectives. The research question of whether the conceptualization of "fading away" reflects the experience of teenagers living with a parent with advanced cancer, as it does for adult children, was addressed. Analysis of the teenager data, within a developmental context, added new insight to the phenomena of the conceptualization of "fading away" and generated a new phenomenon of shielding which was unique to the teenager's experience. Fear of worsening physical symptoms and fear of the future without the parent were discussed as major components of the emotional impact on the teenagers of living with a parent with advanced cancer. Finally, the physical impact of the situation and the potential risks to the teenager were highlighted prior to discussion of the implications of the findings from this study for nursing practice and further research.

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Appendix A

INFORMATION LETTER FOR FAMILY MEMBERS

Dear _____:

My name is JANIE BROWN. I am a Registered Nurse and a student in the Masters of Science in Nursing program at the University of British Columbia.

I have worked as a nurse for ten years caring for individuals with cancer and their families. I believe that we as nurses could provide much better care to families living with cancer in their midst, if we knew more about the experience from the family members themselves.

My thesis supervisor, Dr. Betty Davies and her colleagues have completed a study with families in which one member has cancer. Based on the information provided by the families the researchers developed a description of what the experience is like for families. However, none of the families which were interviewed included families with teenagers, so it is not clear whether the description applies to this type of family. I would therefore like to talk with families with teenagers in order to find out what it is like for them living with a family member who has cancer.

For this reason, I would like to set up an appointment with you, and the person who is most involved with your care (your spouse, partner, a close friend, or another relative) and with your teenage child/children. I would first discuss the study with you and answer any questions you may have. If you all agree to participate I would be asking you to be interviewed on one to two occasions for a total time commitment of about two hours for each person.

At the start of the first interview I would obtain a written consent from each person. I would then like to interview each family member separately for about 30-60 minutes each and finally talk with the whole family for a final 30 minutes or so. If necessary a second visit will be arranged to clarify the information received in the first interviews.

You are under no obligation to participate in this study and are free to withdraw from it at any time, without jeopardizing care in any way. If you are interested in learning more about the study and/or wish to participate please inform the nurse who gave you this letter and she or he will contact me. Thank you for your interest and I look forward to discussing this project with you.

Sincerely,

Janie Brown. R.N., M.A.

Appendix B

CONSENT TO PARTICIPATE

PROJECT TITLE: The Experience of Families with Teenagers Caring for an Adult Family Member with Advanced Cancer at Home

CO-INVESTIGATOR: Janie Brown, R.N., M.A.
Graduate Student, Masters Program
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PRINCIPLE INVESTIGATOR: Dr. E. Davies
Associate Professor
School of Nursing
University of British Columbia
Tel: 228-7456

PURPOSE OF THE STUDY

The intent of this study is to describe the experience of families with teenagers who are caring for a parent with cancer at home. It will verify whether the description proposed by Dr. Davies and colleagues of the experience of families who are caring for a parent with cancer at home actually reflects the experience of families with teenagers in the same situation. There is a need to hear directly from families living with cancer if nurses are to provide high quality nursing to these families.

I, _____, agree to participate in the research study described above. I have had the study explained to me and I understand that:

- a) I may refuse to comment or answer any question at any time;
- b) I may withdraw from the study at any time without a negative effect on care;
- c) I am free to stop the interview at any time;

I expect that:

- a) Although the length of the interview will depend on my tolerance, the average length of the interview(s) will be 30-60 minutes;
- b) I will be interviewed in my home, (at most, twice with my family and twice alone);
- c) The researcher will be observing me during the interviews;
- d) The interviews will be audiotaped and transcribed and the tapes destroyed after completion of the study;
- e) The tapes will be listened to only by the researcher and faculty advisors;
- f) The transcriptions will be kept in a locked drawer and destroyed within three years of completion of the study;
- g) All transcripts will be identified only by code number; my name or the name of other family members will not appear in any research report, unpublished or published;
- h) The content of my discussions with the researcher will be held in strict confidence by the researcher and faculty advisors.

I have been given the opportunity to ask whatever questions I desire of the researcher and have had all such questions answered to my satisfaction. I realize I can ask for additional information at any time. I will be given a copy of this consent form, and I will be given an opportunity to see a summary of the final report.

Patient

Witness

Spouse/Partner/Primary Caregiver

Teenage Son/Daughter

Parent for Teenager

Teenage Son/Daughter

Parent for Teenager

Date

Appendix C

INTERVIEW GUIDELINES

We believe that when a person is ill, like _____, there is an effect on the whole family. We are interested in learning more about how families manage these kinds of situations as a way of planning for better care. The questions I am about to ask you arose from previous studies of others who were in similar situations to yourselves. These studies found that patients and families seemed to be going through a series of changes and reactions. Family members often had to deal with a number of things such as managing confusion and uncertainty, feeling a burden and so on. What I would like to do in our interviews is to ask you some questions about how you view these various changes and reactions.

Please let me know if you get tired or need a break from the interview. Also, if there are any questions which you do not wish to answer let me know and I will move to the next question.

1. I would like to begin by asking you to describe how things have been for your family since _____ became ill?

Probes:

- a. What has it been like for all of you caring for _____ at home?
- b. What kinds of things stick out in your mind about the experience?

2. (Redefining) When someone in a family has become ill and they're not able to function in their usual way, people begin to view them in a different way. In some ways they are still the same and in other ways they are different. How has this been for you? What things can you identify from your own experience that fits with this idea?
3. (Burdening) When someone is ill that person is often unable to do what they used to do so other members take on their work plus the responsibility of caring for the ill person. When this happens in families, people often feel differently. Some people feel overworked and others don't, sometimes people protect each other or feel they're holding others back. How has this been for you?
4. (Contending with change) When someone in the family is ill, people can't always do their usual jobs, things are done differently or people see things differently. Household tasks are handled differently, usual routines change. How has your outlook changed? What other changes have you had to deal with? How has your health been?

5. (Struggling with paradox) In situations of caring for someone who is very ill, people often feel like they are being pulled in two directions at the same time, for example, wanting to fight and wanting to give up, wanting to know answers and yet not wanting to ask the questions. What has been your experience? Would you agree that this occurs? How else might you describe this reaction?

6. (Searching for meaning) When someone in a family is very ill, people often try to find some meaning in the experience, they try to learn from what is happening to them. Has this been the case for you? What has helped you deal with this situation?

7. (Living day-to-day, preparing for death) Some of the other families reported that there came a point when they realized that the patient was not going to get better, they then tried to make the best of things, to make the most of the time. Others spent more time with the patient, and put things in order, for example, possessions, wills, household information and so on. What has been your experience?

8. (Neutral zone) When someone in a family is very ill, people often feel like that everything is up in the air, on hold, they feel like they are in limbo, at a standstill, confused. in chaos, where everything seems up in the air. Has this been true for you? How would you describe your experience, your reactions?

9. (New beginnings) Some people have told us that there came a point when they realized that given the situation there were certain things that they wished to accomplish and that they could not let the situation overwhelm them. Does this fit for your experience? How would you describe your experience?

10. (Ending). When someone is ill for a long time, people are always hopeful that the ill person will recover. Sometimes, there comes a point when people realize that the ill person will not recover. Would you agree with this? Was there a point like that for you? Would you describe your experience?

11. (Transition, fading-away) We were trying to find a word or phrase that would help us describe this process of dealing with a family member who is not going to recover. In our previous discussions with families and patients their descriptions of the patient seemed to suggest the person was losing abilities and that this made them realize that the person was not going to recover. One person used the words fading-away. We used the same phrase to describe this transition. How does this fit with your experience? How would you describe it differently? What other words would you use? Is it the person, or life as it was, or is it hope which fades?

12. (Past experience) Most of the people we talked to discussed their past experiences with illness, death, or other major problems, in their lives and indicated that these all impact on how they handled this situation. Is this true for you? In what ways have your past experiences affected how you are handling this situation.

13. (Style) In dealing with the whole situation, did you find that you recognized certain patterns of behaviour that you and your family has used in the past to deal with other stressful situations? In dealing with this situation have you used similar patterns or have you had to find new ways of dealing with this situation? How has it been for the rest of the family?

14. What would you like to add to this interview? Have I missed out anything that you would like to tell me about your experience or that would help us understand this situation better?

Appendix D

Decision Trail of Conceptual Analysis

MAJOR CATEGORIES	INITIAL CATEGORIES	INITIAL CODES
SHIELDING		
INTERVENING VARIABLES	Personal Factors	<ul style="list-style-type: none"> - gender - age - sibling order - personality
	Situational Factors	<ul style="list-style-type: none"> - relationship with ill parent prior to illness - length of illness - family communication - family coping style - ill parent's attitude toward death/dying - level of independence encouraged by parents - amount of care provided by well parent - location of care
ACTION/ INTERACTIONAL STRATEGIES	Encountering Hindrance	<ul style="list-style-type: none"> - Feeling trapped - Resenting more responsibilities - Feeling guilty if not home - Feeling guilty if not with friends - Dwelling on parent's illness - Unable to move out - Longing to be closer - Unable to get closer - Feeling used - Keeping the peace - Lacking concentration at school - Not talking about the situation - Perceiving friends do not understand - Shifting dependency roles parent/child
	Being There	<ul style="list-style-type: none"> - Reassuring parent - Assisting with physical care - Spending more time with family - Empathizing with ill parent - Checking-in - Taking on responsibility for family after death

Riding the
Emotional
Roller-Coaster

- Repressing feelings
- Emotional outbursts
- Changing moods
- Reacting to physical symptoms
- Fearing parent will die
- Fearing being alone
- Arguing with siblings
- Hoping parent will recover
- Blaming parent for not assisting in recovery

Getting-On

- Pushing thoughts away
- Refusing to acknowledge seriousness of illness
- Choosing to be with friends
- Engaging in self-destructive behaviours
- Taking breaks
- Questioning the future
- Not wanting answers to questions
- Feeling sense of urgency
- Wishing it would be over
- Wishing parent would get better
- Making commitment to own future
- Searching for career directions

CONSEQUENCES

- Growing up fast
- Outgrowing friends
- Being fatalistic
- Taking life more seriously
- Feeling self stronger
- Feeling closer to family
- Confronting own health issues
- Maintaining positive attitude

Appendix E

Fitting Initial Codes into Conceptualization of Fading Away

THE ENDING	<ul style="list-style-type: none"> - Reacting to physical symptoms - Fearing parent will die - Fearing being alone
Redefining	<ul style="list-style-type: none"> - Refusing to acknowledge seriousness of illness - Fearing being alone - Feeling used - Engaging in risk-taking behaviours
Burdening	<ul style="list-style-type: none"> - Feeling trapped - Resenting more responsibilities - Feeling guilty if not home - Feeling guilty if not with friends - Dwelling on parent's illness - Unable to move out - Longing to be closer - Feeling used - Keeping the peace - Lacking concentration at school - Not talking about the situation - Perceiving friends do not understand - Shifting dependency roles parent/child
NEUTRAL ZONE	
Struggling with Paradox	<ul style="list-style-type: none"> - Wishing it would be over - Hoping parent will recover - Feeling guilty if not home - Feeling guilty if not with friends - Choosing to be with friends - Spending more time with family - Taking breaks
	<ul style="list-style-type: none"> - Pushing thoughts away - Refusing to acknowledge seriousness of illness - Dwelling on parent's illness
	<ul style="list-style-type: none"> - Empathizing with ill parent - Reassuring parent

- Assisting with physical care
- Feeling used

- Longing to be closer
- Unable to get closer
- Not talking about the situation

- Having questions about future
- Not wanting answers to questions

- Contending with Change
 - Shifting dependency roles parent/child
 - Feeling closer to family
 - Spending more time with family
 - Arguing with siblings
 - Taking on reesponsibility for family after death
 - Assisting with physical care
 - Checking-in
 - Growing up fast
 - Outgrowing friends
 - Perceiving friends do not understand
 - Taking life more seriously
 - Changing moods
 - Repressing feelings
 - Emotional outbursts
 - Feeling self stronger
 - Contending with own health issues
 - Lacking concentration at school
 - Feeling sense of urgency

- Searching for Meaning
 - Having questions about the future
 - Fearing being alone
 - Fearing the future
 - Making commitment to own future
 - Maintaining positive attitude
 - Being fatalistic
 - Engaging in self-destructive behaviours
 - Feeling a sense of urgency
 - Hoping parent will recover
 - Blaming parent for not assisting in recovery
 - Searching for career directions

- THE BEGINNING
Living Day to Day
 - Making commitment to own future
 - Pushing thoughts away
 - Getting-on
 - Feeling sense of urgency

Preparing
for death

- Fearing parent will die
- Not talking about the situation
- Reacting to physical symptoms
- Hoping parent will recover
- Refusing to acknowledge seriousness of illness
- Pushing thoughts away
- Wishing it was over