INTERACTION PATTERNS BETWEEN PARENTS
WITH ADVANCED CANCER IN HOSPICE
AND THEIR ADOLESCENT CHILDREN

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ABSTRACT

Cancer profoundly affects the lives of those with the diagnosis and their families. When the life of a parent is threatened by advanced cancer, the children are faced with living their lives first with a seriously ill parent and then without the physical presence of the parent.

The purpose of this study was to develop a theoretical framework to describe interaction patterns between parents with advanced cancer and their adolescent children. The sample included 26 participants from 9 families; 7 parents with advanced cancer enrolled in a hospice program, 9 spouses, and 10 adolescents (12-18 years old). Grounded theory methods using unstructured interviews were used to illuminate the processes ill parents and adolescents used to manage their lives within the context of the parent’s impending death, and to respond to changes over time.

The adolescents and their ill parents described a process of becoming closer to each other by spending more time together. Participants described their experiences as a conscious effort made in direct responses to the parent’s impending death. Limited time together was the core concept that led to spending more time together and developing means to extending their time together after the parent’s death. For some adolescents the process culminated in a choice to give up their time with their ill parents when dying became too difficult to watch. The ill parents made a concerted
effort to remain close to their adolescents after death by writing letters to them, and by giving them other tangible objects by which to remember them. Several ill mothers identified specific women to serves as guides and role models for their daughters after the mother’s death.

There are a number of direct implications for clinical practice that arose from this study. Generally, adolescents need guidance in traversing this new and unexpected experience of facing their parent’s impending death from clinicians who convey empathy and understanding and help adolescents begin a conversation with the ill parent. Clinicians should be aware that friends are a major source of support and should appreciate their contributions by including them in adolescent support groups.
DEDICATION

I dedicate this dissertation to my family and friends who have traveled this doctoral journey with me. Their love and laughter has sustained me through it all.
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Cancer profoundly affects the lives of those with the diagnosis and their families. When the life of a parent is threatened by advanced cancer, the children are faced with living their lives first with a seriously ill parent and then without the parent. The demands and uncertainties associated with life-threatening illness present challenges to maintaining a stable family life. While parents are expected to nurture and to provide emotional security for their children, this may become challenging when a parent becomes seriously ill and focusing on the children’s needs becomes difficult (Davis Kirsch, Brandt, & Lewis, 2003; Elmberger, Bolund, & Lutzen, 2000, 2002; Siegel, Raveis, Bettes, Mesagno, Christ, & Weinstein, 1990).

Investigators have focused on responses of individual family members to a parent’s diagnosis of cancer by examining discrete factors, such as anxiety and depression, rather than considering families’ complex responses that change over time. Much of the literature on parents with cancer published during the last two decades has focused on the negative effects of the illness on the family and has ignored the growth and healing that may occur.

Little is known about how parents with advanced cancer interact with their children after they are diagnosed or how they develop strategies to prepare their
children for the possibility of living without the parent. Adolescents with a seriously ill parent are at greater risk for depression and anxiety than children at any other developmental age (Heiney, Bryant, Walker, Parrish, Provenzano, & Kelly, 1997; Welch, Wadsworth, & Compas, 1996). A strained relationship with the well parent and the developmental need to separate from the parents during a time when adolescents are expected to take on additional responsibilities because of the parent’s illness may add to their psychosocial distress. The interaction patterns between parents with advanced cancer and their adolescent children are likely to have a salient role in how both the parent and the adolescent experience the parent’s dying process. Research is needed to describe these interactions so healthcare providers can gain a comprehensive understanding of the needs of families who face similar challenges.

Background and Significance

The research literature on parents with advanced cancer and their children has focused primarily on the negative sequelae for members of the family. In this review, the prevalence of the problem of advanced cancer as it affects parents will be discussed. Research on children’s and parents’ psychosocial distress, their coping strategies, and parent-child interactions will be presented.

Incidence and Prevalence

According to current estimates, 559,650 Americans will die from cancer in 2007. Lung cancer is predicted to be the leading cause of cancer death in both men and women. In 2004, 553,888 cancer deaths were recorded in the United States (Jemal, Siegel, Ward, Murray, Xu, & Thun, 2007). Many individuals are diagnosed with cancer at ages when they have minor children. In 1998, approximately 128,089
children had a parent diagnosed with cancer (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999). Cancer was by far the leading cause of death among women aged 40-59 and ranked second in women aged 20-39. The leading causes of cancer deaths in 20- to 59-year-old women was breast cancer, followed by cervical cancer in 20- to 39-year-old women, and lung cancer in 40-59 year olds (Jemal et al., 2007). Cancer ranked second as the cause of death among 40- to 59-year-old men and fifth in men aged 20 to 39. The leading causes of cancer deaths were leukemia in 20- to 39-year-old men, and lung cancer in 40-59 year olds. The second most common causes were cancer of the brain and nervous system in 20- to 39-year-old men, and colon and rectal cancer in 50-59 year olds.

**Children’s Psychosocial Responses**

**Stress of parental cancer.** Children’s psychosocial responses to the parent’s diagnosis of advanced cancer will likely influence parent-child interactions. Because parents typically play a central role in the child’s life, the magnitude of the impact of a parent’s cancer for the children is usually profound. The children’s lives are most disrupted at the time of initial diagnosis and when the illness changes significantly.

Having a parent with advanced cancer is a stressful life experience for children. Changes in the family’s lifestyle, embarrassment over the ill parent’s appearance, hospital visiting, and difficulty obtaining information are stressful to school age children, as reported by their parents in quantitative and qualitative research studies (Elmberger, Bolund, & Lutzen, 2000; Hymovich, 1993). In a retrospective study, researchers interviewed 16 children who were 11 to 18 years old at the time of the study and 8 to 12 years old when their mothers were diagnosed with early stage breast
cancer (Zahlis, 2001). The children reported feeling confused about what was happening in the present and what would happen next, despite explanations from their parents. They tended to worry more when their mothers did not look good to them and thought about the possibility of death of other family members including themselves. The children imagined their mothers’ deaths and worried about their fathers’ abilities to manage the family. In another study of latency age children with a parent with advanced cancer, the uncertainties related to the parent’s illness were shown to be difficult for the children to understand during a time when they need explicit concrete information (Christ et al., 1993). As a result of the lack of information, the children sometimes inferred erroneous causal connections that were often worse than the truth. For example, they worried that they had caused or exacerbated their parent’s illness. The children worried that something bad would happen and feared being separated from their well parent. They were frightened by the parent’s symptoms related to the cancer and of the side effects of the treatments; they identified with their parents so strongly that they sometimes experienced somatic symptoms themselves. The children were unable to concentrate in school and complete assignments. They also experienced increased conflict with parents and siblings, and conflict or withdrawal from peers and adults.

Researchers have concluded that children of all ages commonly fear losing their parent through death even when the cancer is diagnosed in the early stages (Christ et al., 1993; Christ et al., 1994; Elmerger et al., 2000, 2002; Huizinga, van der Graff, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Zahlis, 2001). When a parent is diagnosed with advanced cancer, the child faces many losses beginning with the loss of
a healthy parent. The child loses the parent’s physical presence when they are separated from each other during hospitalizations (Siegel, Mesagno, Karus, Christ, Banks, & Moynihan, 1992). Children also experience losses related to the limitations in both parents’ emotional and physical availability and role functioning, changes in family routines and emotional climate, and decreases in financial resources. Time, energy, and finances were focused on prolonging the parent’s life, ensuring adequate caregiving, and difficult decision making regarding treatment options. The loss of normalcy and support, peer contacts outside of the classroom, and extracurricular activities have been found among children with a terminally ill parent (Christ et al., 1993; Christ et al., 1994).

*Psychosocial distress.* Stress associated with having a parent with advanced cancer often leads to psychosocial distress in the children. Researchers have studied depression (Compas et al., 1994; Siegel et al., 1992; Worden & Silverman, 1996), anxiety (Compas et al., 1994; Heiney et al., 1997; Siegel et al., 1992; Worden & Silverman, 1996), and self-esteem (Siegel et al., 1992; Worden & Silverman, 1996) in children with a parent with cancer. The terms psychological distress and psychosocial distress are used in the literature to describe depression, anxiety, and low self-esteem. Psychosocial distress will be used in this literature review for consistency.

Children who have a parent with advanced cancer tend to experience more psychosocial distress compared to normed groups. Two major studies compared children of parents with advanced cancer (Siegel et al., 1992) and children of a recently deceased parent (Worden, 1996) with community samples to study psychosocial distress, behavioral problems, and social competence. The first study was a cross-
sectional study of 62 children ages 7 to 16 years old from 42 families of patients receiving medical treatment for advanced cancer with a life expectancy of 4 to 6 months as judged by their physicians (Siegel et al., 1992). The average age of the children was 11 years, with adolescents comprising 45% of the sample. The parents completed the Child Behavior Checklist for 64.5% of the children in the study sample. The second study was the landmark Child Bereavement Study (Worden, 1996) in which researchers studied 70 families with 125 children over 2 years to understand the consequences of parental death on children ages 6-17 years old. The average age of the children was 11.6 years, with adolescents comprising 52% of the sample. Sixty percent of the deaths were expected and 40% were sudden. Semi-structured interviews and standardized assessment tools were completed with the surviving parent and children four months after the parent’s death and at the first and second anniversaries of the death. One child from each family was matched with a child from the same community on age, gender, grade in school and family religion. In both studies, the children with a terminally ill or deceased parent had higher levels of psychosocial distress than the children in the community sample, as reported by their well parent and the children themselves. The children in both studies reported higher levels of social withdrawal, depression, anxiety, and lower levels of self-esteem. Their parents reported significantly higher behavior problems and lower social competence in their children. All of these negative psychosocial consequences were evident in Siegel and colleagues’ (1992) study while the parent was receiving treatment for advanced cancer, but were not apparent in Worden’s (1996) longitudinal study until 2 years after the death of the parent. The bereaved children’s anxiety was related to their own safety
and to the safety of their surviving parent. One year after the parent’s death, the bereaved children perceived themselves as performing less well scholastically, and being less well behaved than their peers. They also felt less empowered. These perceptions continued through the second year.

In a study of 14 parents with cancer, 12 partners, and 15 children (ages 7-18 years), researchers found significantly higher rates of anxiety in the parents and the children compared with a normed population sample (Huizinga et al., 2003). In this study, parents with cancer and their adolescent children participated in semi-structured interviews and both parents and adolescents completed standardized scales 2 to 52 months after completing chemotherapy. No significant differences were found in behavioral and emotional problems between the adolescents and a normed sample. In two studies, preadolescent children with a parent with cancer reported low levels of anxiety and depression compared with normed values, and tended to present themselves in a socially desirable light (Compas et al., 1994, Welch et al., 1996).

Parents with cancer, their partners, and their children often respond differently when asked to judge psychosocial distress in the children. Adolescents in Welch and colleagues’ study (1996) reported higher levels of anxiety and depression than their parents recognized in them. In Heiney and colleagues’ (1997) study of 33 parent/child dyads (children 5-17 years), parents with cancer and their children reported higher anxiety levels when compared with a normed population, although the parents did not consider their children to be anxious. In another study, adolescents with a parent with cancer reported higher levels of anxiety/depression and aggression in themselves than their parents reported in them (Welch et al., 1996). In contrast, three correlational
studies revealed agreement between the children and their parents’ perceptions about the child’s behaviors (Birenbaum et al., 1999; Huizinga et al., 2003; Seigel et al., 1992) and social competence (Birenbaum et al., 1999; Seigel et al., 1992).

Although many children experience psychosocial distress in response to their parent’s cancer, the seriousness of the cancer and how the threat of the cancer is appraised affects the degree of distress. In a landmark study of 117 parents with cancer, 76 spouses, and 110 children (ages 6-30), researchers assessed anxiety/depression and stress responses using a variety of standardized instruments 2 months after the initial diagnosis and found that a worse prognosis and the family members’ perceptions of the seriousness and stressfulness of the cancer were positively correlated with greater psychological distress (Compas et al., 1994).

The age and gender of the children and the gender of the ill parent also influences the child’s psychosocial distress. In a landmark study of 87 school-age (7-11 years old) children with a parent in the terminal phase of cancer, children’s responses to their parent’s cancer were shown to differ according to age (Christ et al., 1993). During the interviews, the 7- to 8-year-old children voiced were more concern about changes in everyday functioning while the 9- to 11-year-old children were more concerned with changes in their responsibilities and limitations on their lifestyle. Researchers have reported that preschool children exhibit increased crying and clinging (Hymovich, 1993) and school-aged children and adolescents had difficulty sleeping (Christ et al., 1993; Silverman & Worden, 1992; Worden & Silverman, 1996).

Unlike their younger counterparts, adolescents understand the complexities of the cancer diagnosis, treatment, and prognosis so they are better able to identify the
ramifications for the future. Christ and colleagues (1994) found that adolescents were confident in their ability to meet their own needs, but were fearful of the overall stability of the family unit. The older school age children and adolescents in Hymovich’s (1993) study were concerned about what might happen to them in the future. In other studies, adolescents of parents with cancer have reported higher levels of anxiety/depression than younger children (Compas et al., 1994; Welch et al., 1996) and adolescent girls have reported higher levels of anxiety/depression than boys (Welch et al., 1996). Symptoms were greatest for daughters whose mothers were ill (Compas et al., 1994; Welch et al., 1996) and sons whose fathers were ill (Compas et al., 1994). Adolescent girls with mothers who were ill reported the highest levels of stress-related symptoms (Compas et al., 1994; Welch et al., 1996), but also became closer to their ill mothers while boys tended to separate from them (Christ et al., 1994). Adolescent boys were more withdrawn and had more social problems than their non-bereaved counterparts 2 years after their parent’s death (Worden & Silverman, 1996). Adolescents describe contradictory feelings of wanting independence from their mother with cancer yet knowing she may die and wanting to spend more time with her (Huizinga et al., 2003).

Although it would be reasonable to expect that psychological distress would change over time, few longitudinal studies have been conducted. In Huizinga and colleagues’ (2003) study, parents with cancer noticed anxiety, withdrawal, boisterous behavior, and hyperventilation in their adolescents shortly after the diagnosis. These symptoms normalized within 6 months while sleeping disorders, regressive development, and compulsive behavior persisted longer than 6 months. Six of the
seven adolescents who experienced anxiety were continuously afraid that their parent would die. These problems were revealed during semi-structured interviews but were not evident in the standardized rating scales. The adolescents in Welch et al’s (1996) study reported a decrease in anxiety/depression in themselves over 4 months, but the parents’ reports of no psychosocial distress in their children remained stable over time. Silverman and Worden (1992) asserted that sleep disturbance, crying, and lack of concentration are normal grief behaviors in the first year after the parent’s death and should not be misinterpreted as problematic behaviors.

The quality of the parenting provided by the well parent significantly influences the child’s adaptation to the loss of the other parent. The well parent, however, often takes on additional roles and responsibilities and may feel overwhelmed and emotionally unavailable to the child (Worden, 1996). The majority of the spouses reported a decline in their confidence in parenting after the other parent was diagnosed with terminal cancer, especially in the areas of establishing and maintaining rules and discipline and being emotionally sensitive to their children’s needs (Seigel et al., 1990). Researchers have concluded that the quality of the relationship between the child and the surviving parent is also important in the child’s adjustment (Gray, 1987; Siegel, Mesagno, & Christ, 1990; Worden, 1996). Adolescents who had a good relationship with their well parent and those who rated their well parent as very helpful were significantly less likely to be depressed (Gray, 1987). Researchers have found that children’s adjustment to the death of their parent can be mediated by the surviving parent’s ability to support and care for the children, maintain consistency and stability, and provide an environment in which the children feel comfortable expressing painful
feelings, thoughts, and fantasies about the ill parent (Seigel et al., 1992; Siegel et al., 1990; Worden, 1996). Children of less well functioning parents experience more sleep and health problems, anxiety and depression (Worden, 1996). Researchers have also found that the emotional responses of the parents influence the children’s responses (Heiney et al., 1997). The more upset the parents were when talking to their children about the cancer, the more upset the children were as well. As the parents’ anxiety increased, they were less likely to accurately judge the inner emotional state of their children. Heiney and colleagues (1997) asserted that parents’ high anxiety make it more difficult for them to judge their children’s emotional state and mental health needs and suggested that the children may mask their emotions to protect their parents.

In summary, having a parent with advanced cancer is a stressful life experience for a child. These children frequently experience psychosocial distress, behavioral problems, and a decline in social competence. Parents may not recognize their children’s symptoms of psychosocial distress (Heiney et al., 1997; Welch et al., 1996). Frequently psychosocial distress is present in children shortly after the diagnosis, but, in some cases, problems are not evident until up to 2 years after the parent’s death (Worden, 1996). The discrepancy between the parents’ and children’s reports highlights the importance of including the children’s reports with an eye on the possibility of the children wanting to present themselves in a favorable light. Some researchers have suggested that the use of standardized instruments do not capture the depth or breadth of the children’s distress.
Children’s Coping Strategies

Parent-child interactions will likely be affected by the ways children cope with the parent’s illness. Researchers have described several coping strategies that children use in response to their parent’s cancer.

Some coping strategies are used by children of all ages. They may cope by sharing their experiences and feelings with their parents, but often wish to protect their parents from their own suffering (Christ et al., 1994; Heiney et al., 1997; Helseth & Ulfsaet, 2003). The children in Helseth and Ulfsaet’s (2003) study rarely initiated discussions about their parent’s illness and only discussed it when the parent brought up the subject. The children who were well informed about the illness and felt included in the discussions saw no need to talk about it. The children in Elmberger and colleagues’ (2002) study benefited from talking to other children experiencing the same adversity.

Some coping strategies differ according to the child’s age. Researchers have concluded that school-aged children utilize specific coping strategies to deal with their parent’s illness. In the Christ and colleagues’ (1993) study, school-aged children used denial as a protective coping strategy in the earlier stages of their parent’s cancer, but found it increasingly difficult to maintain their denial in the face of the parent’s imminent death. The school aged children in Helseth and Ulfsaet’s (2003) study used positive thinking by hoping their parent would get well. They also covered up their feelings of sadness and anxiety by being angry or moody because these feelings were easier to handle. Researchers found that going to school, spending time with friends, and helping their parents distracted the children from their parent’s illness and
provided balance and normalcy in their lives (Christ et al., 1993; Hymovich, 1993). It became more difficult for them, however, to get away from it, be happy, and live normally as the parent’s illness got worse (Christ et al., 1993). In the same study, children who maintained their academic performance felt a sense of mastery in this area of their lives during a time when the rest of their life seemed out of control.

In general, adolescents use different coping strategies than younger children. Researchers found they often used emotional detachment to deal with their intense empathic feelings toward the ill parent and helplessness at their inability to provide comfort or mitigate symptoms (Christ et al., 1994). The search for meaning and a deeper understanding of the illness were found to be powerful coping strategies for managing the adolescent’s emotions and responding to the demands of their parent’s illness. They aggressively and assertively sought information about the illness and treatment (Christ et al., 1994; Hymovich, 1993). Adolescents were able to obtain information and elicit support from their parents, friends, relatives, and siblings (Berman, Cragg, & Kuenzig, 1988, Christ et al., 1994; Gray, 1987), but did not identify health care providers as sources of support. Researchers have found that adolescents who were well informed about the diagnosis and treatment found it easier to talk with family and friends and receive support (Huizinga et al., 2003). One year after their parent’s death, adolescents reported that they felt closer to a sibling than to any other family member (Worden, 1996).

Grief theorists have recently recognized the importance of reconstructing meaning and retaining bonds with the deceased (Field, Gao, & Paderna, 2005; Stroebe & Schut, 2005). Parents provide safety and security for their children. The parent’s
death threatens this security. Although physical proximity to the parent becomes impossible after death, psychological proximity has been shown to be beneficial to the child (Field, Gao, & Paderna, 2005). The child remains close to the parent by cultivating the parent’s comforting presence and seeing the parent as a role model. Researchers have found that making meaning of the loss can mitigate complicated grief when the story of the loss is told and retold within the context of reviewing and revising life goals (Shear, Frank, Houch, & Reynolds, 2005).

In summary, children use a wide variety of coping strategies to maintain balance and normalcy in their lives when a parent is diagnosed with a serious life threatening illness. Adolescents try to understand their parent’s illness and derive support from family and friends. The strategies change over time as the illness progresses to imminent death. Although many of the strategies differ according to age, the children share a common need for interaction with their parents to support them during this very stressful time.

Parents’ Psychosocial Distress

Just as the children’s psychosocial distress will likely influence parent-child interactions, so will the parents’ distress. The diagnosis of a serious life threatening illness in one parent is a stressful experience for both parents. Compas and colleagues (1994) found that anxiety, depression, and responses to stress were similar in the ill parent and spouse, suggesting that the diagnosis of cancer is an equally significant stressor for both people. Both parents in Huizinga and colleagues’ (2003) study experienced disease and treatment as a continuous process with constant stressful fluctuations during the phases of diagnosis, treatment, and recurrence. In a study of
386 adult cancer patients randomly selected from oncology outpatient departments across the United States, the prevalence of psychosocial distress, including anxiety and depression, was 30% at diagnosis and recurrence (Zabors et al., 1997). In the same study, the prevalence of psychosocial distress varied significantly during the terminal phase of the continuum.

Psychosocial distress is frequently manifested in depression and anxiety. In a study of 23 people with terminal cancer, 61% reported depression and anxiety (Vachon & Fitch, 1993). In a study of 203 terminally ill people living at home, 37% reported anxiety and 52% reported depression (Addington-Hall et al., 1992). In a study of 90 people with advanced cancer, 21% reported anxiety and 8% reported depression in the last 4 weeks of life (Coyle, Adelhardt, Foley, & Portenoy, 1990). In the same study, these numbers dropped to 18% reporting anxiety and 4% reporting depression during the last week before death.

Physical and psychosocial symptoms influence the individual’s function and sense of well-being (Coyle et al., 1990). Physical symptoms are associated with increased psychosocial distress in the ill person. Over 90% of the participants in Vachon and Fitch’s (1993) study who reported pain during the week prior to the interview also experienced high distress.

Psychosocial distress is common in the spouses of people with advanced cancer who often serve as the ill partner’s caregiver. In a study of 37 people with incurable cancer and their spouses, higher anxiety was reported by the spouses compared with patients (Axelsson & Sjoden, 1998). Hinton (1994) found increasing anxiety among spouses prior to the patient’s admission to the hospital. In the same study, depression
was more common among spouses than patients. In a study of 31 dyads of hospice patients and their family caregivers, caregiver strain was significantly correlated with limitations in the patient’s activities of daily living needs and the patient’s psychological distress (Redinbaugh, Baum, Tarbell, & Arnold, 2003). As the patient’s need for help with activities of daily living increased, so did caregiver strain. Although the patient’s psychological distress was related to caregiver strain, the patient’s physical distress and caregiver strain were not related. In a study of 42 people caring for a person with advanced cancer at home, anxiety was higher than population norms and decreased over time in men, while it increased over time in women (Aranda & Hayman-White, 2001).

In addition to the stress of the illness and its treatment, parents experience distress in response to changes related to parenting. In a grounded theory study of nine mothers with breast cancer, the mothers described guilt about not fulfilling the role of “good mother” and concern about their children not wanting to leave their side as exhausting (Elmberger, et al., 2000). Concurrent life events such as children moving from the home, unemployment, illness, and death in the family compounded their exhaustion. The women perceived themselves as a failure in their mothering role because they might not live to see their children and grandchildren grow up. They saw themselves as inadequate role models when they did not notice their child’s reactions to the cancer that had been noticed by other people.

In summary, psychosocial distress in the ill parent and his or her spouse is manifested in anxiety, depression and other stress-related symptoms. The severity of the ill parents’ physical symptoms influences psychosocial distress in themselves, but
not in their caregivers. The ill person’s psychosocial distress and limitations in their abilities to perform activities of daily living are associated with caregiver strain. Both parents experience stress related to their role as parents.

*Parents’ Coping Strategies*

Ways in which the parents cope with the diagnosis of advanced cancer will likely influence the parent-child interactions. Hymovich’s (1993) study revealed the most common parental coping strategy was to tell the children not to worry and to continue activities as usual. While the maintenance of normalcy in everyday life has been found to be helpful, children still tend to worry about their parents and their future.

The meaning the person ascribes to the cancer, concurrent symptoms, and related problems influences coping strategies. The meaning the cancer pain had for the person with terminal cancer has been found to be the most important determinant of effective coping (Hinton, 1994). Participants who perceived their pain as a challenge had significantly lower depression scores, lower pain scores, and higher coping scores compared with those who interpreted their pain as the enemy or as punishment. In Redinbaugh and colleagues’ (2003) study, family caregivers who accepted their loved one’s terminal illness, reframed problems related to the illness in more manageable ways, and felt capable of solving those problems, experienced less caregiver strain than caregivers who did not use these coping strategies.

The caregiver’s ability to take care of themselves influences their psychosocial distress. In a study of 44 caregivers of people with advanced cancer, those who continued to participate in activities and interests that were important to them
experienced less emotional distress as measured by standardized tools (Cameron, Franche, Cheung, & Stewart, 2002). Continuing to pursue existing interests was also a coping strategy revealed in a study of 20 caregivers of people with advanced cancer (Grbich, Parker, & Maddocks, 2001). In the same study, additional coping strategies included going for a walk, talking to family and friends, and being flexible and adaptable in caregiving duties.

The gender of the ill parent may make a difference in coping strategies related to the parent’s role. Mothers with cancer were most concerned about changes affecting their mothering role, whereas fathers with cancer were more concerned about changes in their working role and changes in the fathering role were secondary (Elmberger et al., 2000, 2002). In the same studies, mothers with cancer experienced increased inner strength and independence after their diagnosis and fathers with cancer revised their priorities to spend more time with their family and experienced greater appreciation for life. Saldinger and colleagues (2004) also found that fathers revised their priorities leading to a deeper commitment to their children.

Although both parents may cope with the diagnosis by seeking information and planning for the children’s future, these behaviors differ among fathers and mothers. Fathers with cancer vacillated between a need to know and a fear of knowing (Elmberger et al., 2002). The fathers attempted to gain control through strategic planning to control their personal finances in the present and in preparation for their death to take care of the surviving family. Mothers with cancer described the need to face uncertainty, loss of control, fear of dying, and the risk of not being able to give their children adequate attention (Elmberger et al., 2000). Planning for the future was
difficult in light of the uncertainty around treatment, reactions, and relapses. Mothers planned for their children’s future by making funeral plans and including childcare in their wills.

Gender differences are also suggested in perceived support. Mothers with cancer did not feel supported by their partners and were reluctant to ask family members for help (Elmberger et al., 2000). They struggled to find support for their children who were often left alone without an adult with whom to share their feelings. In contrast, the ill fathers appreciated support from their wives, parents, and parents-in-law (Elmberger et al., 2002). Hiring people to clean their home and making arrangements for childcare provided tangible support for both parents (Hymovich, 1993). Initiating support from other adults was sometimes difficult, and parents feared they might exhaust their network of support by returning repeatedly to the same people with their fears and concerns (Davis Kirsch, Brandt, & Lewis, 2003; Elmberger et al., 2000).

In summary, parents cope with the diagnosis of a serious life threatening illness in a variety of ways. Coping strategies related to parental role and perceived support differ among mothers and fathers. Mothers tend to focus on people to care for their children and some may not feel supported by their partners. Men may focus on finances to support their family and appreciate the support of their wives and family.

Parent/Child Interactions

Although much research has focused on parent’s and children’s individual responses to the parent’s diagnosis, some researchers have examined the interactions between parents and children in these families. Interactions between mothers
(Elmberger et al., 2000; Shands, Lewis, & Zahlis, 2000) and fathers with cancer (Elmberger et al., 2002) and their children have been described from the ill parent’s perspective. Elmberger et al. (2000) and Shands et al. (2000) interviewed mothers with breast cancer to describe the mothers’ impressions about interactions between themselves and their children. In another study by Elmberger et al. (2002) fathers with cancer described their role transition since being diagnosed with cancer. In all three studies, the parents spent more time with their children than before the cancer diagnosis and tried to maintain normalcy. Parents in both of Elmberger and colleagues’ (2000, 2002) studies reported more open communication in the families after the diagnosis. Family members were more concerned about each other and became closer than before the diagnosis.

Parents with cancer are concerned about how they interact with their children. Two grounded theory studies revealed parental concerns. Hymovich (1993) found that parents with cancer and their spouses were concerned about who should talk with their children about diagnosis, prognosis, and expected changes, when they should talk with them, and how much information should be shared. In Elmberger et al.’s (2000) study, mothers with breast cancer lacked knowledge about cancer and ways to convey information to their children in ways they would understand it. Lack of information contributed to parental reports of anxiety in the children. The mothers felt frustrated and powerless and wanted to know what reactions they could expect from their children. Although children prefer to talk with their parents, Christ et al. (1993) found that school aged children were afraid to ask their parents questions because they seemed more impatient with the children. In Gray’s (1987) study of 50 adolescents
(12-19 years old) with a deceased parent, talking with or listening to the adolescent was identified as the well parent’s most helpful behavior. The adolescents in this study also valued being able to comfort the well parent while receiving comfort themselves.

The gender of the ill parent influences parent-child interactions. In work by Elmberger and colleagues (2000, 2002), although both mothers and fathers found it difficult to redefine their parenting roles within the context of a cancer diagnosis, the changes related to the mothering role were primary whereas the changes related to the fathering role were secondary compared with the changes in the father’s working role. Mothers with cancer and their children moved from a stable relationship through a period of disrupted relations toward a new closeness. Fathers with cancer developed a new closeness to their children through spending more time at home sharing the everyday lives of their children. The fathers’ values changed to reflect greater emphasis on their family and less on their job and money.

Other researchers have also reported that although both parents spent more time with their children and tried to act normal to help their children cope, mothers identified spending more time with their children as being crucial to their relationship (Davis Kirsch et al., 2003; Shands et al., 2000). Shands et al. found that mothers interacted with their children in a variety of ways. They talked with them about the cancer in a positive light and remained open to questions. They explained the various treatment modalities and took their children to the treatments with them. The mothers showed their children their scar or prosthesis and gave their children books. The mothers in Elmberger et al.’s (2000) study found inner emotional strength to deal with
their children’s fears, but in Shands et al.’s (2000) study they tended to respond to the children’s ideas and thoughts, but not to their fears, worries, or feelings.

Parents sometimes find it difficult to interact with their children regarding life after their death because they are focused on living, not dying. In a retrospective study of 58 parentally bereaved children (6-16 years old) and their surviving parents, the children and their ill parent wanted to remain connected throughout the terminal illness (Saldinger, Cain, Porterfied, & Lohnes, 2004). In the same study, researchers found that ill parents and their children were less likely to engage in interactions related to remembering the parent after death because the interactions undermined coping strategies based on their denial of the parent’s impending death. Furthermore, many of the dying parents who were usually available to their children could not act upon suggestions to leave something behind for their children. The researchers posited that creating a legacy such as a letter or video would be to acknowledge imminent death and increase the parent’s sense of helplessness and despair. In contrast, the mothers in Elmberger et al.’s (2000) study set up a mechanism for interacting with their children in the future by preparing videotapes for their children to play during specific times during their lives after the mother’s death.

In summary, mothers and fathers may interact with their children differently when one parent has advanced cancer. Their interactions take place within the context of their relationship with their children and their perception of their parenting role. Parents may lack adequate information to discuss what is happening with their children and often worry about the content and the timing of discussions with their children. Lack of discussions between parents and their children lead to frustration in the parents
and anxiety in the children. In contrast, appropriate discussions enhance the parent-child interaction. Although some parents find it difficult to prepare their children for living after the parent’s death, others leave videos or letters for their children as a way to interact with them after their death.

**Adolescent Development**

The normal developmental tasks of adolescents as they relate to the parent’s illness will influence parent/child interactions, and are therefore discussed here. In addition to adapting to the illness and imminent death of the parent, adolescents must also negotiate normal developmental tasks. Adolescence is often divided into early (12-14 years) and middle (15-17 years) stages. This discussion of adolescent development is based on European Americans.

The developmental tasks of young adolescents include withdrawing emotionally from their parents, achieving emotional independence, and being accepted by their peers. Their values, standards, and morals become independent of parental authority. They are ambivalent about dependence and independence and have a tendency express their anger when they lose self-control (Blos, 1962; Christ, 2000; Fleming & Adolph, 1986).

Researchers have identified ways in which young adolescents respond to a parent’s serious illness. In a study of 157 children from age 3 to 17 years, Christ (2000) found that detailed or too much information about the ill parent threatened the defense of denial and adamant optimism among the 12 to 14 year olds (Christ, 2000). The young adolescents in this study reported hiding their emotions in public and describing their feelings in diaries, poetry and fiction writing. Researchers found that
the young adolescents’ intense involvement with friends distracted them from their parents’ life-threatening illness, but they were hesitant to confide in their friends about their parents’ illness because they feared rejection. Demands for emotional involvement and closeness to the family at the time of the parent’s death occur during a time when they may be distancing themselves from their parents as they develop their own identity. Parents may perceive the adolescent’s anger and emotional withdrawal as uncaring and selfish within the context of a life-threatening illness (Blos, 1962; Christ, 2000).

The developmental tasks of middle adolescence include beginning to establish intimate relationships outside the family, separating from the family, and altering their relationships with their parents. The latter is especially true for girls. Adolescents begin to negotiate between their needs and the needs of others and to realize that it is possible to take care of themselves and others simultaneously (Silverman, 2000). The adolescent’s sense of self and who they will become is shaped by their interactions with others.

Middle adolescents with a parent with cancer are more likely to understand the situational demands placed on them and to be more empathetic toward their parents while remaining resentful especially when demands in the home are excessive (Blos, 1962; Christ et al., 2002; Gilligan, 1982). They are able to integrate future with present and past. Several studies have explored the middle adolescent’s responses to a parent’s serious illness and death. In the Christ et al. (2000) study, middle adolescents experienced overwhelming sadness and painful memories similar to adult grief, but shorter in duration. Intense sadness, longing, despair, helplessness, and hopelessness
interfered with their functioning in activities like school, sports, and after school activities. The adolescents reported being overwhelmed by the surviving parent’s grief, concerns, and emotional dependence. Researchers have concluded that boys tend to separate from their parents and are less likely than girls to talk about their feelings (Christ, 2000; Silverman & Worden, 1992; Worden, 1996). In general, boys are more likely than girls to be told to “grow up” than are girls in the early months after the parent’s death (Worden, 1996). Girls tend to work toward a more mutual relationship, especially with their mother, tend to become surrogate caregivers if a mother dies, and become their surviving parents’ ally. The adolescent girls in Worden’s (1996) study experienced more anxiety than the boys as manifested in greater concern over the safety of the surviving parent and their own safety. The girls were also more likely than the boys to cry throughout the first year of bereavement and to idealize the deceased parent one year after the death. Christ (2000) asserted the importance of supporting adolescents who fear independent functioning without the deceased parent.

In summary, the adolescent’s developmental stage influences their interactions with the ill parent. Whereas young adolescents are just beginning to separate themselves from their parents, middle adolescents understand changes in the family’s needs as the parent’s illness progresses.

Interventions

Although this is not an intervention study, work done to develop clinical interventions adds to an understanding of parent/child interactions. I reviewed this literature as I believe it reflects the current clinical wisdom related to what is important in interactions between parents with advanced cancer and their children. Although the
empirical literature on parent/child interactions is sparse, clinical literature is informative as it relates to aspects of the parent/child interactions that are important to this study.

Clinically based interventions to enhance the interaction patterns between parents with advanced cancer and their children are discussed in the literature, but few have been empirically evaluated. Psychosocial intervention programs have included only the parents (Adams-Greenly & Moynihan, 1983), parents and children (Davis Kirsch et al., 2003; Siegel, Mesagno et al., 1990), or only the children (Taylor-Brown, Acheson, & Farber, 1993). One program was implemented to enhance the quality of the interactions between children and their mothers while the mother was undergoing treatment for early stage breast cancer (Davis Kirsch et al., 2003). The remaining programs focused on families of parents with advanced cancer with the goal of facilitating the children’s adjustment to the parent’s illness and death. The psychosocial interventions were intended to guide parents as they interacted with their children throughout a terminal illness and after the death of the parent, a time when parents and children experience the greatest distress and family disorganization (Adams-Greenly & Moynihan, 1983; Siegel, Mesagno, et al., 1990). The clinical literature includes general guidelines and recommendations for clinicians working with families with a parent with cancer (Adams-Greenly & Moynihan, 1983) as well as descriptions of structured intervention programs (Davis Kirsch et al., 2003; Siegel, Mesagno, et al., 1990; Taylor-Brown et al., 1993).

Researchers have asserted that the quality of parenting by the surviving spouse has been one of the most consistently identified factors influencing a child’s adaptation
to the loss of a parent (Siegel, Raveis, et al., 1990; Worden, 1996). Recommendations have been proposed for clinicians to guide the well parent in helping the child adjust to the stresses associated with the ill parent’s cancer and subsequent death. Experts recommend that clinicians approach parents as colleagues by combining the parents’ expertise in parenting with the clinicians’ expertise in mental health (Adams-Greenly & Moynihan, 1983; Siegel, Mesagno, et al., 1990). This collaborative effort focuses on the parent’s strengths, diminishing anxiety and dependency. Interventions should be tailored to the parents’ perceptions of their children’s needs. Clinicians may advise parents to begin conversations with their child’s thoughts and observations and to communicate age appropriate information about the illness including gradually preparing the children for the parent’s death (Adams-Greenly & Moynihan, 1983; Siegel, Mesagno, et al., 1990). When parents understand what behaviors they can expect from their children and what is considered “normal,” they are better able to assess their children’s behaviors. Realizing that their children’s behavior is normal alleviates some of the anxiety associated with an unfamiliar stressful situation.

Experts recommend that parents be helped to understand that children mourn differently than adults, depending on their developmental age (Adams-Greenly & Moynihan, 1983; Siegel, Mesagno, et al., 1990). For example, children strongly defend themselves against intolerable feelings. The parent may perceive this behavior as callous or unfeeling and become angry with the child. The well parent is encouraged to interpret the medical status of the ill parent and set behavioral expectations for the children (Adams-Greenly & Moynihan, 1983).
The clinical literature indicates that adolescents especially need to know about the parent’s imminent death and may need guidance regarding when to visit their ill parent. Preparing children for hospital visits and supporting them throughout the visit can prevent frightening fantasies and fears of abandonment (Adams-Greenly & Moynihan, 1983). All children need reassurance that they will be informed about crises. The surviving parent should be encouraged to inform the children of the parent’s death as quickly as possible.

Intervention programs have been shown to enhance parent/child interactions. Four married couples participated in Davis Kirsch et al.’s (2003) grounded theory study to determine the parent’s perception of an intervention program designed to enhance the quality of interactions between the mothers and their school-aged (8-12 years old) children while the mother was undergoing treatment for early stage breast cancer. Five educational sessions were held in the home with the mothers who then worked with their children. The sessions included role-playing, assignments, handouts, and workbooks to use with their children. The information provided concrete strategies and materials that were age appropriate. The researchers found that the fathers noticed open communication between the mothers and the children and enhanced ability to discuss sensitive issues related to the illness. The mothers all agreed that truthful communication and their willingness to talk freely were key elements in their relationship with their children, resulting in a shared understanding of the family’s experience with cancer. The mothers’ sensitivity to their children’s thoughts and feelings enabled them to listen more attentively and let the children set the agenda for their interactions. The mothers also learned to listen to their own needs
for self-care and replenishing the self while maintaining the primary parenting role. Both parents were able to construct positive meaning from the illness experience through reflection.

Some intervention programs focus on the well parent. Spouses of people with advanced cancer participated in an intervention program designed to enhance their ability to meet their children’s needs through open communication and maintaining stability and predictability in the children’s environment (Christ et al., 1991). The intervention was designed to support the well parent in their grief and in the parenting role and to enhance the parent’s understanding of their children’s bereavement reactions. A parent guidance model was used to indirectly help the children through interventions with the healthy parent. The program began approximately six months prior to the parent’s death and continued 4 to 6 months following the death. A social worker met with the healthy parent in the home for most of the sessions. A comprehensive assessment was done with each of the children alone, and 1 session included the healthy parent and the children. The program has not been evaluated.

Other intervention programs target the children. Two of these programs used small group sessions (Greening, 1992; Taylor-Brown et al., 1993). In Greening’s (1992) program, one of the parents and their 4- to 8-year-old children met concurrently in separate groups. The ill parents were receiving treatment for their recurrent or metastatic cancer. The children’s program included stories, crafts, and activities based on a different theme each month. The parents’ program was structured to parallel the themes, but expanded to encompass discussions about changes in priorities, how to create meaning in difficult situations, how to maintain hope and energy, what to tell
their children, and how to keep the family intact. The parents reported that they benefited from the support provided by the facilitators and other parents as well as from the opportunities to exchange information and insights with each other.

Taylor-Brown et al.’s (1993) intervention program included weekly sessions for 5- to 18-year-old children of parents with cancer. In the majority of families, the parent had metastatic disease or a poor prognosis. The children were divided into small groups based on their age and level of maturity. They met after school with a social worker and nurse for six weekly sessions. The sessions focused on building trust, learning about the physical aspects of cancer and treatment modalities, expressing the children’s feelings, and discussing changes in the family. The children also had opportunities to visit and touch the radiation therapy machines and the components used to administer chemotherapy. The sessions progressed from building trust to identifying coping skills and strategies. An information session was held for the parents during the final week of the program to give general feedback about the themes and concerns that the children discussed as a group. The adolescents struggled with moving away from their parents while recognizing their added responsibility as a result of the cancer. The program provided a safe haven for ventilating feelings of anger and guilt. Although the program was not evaluated, the authors noted their perceptions of the positive outcomes. The authors believed the children’s level of trust increased, they understood the illness and treatment better, and coping strategies were enhanced. Taylor-Brown and colleagues (1993) posited that when families are faced with likelihood that a parent will die, they seek resources to help them prepare for the death. Researchers have concluded that both well and ill parents are interested in concrete,
developmentally appropriate strategies to help their children understand what is happening in the present and ways to prepare the children for the future (Adams-Greenly & Moynihan, 1983; Davis Kirsch et al., 2003; Siegel, Mesagno, et al., 1990).

In summary, a variety of guidelines and intervention programs have been developed and implemented for families with a parent with cancer. It is difficult to determine which interventions are best suited for the family because the programs have not been empirically tested. Research approaches that begin from the family’s perspectives and are rigorously evaluated are necessary to develop effective and appropriate interventions.

Limitations in Current Research

The research provides evidence that parents with advanced cancer, their spouses, and children have higher levels of psychosocial distress than normed populations. Although children have more behavioral problems and lower social competence than normed populations, parents may not recognize their children’s symptoms of psychosocial distress. Anxiety and depression are higher among adolescents than younger children. Adolescent girls with ill mothers experience the highest levels of distress. Researchers have identified a variety of coping strategies used by parents and children. The psychosocial distress and coping strategies of family members, however, are likely to change over time and the dynamic nature of family responses has not been addressed in the literature. Most studies have measured negative responses cross sectionally at one point in time; only three longitudinal studies have been conducted to examine parents’ and children’s responses to a parent’s illness or death (Huizinga et al., 2003; Silverman & Worden, 1992; Welch et al., 1996).
Although there are two well designed studies that compared children with a parent with advanced cancer with a normed population (Siegel et al., 1992; Worden, 1996), less is known about what factors influence psychosocial distress. While it would be reasonable to assume that how the individual appraises the threat of the illness would influence psychosocial distress, there has been only one study that looked at threat appraisal (Compas et al., 1994) and only a few studies that identified other predictors of distress (Gray, 1987; Heiney et al., 1997; Siegel, Mesagno, et al., 1990; Siegel, Raveis, et al., 1990; Worden, 1996; Worden & Silverman, 1996).

Out of all of the studies reported here, only 13 reported race (Aranda & Hayman-White, 2001; Birenbaum et al., 1999; Christ et al., 1993; Christ et al., 1994; Hymovich, 1993; Redinbaugh et al., 2003; Saldiger et al., 2004; Shands et al., 2000; Siegel et al., 1992; Siegel, Raveis, et al., 1990; Singer, Martin, & Kelner, 1999; Zabora et al., 1997; Zahlis et al., 2001), 11 reported socioeconomic level (Addington-Hall et al., 1992; Cameron et al., 2002; Christ et al., 1993; Christ et al., 1994; Hymovich, 1993; Redinbaugh et al., 2003; Saldinger et al., 2004; Shands et al., 2000; Siegel et al., 1992; Siegel, Raveis, et al., 1990; Worden, 1996), 9 reported religion (Birenbaum et al., 1999; Christ et al., 1993; Christ et al., 1994; Redinbaugh et al., 2003; Saldinger et al., 2004; Siegel et al., 1992; Siegel, Raveis, et al., 1990; Worden, 1996; Zabora et al., 1997), and 7 reported educational level (Birenbaum et al., 1999; Cameron et al., 2002; Christ et al., 1993; Elmberger et al., 2000; Redinbaugh et al., 2003; Siegel et al., 1992; Singer et al., 1999; Zabors et al., 1997; Zahlis, 2001). The majority of the studies include Caucasian people from middle to high socioeconomic backgrounds. For example, of the studies that reported race, 80 to 100% of the samples were Caucasian,
with 2 studies (Shands et al., 2000; Zahlis, 2001) including only Caucasians.

Hymovich’s (1993) study included 20% African Americans, the highest percentage of people of color included in any of the studies. The majority of the studies reported an annual family income of greater than $50,000. Of those studies that reported educational level, most included people who had at least some college education. Lack of diversity limits generalizability of the findings in quantitative studies.

Recommendations for Research

Scholars have called for research to address the family’s experiences at different stages of the cancer illness trajectory (Kristjanson & Ashcroft, 1994) including cancer research that focuses on the needs of families where one member has received a poor prognosis (Elmberger et al., 2000). Shands and colleagues (2000) called for research that includes extensive elaboration of the mothers’ behavioral interactions with their children by inviting mothers to describe in detail how they talk about their cancer with their children.

Most of the published literature about parents with cancer and their children focuses on psychosocial distress and negative functional changes within the family even though the end of life can be an opportunity for growth and healing. Few studies have described the complex and dynamic psychological processes of families who are responding to a parent’s advanced cancer. In her extensive review of the literature, Thornton (2002) posited that current recommendations for assisting individuals to interpret the benefits in their illness were based predominantly on clinical experience and need to be substantiated by research. Studies that explore the perceived benefits of
advanced cancer from the ill parents’ and child’s viewpoints are necessary to inform clinical practice.

The purpose of this research is to develop a theoretical framework to describe interaction patterns between parents with advanced cancer and their adolescent children and to identify strategies parents use to prepare their children for their lives after the parent’s death. Nurses are the primary providers of care at the end of life. By understanding the processes, nurses and other health care providers can better support and advise parents who face the challenge of parenting children in the face of their impending death and work with children experiencing this profound life stressor. Identification of these processes will also provide the basis for development of interventions aimed at assisting parents and children cope with advanced cancer.

Guiding Framework

The guiding framework for this study is symbolic interactionism (Blumer, 1969). Symbolic interactionism rests on three primary premises, (a) human beings respond to things in their environment based on the meanings the things have for them, (b) meanings are not seen as inherent, they emerge from social interaction, and (c) these meanings are modified through an interpretive process used by the person as they are encountered in the environment. A basic principle of symbolic interactionism is that empirically oriented studies of human beings must respect the fact that society consists of people engaging in action. Social interaction forms much of human conduct. Therefore, individuals respond to each other based on the shared meaning of gestures.
People interact with each other differently depending on their relationship to each other and the circumstances in which they find themselves (Blumer, 1969). Both parents and adolescents respond to the meaning the parent’s illness has for them. The meanings emerge from their interactions and are modified through interpretation. A parent with advanced cancer will interact differently with a spouse, a child, or a colleague. The parents are physically closer but not necessarily more open to their children by virtue of living in the same home. Over the years, they have developed ways of interacting with each other as a family. The diagnosis of advanced cancer and the potential for an early death, however, may change the interactive process. The timeline for being together is suddenly reduced. The time available may be further shortened by the parents’ extreme fatigue and desire to protect the children by not discussing their imminent death.

Recurrent patterns form the basis for understanding how people will act toward one another in advance (Blumer, 1969). This shared meaning of what is expected guides the individual’s behavior. But in most of these cases, dying and death are a new experience, so the dimension of expectation is great. New situations are constantly arising for which pre-existing rules are inadequate.

In summary, people sharing common circumstances experience common meanings and behaviors. I believe parents who are near the end of their lives and their adolescent children share a common problem and the ways in which they and their families manage their experiences are best understood as a series of complex interactions that change over time and are influenced by sociocultural context. Therefore, grounded theory methods, which are based on symbolic interactionism,
were used to focus on the interactions between parents with advanced cancer in a hospice program and their adolescent children in order to build a theoretical framework.
CHAPTER II
METHODOLOGY

The goals of this study were to develop a theoretical framework that explains interaction patterns between parents with advanced cancer in hospice and their adolescent children and to identify strategies parents use to prepare their children for their lives after the parent’s death. Therefore, a grounded theory approach was used. The primary research questions were:

1. How do parents with advanced cancer and their adolescent children interact following the cancer diagnosis?
2. How do parent-adolescent interactions change as the disease progresses?
3. What strategies do parents use to prepare their adolescent children to live with the illness and to live their lives after the parent’s death?

Methods

Grounded theory methods (Glaser, 1978; Glaser & Straus, 1967) were used to build the theoretical framework. Grounded theory is informed by Blumer’s theory of symbolic interactionism, which has its roots in Mead’s philosophical concept of the emergent self (Blumer, 1969).

Grounded theory is a method used to determine how people manage their lives in the midst of health challenges and to identify the process that people use to
understand and respond to what is happening to them over time in changing circumstances (Schreiber, 2001). It is a method of inquiry for developing theory grounded in data that are systematically gathered and analyzed. A basic assumption of grounded theory is that human experience is interpreted through social interactions and influenced by the sociocultural environment. The method focuses on the complexities of people undergoing change, the influence of societal interactions on outcomes, critical junctures that affect processes of adaptation, and influences of the social environment on human experiences (Benoliel, 1996).

Grounded theory methods involve overlapping processes of data collection, categorization, reduction of data, and hypotheses formation. Constant comparison analysis yields codes, categories, hypothesized relationships between categories, basic psychosocial processes (common changes in action/interaction patterns of individuals who share a similar experience or problem), and a core category (a category that explains much variation in the data). Constant comparisons among concepts, categories, incidents, and data help to identify relevant connections and the contextual conditions influencing them. In this method, researchers use memo writing to record thoughts, ideas, insights, and questions to assist in exploring codes and their interrelationships, thus enhancing understanding of the data (Glaser, 1978).

Analysis begins with substantive coding, the abstraction of facts and strategies as concepts that are then identified by code words (Glaser, 1978). The codes are compared for similarities and differences and then organized into theoretical categories. The categories are reduced by determining higher order connections.
Investigators compare categories looking for similarities and differences, develop categories of increased abstraction, and relate the categories (Glaser & Strauss, 1967).

The accumulating interrelations form an integrated theoretical framework known as the core of emerging theory. The core category becomes a theoretical guide to the continuation of data collection and analysis. It is the central phenomenon or the main concern for individuals in the setting and explains the variation in the data. The core category integrates the theory rendering it dense and saturated as the relationships are discovered (Strauss, 1987). The core category, which explains much variation in the data and links the categories into a descriptive framework, is identified and labeled (Glaser, 1978). The investigator identifies common processes shared by the participants and explores variations in their trajectories. Through constant comparison and reflection on the data, selective sampling of the literature, and selective sampling of the participants, the theoretical framework is developed until substantively dense.

Grounded theory was an appropriate method to answer the research questions because parents with advanced cancer share a common problem and parent-child interactions are complex interpersonal processes that change over time.

**Sample**

In grounded theory, participants are initially selected because they have knowledge of the domain being studied. Parents with a diagnosis of advanced cancer with adolescent children between the ages of 12 and 18 years old were recruited from a large hospice in Ohio. The spouses and adolescent children of these participants were also invited to participate because they were able to offer important perspectives on the
ways in which the parent and adolescent interact that may have been unknown to the parent with cancer.

The community-based hospice served over 5,000 people and their families in 2006. Of the 5,948 people admitted to the hospice program in 2006, 81% were White, 17% were Black, and 2% were other. Nine hundred sixty-nine (16%) were 18-64 years old. Forty-four percent of the hospice patients had a cancer diagnosis. The Director of the Hospice Institute was the researcher’s contact person.

A concerted effort was made by the researcher to recruit minority participants by enlisting the help of African American staff and volunteers who provided direct care or support to potential participants. Hospice home care offices that served a greater number of African Americans were also targeted.

Sample Size

In grounded theory, an exact sample size cannot be established prior to beginning the interviews. It can, however, be estimated based on typical sample sizes in grounded theory studies and the complexity of the research question. Qualitative methodologists suggest that between 20 and 30 participants are typical in grounded theory studies (Morse, 1994), but the scope and complexity of the study and the homogeneity of the group must also be considered (Schreiber, 2001). The sample included 26 individuals including both parents and adolescents.

Recruiting

Fatigue is a major consideration for people with advanced cancer, so it was reasonable to conduct the interviews in places where the parent would ordinarily go for
treatment or in the participant’s home. Interviews were conducted in person at the freestanding hospice, skilled nursing facility, and in the participants’ homes.

The researcher met with the hospice staff to discuss the study, answer questions, clarify points that were unclear, and elicit their help in recruiting participants who met study criteria. Inclusion criteria included adults diagnosed with advanced cancer who (a) had children between the ages of 12 and 18, (b) were able to speak, write, and understand English, and (c) had the cognitive ability and physical stamina to participate in the study. Exclusion criteria included: (a) gross cognitive impairment, and (b) lack of physical stamina needed to be interviewed.

Fliers describing the study were given to the office team leader, nurses, and social workers who were primarily responsible for recruiting potential participants based on the inclusion and exclusion criteria. The nurses and social workers introduced the study to potential participants.

The study announcements included information about the study, a statement indicating that the participants would be paid $35.00 per interview, and a telephone number by which to contact the investigator. The fliers indicated that potential participants included both men and women who had been diagnosed with advanced cancer who had a child between 12 and 18 years old.

The study recruiter introduced the study to potential participants (see Appendix A), gave them a flier if they were interested in learning more about the study (see Appendix B), and asked their permission to give their telephone number to the investigator. If the participant agreed, the recruiter inquired as to the best time for the investigator to call. The study recruiter also called the investigator. The investigator
then called the potential participants to answer their questions, conduct a brief interview to screen out any individuals who did not meet inclusion criteria using the screening script, and reviewed the requirements, benefits, and risks of participation in the study (see Appendix D). The screening script included questions to determine whether they met study criteria and a question related to physical stamina. An interview time and place was arranged that was convenient for the participant. The parent with advanced cancer was asked if subsequent interviews may be arranged with the participant’s spouse or partner, and adolescent. Interviews were held in a private room at the freestanding hospice, skilled nursing facility, and in the participant’s home. The investigator followed the hospice’s policies and procedures for home care visits (see Appendix E).

Upon arrival at the interview site, the investigator described the research project, discussed the benefits and risks of participation in the study, and asked the participant to sign the consent form (see Appendix F), the consent for their adolescent to participate (see Appendix G), the audiotape consent form (see Appendix J), a brief demographic data sheet (see Appendix K), and a form indicating whether they would like a copy of the findings (see Appendix L). The interview questions were open-ended to encourage participants to freely describe their experiences. Although sample questions were outlined (Appendix M), the interviews were guided by emerging data according to grounded theory principles. The spouse or partner was interviewed using a similar format (Appendix H). Each participant was given a code number that appeared on all participant materials. No identifying information appeared on the transcripts. The investigator has kept a code list in her home office that links
participant data. Consent forms and other forms with identifying data are kept in a locked file cabinet in the dissertation advisor’s office at Kent State University.

Adolescents and partners were also interviewed separately in a private room at Hospice House or in their homes. Researchers have suggested that allowing adolescents some degree of control over location can enhance data collection (Faux, Walsh, & Deatrick, 1988). Familiar relaxed settings such as the home can help the adolescent to see the researcher as an interested adult rather than an authority figure in a healthcare setting. The interview format was similar to the parent’s interview (Appendix O).

Because interviews about dying can be emotionally distressing, the interviewer was an advanced practice palliative care nurse with expertise in oncology who was accustomed to working with individuals who are near the end of their lives and their families. The investigator recognized the importance of establishing clear boundaries as a nurse researcher (Murray, 2003). The investigator established connections with the participants without counseling or educating them as she would in her role as a clinician. The investigator listened to their stories and asked questions to clarify and guide the storytelling without attempting to direct their responses. The interviews began after informed consent had been obtained from the participant.

Participants were interviewed separately so their responses would not be influenced by the presence of the other. The participants were paid $35.00 per interview. The interviews were audiotaped and transcribed. The investigator informed the participants that the study results would focus on the group as a whole, and would be disseminated in professional journals and presentations. They were told
confidentiality would be maintained, although individual anonymous quotes may be used to illustrate examples. All of the participants were interested in receiving a summary of the findings by mail.

One interview per participant was conducted. None of the participants found the interview too draining to complete in one session, nor decided after the interview was over that she or he wished to discuss something further. The investigator, after reviewing the transcripts, did not wish to clarify or augment information provided by the participants in a second interview.

Human Subjects Concerns

Parents with advanced cancer are considered a vulnerable population because of rapidly declining health and the precious commodity of time (Agrawal & Danis, 2002). The participants in this study were at risk for fatigue and heightened distress related to previously undisclosed problems (Ferrell & Grant, 2001). Researchers have found that some participants experience emotional demands by recalling painful memories during data collection (Grinyer, 2004). The investigator recognized the potential for the participants to experience physical or psychological symptoms which may have limited their ability to participate in the research (Bruera, 1994; Dobratz, 2003). The investigator took specific precautions related to the potential emotional distress of participants by securing informed consent with detailed information regarding the nature of the questions, and the potential for distress. The hospice has a procedure in place by which individuals may receive counseling or psychological support as necessary from their social worker. None of the participants reported or appeared to experience distress during the interviews.
The researcher recognized that the adolescents and spouses may also be vulnerable given the serious nature of the parent’s illness, and took appropriate precautions to ensure their comfort and safety. The adolescent was given the opportunity to terminate the interview if the researcher observed increasing reluctance to reply or at the participant’s request (Faux et al., 1988). None of the interviews were terminated. The researcher recognized that confidentiality was especially important to adolescents during a time when they are trying out new ways to present themselves (Docherty & Sandelowski, 1999; Faux et al., 1988). The researcher assured the participants that their responses would not be shared with parents, teachers, or other children except as required by law. The researcher assured them verbally throughout the interview if they seemed to be reticent to respond to questions. A private area with a closed door also reassured the adolescent of confidentiality (Deatrick & Faux, 1989). The researcher clarified the purpose of the study and the role of the adolescent so the participant knew what to expect during the interview (Docherty & Sandelowski, 1999; Faux et al., 1988). The interview began with non-threatening questions to allow time to build rapport and trust between the investigator and adolescent (Faux et al., 1988). Researchers have suggested that adolescents can participate in an interview for an hour or longer, but discussing a sensitive topic may limit their endurance. At the end of the interview, participants were asked if they would be interested in being contacted about future research. If interested, they were given a paper to sign with their contact information. All of the spouses and adolescents were interested in being contacted about future research and signed the paper signifying their interest.
There are potential benefits as well as risks to the participants. Researchers have found that being able to help others at the end of life was significantly important to seriously ill patients (Steinhauser et al., 2000). Participating in research provides opportunities to derive meaning from illness and to use the experience of one’s own suffering to benefit others (Agrawal & Danis, 2002; Wilson-Barnett & Richardson, 1998; Bruera, 1994; Dobratz, 2003). The participants in Grinyer’s (2004) study believed they had benefited from contributing to the research and perceived the research outcomes as significant. Ferrell and Grant (2001) noted that participants have thanked them as nurse researchers for studying topics in end of life care perceived to be very important to the participants and their caregivers. Participants have also commented on the experience of completing written instruments or participating in interviews as a mechanism for communicating needs, thoughts, and feelings that had not previously been voiced (Draucker, 1999; Ferrell & Grant, 2001). Murray (2003) asserted that providing a trusting participant-researcher relationship for adolescents to tell their stories may have been therapeutic in itself. The storytelling provides an opportunity to form new perceptions of the self. I believe the knowledge to be gained from these interviews outweighed the risks of participation. Parents with cancer, their spouses, and adolescent children had the opportunity to tell their stories to an interested researcher who would give voice to parent/child interactions. The participants also had the opportunity to help others with similar experiences by adding their stories to the study.
Data Analysis

The investigator analyzed the data using the grounded theory method in consultation with her dissertation committee chair, a nationally recognized expert in grounded theory, and other doctoral students who were also conducting qualitative research. The data were transformed into theory as it moved through three levels of coding (Schreiber, 2001).

The analysis began with first-level coding (Schreiber, 2001). The transcripts were read carefully to select words or phrases that contained a single unit of meaning. The participant’s words were used in the labeling to stay close to the data. Sentences or paragraphs were labeled with code words that described a single unit of meaning. Incidents were compared to identify similarities and differences. Existing codes were used throughout the transcript and new codes were only added when the data did not fit the existing codes. First level coding produced a list of coded concepts.

In second level coding, the concepts were compared for similarities and differences and collapsed into categories or higher level concepts. This coding was more abstract. First level codes were constantly compared against incoming and existing data. As the categories were identified, they were compared with data and codes. Similarities and differences were determined through the iterative process of moving from specific incidents to abstraction and then checking the abstractions against the incidents.

The relationship between and among categories was examined in third level coding. The core variable, which explained much variation in the data and linked the categories into a descriptive framework, was identified and labeled (Glaser, 1978).
The researcher identified common processes shared by the participants and explored variations in the trajectories. Through constant comparison and reflection on the data, selective sampling of the literature, and selective sampling of the participants, the theoretical framework was developed until substantively dense.

Evaluation Framework

Criteria for trustworthiness were used to evaluate rigor (Lincoln & Guba, 1985). By establishing trustworthiness, others will have valuable information to determine confidence in the study findings. Trustworthiness was established by applying several techniques to enhance the credibility, transferability, dependability, and confirmability of the findings.

Credibility ensured the findings were truthful within the group and context where the research was done. In this study, credibility was enhanced through the use of triangulation and peer debriefing. Triangulation increased the probability of credible findings by obtaining information from multiple sources. In this study, data were obtained from the perspectives of the ill parent, the spouse/partner, and the adolescent.

Peer debriefing provided opportunities to test working hypotheses that emerged in the researcher’s mind, develop next steps in the emerging methodological design, and clear the researcher’s mind of emotions or other responses that may cloud more objective evaluation. Peer debriefing was done with doctoral students, hospice colleagues, and dissertation chair.

Transferability is a technique used to provide a thick description of the participants and data so that the reader can judge whether the findings can be applied to other people. The researcher bases the thick description on a determination of which
variables are likely to influence the findings. To ensure transferability, the sample was
described by detailed demographic data, information regarding their health status, and
data pertinent to their family situation.

Dependability ensures that the inquiry decisions and methodological shifts are
appropriate. Dependability was enhanced by reflective journals kept by the
investigator that include a record of study activities, personal reflections, and the
rationale for all methodological and theoretical decisions.

Confirmability ensures the findings are grounded in the data. Maintaining an
extensive audit trail including all transcriptions, memos, and diagrams to track
decisions related to the changing conditions within the research and noting all
theoretical decisions.
CHAPTER III

ANALYSIS

Of the 10 families approached, 9 agreed to participate in the research. At least one member of each family was interviewed. During each screening telephone call, permission to conduct interviews with all eligible family members was given. The interviews were scheduled when it was convenient for the families, usually within several days. On the day of the interview, however, some of the ill parents did not feel well enough to participate and did not want to reschedule the interview. In several cases both parents initially agreed to the adolescent being interviewed, but asked to reschedule the adolescent’s interview for another day. Although several attempts were made to reschedule, the adolescents were never interviewed because the parents continued to request another call at a later date. The ill parent died before the adolescent was interviewed.

Appendix Q illustrates the sample. Three of the ill parents were male and six were female. The majority of the ill parents were in their 40s with one in his 70s. Most of the ill parents were Caucasian, and two were African-American. This is consistent with the ethnic makeup of the hospice. The majority of the ill parents were married to the well parents. The most common primary cancer sites were breast and lung. This is consistent with national data (Jemal et al., 2007). The ill parents reported
a variety of occupations, although none were currently working at the time of the interview. The parents reported a variety of religious affiliations. The parents reported annual household incomes from $10,000.00 or less to $90,001.00 or more. The ill parents’ education ranged from completing seventh grade to completing 4 years of college. Overall, the time between the interviews and death were quite short, ranging from 1 to 12 weeks, with six being 3 weeks or less.

Nine well parents participated in this study. An ill father had been divorced twice and both ex-wives had knowledge of the interactions between the ill parent and the adolescent, so both ex-wives were interviewed. In another case the adolescent’s aunt was interviewed in place of the well parent; she had been raising the children since their mother’s death from cancer several years earlier.

Ten adolescents between the ages of 12 and 18 were interviewed. The majority were male and Caucasian. Most of the adolescents lived with both of their parents. In those families in which the parents did not live together, the adolescents lived with the well parent.

Despite the crisis of the ill parents’ impending death, the participants seemed to welcome the opportunity to talk about interactions between the ill parents and their adolescent children. All of the ill parents were in a hospice program. Despite being close to death, all were willing to talk about their experiences. The well parents and adolescents also seemed eager to talk, although they had many other priorities. Every participant was willing to answer every question. As the interviews progressed, the participants became increasingly comfortable with the open-ended questions, were
more self-directed, and elaborated more on their stories. Although several of the participants cried, they all declined offers to end the interviews.

The majority of the interviews (n = 22) took place in the families’ homes. Three interviews were conducted at the freestanding hospice and one took place at a skilled nursing facility. Each participant chose a private room for the interview that was most comfortable for them. The average interview time was 30 minutes, ranging from 11 to 50 minutes. The hospice social workers were available to talk with the participants after the interviews, but none of the participants accepted this offer.

When asked “How has this interview been for you” all of the participants responded positively, indicating that it “was a relief” to talk with someone about how they were feeling. They said talking about their experiences during the interview made them feel “good,” “better,” “lighter,” or “released.” Several adolescents and ill parents said that it was easier to share their stories with a stranger than with someone they knew; the adolescents believed they could tell the interviewer “everything.” Several participants described the interview as uncomfortable or painful, but the majority found them to be cathartic and “insightful,” indicating it was helpful to reflect on their experiences.

Although the focus of the interviews was on the interactions between the ill parent and the adolescent, the participants talked about a wide variety of experiences, as well as about feelings related to living with the ill parent’s imminent death. The ill parents and adolescents talked about their experiences with each other, whereas the well parents described their interpretations of the experiences they observed between the ill parents and adolescents.
The interviews revealed that all three groups were concerned about uncertainty, or not knowing what would happen next. They described uncertainties about both the short term, as the cancer progressed, and the long term, after the parent’s death. For example, the majority of the participants described changes that had occurred since the cancer diagnosis and feeling uncertain about how to respond to future changes. Several ill parents described being “in limbo” not knowing what is next, waiting to see what the next test will show, and “waiting for their body to heal.” The participants explained how things that are normal today may not be normal tomorrow; the simple mundane things that were taken for granted yesterday are cherished today. The ill parents were most concerned about the uncertainties of the adolescent’s future without them. The adolescents were also concerned about not having the parent as a guide, especially during uncertain times and significant events throughout their lives.

Two of the adolescents had already experienced the death of one parent. The serious illness of a parent was a new experience for the rest of the adolescents who talked about not knowing what to say or do. It was also a new experience for the well parents who had never lost a spouse to death. The well parents talked about being uncertain about their role as a single parent facing potential changes in family responsibilities, dynamics, and finances after the ill parent’s death.

One of the questions asked of the adolescents was what would be helpful in the current situation. The adolescents responded that the most important thing was to listen. They described “best listeners” as those who were empathetic and those who had also experienced the death of a parent. For example, teachers, school counselors,
and friends whose parents had died seemed to make a connection with the adolescents based on their mutual experiences. The listeners reached out to the adolescents.

Adolescents and well parents found each other to be empathetic listeners because of a shared experience of a dying family member; however, siblings were described as the best listeners because they were each experiencing the loss of a parent. The impending death of a spouse was perceived as a qualitatively different experience because of the different underlying relationship (spouse versus sibling). In addition to listening, the adolescents sincerely appreciated friends who visited with the ill parent. Many adolescents also spent time at their friends’ homes to escape the intensity in their own homes.

The adolescents also shared ways in which people were not helpful. For example, many adolescents did not talk with their friends about the parent’s illness because they did not want to be perceived as different. They did not want their friends to feel sorry for them, or were afraid their friends would tell others about these very personal experiences. Many adolescents perceived an inquiry into their parent’s health by friends and teachers as superficial, not believing the other person really cared. When the adolescents did not think the person was sincere, they replied with superficial answers such as “she’s fine,” “everything’s okay.”

Several participants talked about maintaining normalcy in their lives whenever possible. They described a tension between wanting to maintain normalcy and not always being able to accomplish this goal. For example, when the ill parent was mobile and able to continue routine activities, the family perceived life as being normal although their fears may have remained in the back of their minds. Critical experiences
like hospital and hospice admissions, however, highlighted the ill parents’ declining health and the reality of impending death. Many of the participants talked about continuing their activities and being strong for each other. Adolescents continued activities they enjoyed prior to the parent’s diagnosis. They described the importance and challenges of balancing the intensity of knowing their parent will die soon with efforts to maintain normalcy. Maintaining normalcy meant participating in sports, going to school, work, and going out with friends.

The interviews revealed a wide variety of emotions among the participants. A large portion of the interviews were about feeling anxious, scared, and worried. Sadness and feelings of loss were the most commonly described emotions. While some of the participants talked about crying alone so as not to upset other family members, others talked about crying together. Most of the adolescents talked about thinking and worrying about their ill parent often, especially during school. While several participants talked about the adolescent having difficulty focusing in school and declining grades, others described adolescents maintaining good grades.

Although the participants talked about a wide variety of experiences, the findings indicate that parents with advanced cancer and their adolescent children struggle most with knowing they do not have enough time together, confronting the relative immediacy of their separation by death. While the topic of this study was parent-adolescent interactions, the narratives reveal how families who have a member with advanced cancer reframe parent-adolescent relationships within the context of limited time.
The basic psychosocial problem of this group was considered to be Not Having Enough Time Together. The resolution of the problem of Not Having Enough Time Together is a psychosocial process labeled Making the Most of the Time We Have Left Together. References to time are replete in all of the transcripts. The participants used a variety of words to delineate time. They talked about “best times,” “worst times,” “fun times,” “good times,” “old times,” “first time,” “last time,” “longest time,” “long time,” “special time,” and “painful time.” References to time were not bound by the context of advanced cancer. The narratives revealed references to time before and after the ill parent was diagnosed with advanced cancer.

Participants in all three groups used specific labels to describe time within the context of advanced cancer. They talked about “recuperation time” and “limited time.” Many of the participants talked about the ill parent recuperating from the side effects of chemotherapy or from the illness itself, indicating the parent would “get better.” The interviews revealed that all three groups were concerned about limited time before another change took place as a result of the advanced cancer, when the parent would “get worse.”

Participants used time to reference important critical transitions. For all the participants, time of diagnosis was the first critical transition. Four critical periods of transition were “time of diagnosis,” “time in hospital,” “time the cancer came back,” and “time hospice began.” When the ill parent was diagnosed or hospitalized on a holiday, it was cited as a marker in time, “emergency room on New Years Day,” “surgery on Valentine’s Day.” Participants talked a lot about time in terms of days (day by day, one day at a time), months (6 months left, 6 to 12 months, 8 months ago),
years (6 years ago, last year, next year), and periods (one step at a time). They also identified the limits of time such as “dad doesn’t have much time to live,” or “time is limited.”

For parents with advanced cancer and their adolescent children, Making the Most of the Time We Have Left Together is a process by which they respond to the problem of Not Having Enough Time Together. The participants described how the realization of limited time led the ill parent and adolescent to spend more time with each other before the parent’s death. In addition, they actively sought ways to continue their relationship after the parent’s death. Several adolescents explained that they chose to give up their time with their ill parents when it became too difficult to watch their parents’ suffering; watching their parents’ suffering contributed to the adolescents’ suffering. These adolescents perceive death as the only option to relieve the suffering.

The Theoretical Framework

The theoretical framework depicts the psychosocial problem of Not Having Enough Time Together and the psychosocial process of Making the Most of the Time We Have Left Together. The participants’ narratives focused on the interactions between the ill parent and adolescent within the context of their interpersonal relationships. Therefore, each phase represents ways in which the ill parent and adolescent strive to make the most of the time they have left together.

A number of types of interactions are identified for each phase. The progressive nature of the trajectory of each process is represented by arrows leading to the next phase. Although the phases are conceptualized sequentially, the progression
between the components is not completely linear; there is a fair amount of movement
back and forth between the phases. The second and third phases may happen
independently or concurrently. The fourth phase is the culmination of the prior three
phases.

Psychosocial Problem
Not Having Enough Time Together

Psychosocial Process
Making the Most of the Time We Have Left Together

Figure 1. Theoretical framework
Not Having Enough Time Together

Not Having Enough Time Together does not become a problem until the adolescent realizes the parent’s limited life expectancy. Parents with advanced cancer and their adolescent children gradually come to realize they do not have enough time together. Several factors typically contribute to this realization. Some adolescents had heard about the parent’s limited life expectancy at the time of the initial diagnosis. For others, this information came after a period of remission when the cancer recurred and spread to other parts of the parent’s body, and cure was no longer attainable.

All of the adolescents described the first time they heard that their parent had been diagnosed with cancer. In some cases, treatment was recommended and cure was expected. Because these adolescents did not expect the parent to die, limited time together was not immediately a salient concern. Often, treatment worked for a period of time and life seemed to return to normal. In other cases, cure was never a realistic clinical goal, and the parents’ cancer progressed quickly. Some participants described feelings of disbelief related to prognosis because the parent had already lived beyond the physician’s predictions. They wondered if the physician was wrong and the parent would continue to live. These adolescents pointed out their parents had always been strong and overcame other obstacles throughout their lifetime.

All of the adolescents eventually came to understand that time with their parent would be limited by the advanced cancer. Each day the ill parents faced the possibility they might not be alive tomorrow. Although the ill parents try not to dwell on the ramifications of their advanced cancer, including limited time, those thoughts were
unavoidable. Kathy (all of the names in this analysis are pseudonyms), the ill parent in Family 6, explained it this way:

Well it’s, I mean I think it always makes things different knowing that you have cancer because you try not to think about it [crying], but yet it’s always back there that, what is going to happen. And I try not to be like that because I try to be strong. But it’s always some place, and I try to push it back and say okay we’re just going to go on, and I’m feeling fine, and I’m doing this so I should be thankful that I am, and that I have the support system that I have is unbelievable with my brothers and kids and husband.

The nature of the illness of advanced cancer impinged upon the time the ill parent and adolescent had together. The ill parents’ fatigue mitigated against the adolescent and parent being able to spend time together. This was compounded by the sense of urgency that accompanied the realization of impending death. The adolescents described factors such as the parent sleeping more that limited the time they were able to spend together.

Not having enough time together engendered regret, not just about the challenge to having time together in the present, but ill parents and adolescents also described regrets about how they had spent time with each other in the past. Ill parents spoke of not having enough time to do what they would have liked to have done with their adolescents, for example, teaching them to cook. Some of the adolescents described regrets about not spending time with their ill parents while they were healthy and when they were first diagnosed

All the participants described the loss of future time together. They talked about future events the ill parent will not experience such as proms, graduations, weddings, and time with their grandchildren. Pam, an adolescent in Family 4, talked about the loss of the opportunity to become closer to her mother in adulthood. Her
brother, Rick, spoke of the loss for his future children who will never see or know their grandmother.

*Making the Most of the Time We Have Left Together*

The ill parents and adolescents responded to the problem of Not Having Enough Time Together through the psychosocial process labeled Making the Most of the Time We Have Left Together. Donna, a well parent in Family 2, described it this way:

He [adolescent] just knows it’s day by day. And if I [adolescent] want to talk to him [ill parent], I better call and talk to him today because if I want to ask him that he might not be here tomorrow for me to ask him.

A parent’s diagnosis of advanced cancer led to changes within the individual and the family. When the prognosis became terminal, the realization of the parent’s impending death highlighted the limitations in time left to be shared between the adolescent and the parent. This realization, *Coming to Know Our Time is Limited*, is the beginning of a process of adaptation. The adolescents and their parents developed strategies to make the most of the time they had left together by *Spending More Time Together* and *Extending Our Time Together*. For some, *Giving Up Our Time Together* was perceived as the only way to end the ill parent’s and the family’s suffering.

*Coming to Know Our Time Together is Limited*

*Coming to Know Our Time Together is Limited* is the first phase of the process of Making the Most of the Time We Have Left Together. Adolescents expect their parents to die before them, but not until much later in the adolescent’s life. Although adolescence is a time to become more independent of one’s parents, adolescents still rely on their parents and an early death is unexpected.
The participants described specific points in time when the adolescent had acknowledged the parent’s advanced cancer diagnosis and the possibility of death. This acknowledgement was not a linear process. Although the adolescents were intellectually aware of the prognosis, the intensity of the reality was sometimes too difficult to bear. Sometimes the adolescents preferred not to acknowledge things were getting worse. This was easier to do when the parent was able to continue their activities by remaining mobile and communicating. Laureen, the ill parent in Family 8, described her daughter’s response:

I think she understands it for what it is. She understands that my time is limited. But she also has a tendency to ignore the truth or kind of bury the truth in hopes that this isn’t really happening. Ya know, waiting for something to maybe turn around and waiting, I don’t know if she would call it a miracle. But, ya know, she would, she’s just kind of hoping that it’s really not happening.

The adolescents came to know the ill parent had a limited life expectancy by hearing about and seeing the parent’s declining health. The adolescents’ narratives revealed the adolescents’ understanding even when their parents did not think they understood.

*Hearing it’s bad.* Every adolescent except one (n = 9) clearly remembered how they were told about the ill parent’s advanced cancer. They not only described how the information was conveyed to them, but also how they came to “know,” “understand,” or “realize.” Most often, the adolescents’ parents shared this information. Perry, the adolescent in Family 2, described being told by his ill father this way:

It was a while ago. He wasn’t feeling good. We were driving, I was about to get my license. He said he had a couple of things wrong with him and one of them was cancer.”
Although most of the adult participants talked about how they told the adolescent about the ill parent’s diagnosis, several ill parents chose not to talk about it with their adolescents. In these cases, the well parent told the adolescents about the diagnosis. All of the adolescents knew their parent was seriously ill even if the parents did not talk about it. Sam, the ill parent in Family 7, described it this way:

They [adolescents] don’t even talk to me about that. Actually, they don’t really know how sick I really am, ya know. Yeah. I try to keep that part away from them, ya know. About how sick I am. The way the doctor describes it, I’m dying every day. I said yeah, we all are.

Some of the adolescents realized time was limited when they heard about the ill parent’s prognosis. Several of the ill parents were initially diagnosed with advanced cancer and never recovered. Others enjoyed a period of remission before the cancer spread. Once advanced cancer was diagnosed, some parents remembered being told there was nothing more to be done to cure the cancer and hospice was offered. The adolescents understood time was limited when hospice services started.

Seeing it’s bad. The narratives revealed how adolescents came to realize time was limited when, in addition to being told by an adult, they saw physical and functional changes in the ill parent. The adolescents used the terms “hard to see,” “don’t like to see it,” and “watched” to describe how they witnessed their parents’ declining health. Rapid, consistent weight loss was a common physical change indicating something was drastically wrong. Adolescents watched the impact of fatigue and paralysis on the ill parent’s ability to remain independent. The ill parent became more physically dependent on the adolescent and other family members for everyday activities.
Spending More Time Together

The narratives revealed that because the adolescent had now heard, or seen, that time was limited, the ill parents and adolescents made concerted efforts to spend more time together. The ill parents had more time and the adolescents had less time.

The ill parents were no longer able to do the things they usually do. They had more time to spend with their adolescents because they could no longer go to work, run errands, attend meetings, cook meals, clean the house, or do laundry. As they progressively became more tired, they spent more time sleeping. The adolescents continued to go to school and sometimes to work part-time. They also took over many of the things the ill parent was unable to do. The adolescents who lived in a different home than the ill parent visited more often. Those who lived in the same home spent more time at home than they otherwise would have or than they had been. Both the ill and well parents noted the adolescents spent less time at work and with friends, choosing instead to spend more time with the ill parent. The participants emphasized that the adolescents chose to spend more time with the ill parents; there was not an expectation, nor were they forced to do so. The adolescents described their intent to be with their ill parent more; they did note this probably would not have occurred if time were not limited. Walter, the well parent in Family 3, took his children out of school to spend more time with their mother.

The adolescents talked about spending more time with their ill parents while they had the chance. They realized time was limited and so chose to spend it with their ill parent at a time in their lives when they might normally spend time away from their parents. The parents’ limited life expectancy was a main factor in this decision.
Adolescents in general tend to spend less time with their parents and more time with their friends. Rick, an adolescent in Family 4, captured this idea quite succinctly, “Just in general, spending more time with her. That probably wouldn’t have happened if she wouldn’t have gotten diagnosed.”

The participants described physical and psychosocial barriers to Spending More Time Together. Pain, ascites, and fatigue were the most common physical barriers. Anxiety and strained parent/adolescent relationships were the most common psychosocial barriers.

In contrast, many adolescents described factors that facilitated Spending More Time Together. These included a strong relationship with the ill parent, the adolescents’ ability to change their work schedules, and encouragement and guidance from the well parent. Adolescents who had specific goals such as learning more about their ill parent also tended to want to spend more time together. Participants told many stories about spending more time together by Becoming closer and Making it better for the parent.

Becoming closer. The narratives revealed that ill parents and adolescents often did things together specifically for the purpose of becoming closer. The participants described activities to bring them emotionally and physically closer. The participants talked about the adolescents being more affectionate, such as hugging and kissing the ill parent more than before they came to know time was limited. Paul, the well parent in Family 5, described the changes this way:

He’s [adolescent] had a lot more interaction with her…He’s never been physical. Since I’ve lived with Barbara [ill parent], I have never seen a hug or a kiss between mother and son. And she realizes he doesn’t like that
stuff, so she doesn’t push it on him. But the last couple times he’ll come up to her and stand there kinda waiting for that hug. And she’ll come over and grab him and give him a hard time. And he won’t really reach out and hug her back, but he’s making himself available for that touch from his mom. And I don’t know who told him to do that, or if he just took it on his own, or if his dad talked to him about it. I don’t know if it means more to him or to his mom, but she is tickled pink that he’s letting her hug him.

Some of the adolescents engaged their ill parents in conversations to get to know them better. For example, they asked questions about the ill parent’s childhood and young adulthood.

While becoming close to the ill parent was important, the closeness did not exist at all times. At times some pulled away or withdrew from their ill parents. Colleen, the adolescent in Family 8, described feeling unsure about how to respond to her ill mother and being fearful of the future without her mother who had always been a stronghold in her life. Because Colleen was unsure about what to say or do in her mother’s presence, she chose to spend more time in her room. She also chose, however, to be home with her mother when no one else was home and to work when other family members were home.

Several adolescents described the need to get away from the intensity of the situation at home by going to school, work, and out with friends. Others brought their friends home to spend more time with their ill parent. These friends were very comfortable with the ill parent and were supportive of the family.

Some adolescents withdrew from their ill parents as a way to attempt to minimize the pain of the permanent loss of their parent at the time by death. In the majority of these cases, the adolescent or the well parent noted that the adolescent and the ill parent were not close prior to the advanced cancer diagnosis. While being close
was important to all of the adolescents, some of them really struggled with wanting to be close and needing to be distant as a way of trying to prepare themselves emotionally for the parent’s death. For example, Pam, an adolescent in Family 4, explained:

I try to stay away from her sometimes because I don’t want to get even closer to her, then when she passes away then it’s just going to be even harder. So I try to stay distant from her sometimes, which sounds selfish and mean again, but it’s kind of easier, I guess.

*Making it better.* The narratives revealed many ways the adolescents spent more time together as the adolescents did things to make it better for the parent. The participants talked a lot about the ill parent’s gradual loss of independence and the ability to take care of themselves and their family. When the adolescents identified changing needs, they readily did things to make it better for the ill parent thereby making it better for the rest of the family as well.

The narratives revealed specific interactions the adolescent initiated to make the ill parent feel better. Sometimes it was simply saying “I love you” to their parent, or talking to the sleeping parent. Well parents described a change in the way their daughters talked to their ill mothers, more like sisters or girlfriends than mothers and daughters. Things the adolescents did for their parents included holding the ill parent’s hand, rubbing their feet, painting their nails, and doing their hair. The well parents noticed the adolescents being more attentive, compassionate and caring. For example, Walter, the well parent in Family 3, described the following interaction between his wife and son:

Cory is a very huggy, kissy type of a child and I know that there was a time when his mother came home from a doctor visit and she was a little bit startled…that he had gone up to her and gave her a big hug and a kiss and just sat there for a while and said “I love you, Mom” and “you’re going to
be okay” or something like that. And she was very touched by that. It was an encouragement to her not only because she noticed her son loving her in the midst of her cancer, but also that it really, it was almost like maybe God spoke to her through him and said you’ll be alright no matter what, whichever way this goes.

One adolescent found it easier to write letters to her mother than to talk with her. The cards and letters gave the daughter a comfortable means to write her thoughts and feelings and the mother enjoyed reading them over and over again.

The most common way the adolescents made it better for their ill parent was by being helpful. Most of the adolescents took an active role by helping the ill parent and the family by running errands, doing the laundry, cooking meals, and taking care of younger siblings. The narratives revealed many ways adolescents changed their priorities to make it better for the ill parent. In general, this meant putting their family first. Adolescents noted that these changes would not have happened without the parent’s limited life expectancy. Although the well parents sometimes needed to coach the adolescents, most of the time the adolescents were proactive in identifying what needed to be done and doing it. Although the ill parents said their adolescent would do whatever they asked of them, the adolescents talked about anticipating their ill parents’ wishes and needs before they were spoken. The well parents described feeling confident that their adolescent would continue to be helpful in the future. Older siblings accepted more responsibility for their younger brothers and sisters. The participants talked a lot about doing what “needed to be done” around the house. They described housekeeping activities like cleaning the house, washing the dishes, doing the laundry, and cooking meals. Many of the adolescents had never done these things before the parent became ill. The well parents were pleased to have the adolescents’
help, and spoke about relying on them more as the ill parent needed more help. The adolescents and well parents spoke about caring for the ill parent by redistributing their roles within the family.

The adolescents’ efforts included not only helping with daily chores and activities, but also helping during nodal events and projects. The participants described several additional ways the adolescents were helpful, including buying and putting up the Christmas tree, and converting a first floor room to a bedroom where the ill parent could rest during the day. Some of the adolescents talked about “making it better” by attempting to take their ill parents’ mind off their cancer by laughing together, having fun, and continuing to do things together that had always enjoyed, such as baking or working on computers. The ill parent noticed and greatly appreciated the things their adolescents did to make them feel better. The adolescents who did things to make it better for their ill parents noted they felt better themselves.

*Extending Our Time Together*

The participants not only talked about spending more time together while the ill parent was still alive, but also engaging in processes that could extend their time together once the ill parent dies. Because the adolescents and ill parents realized that no matter how much time they spend together while the parent is alive, it would never be enough, they found ways to maintain their relationship by transcending the boundaries of time and death.

*Remaining close.* The narratives revealed many ways the adolescents and ill parents planned to remain close, to continue the relationship after the parent’s death. Some of the adolescents talked about keeping tangible reminders of the parent. They
described specific treasures such as a parent’s ring, cross, and statues that would remind them of the ill parent after his or her death. These reminders were a way to keep the memory of their parent alive. Pam, an adolescent in Family 4, had a butterfly tattooed on her hip to remind her of her mother who would soon be free of suffering. She also chose to remember her mother by writing her thoughts and feelings in a special diary. Laureen, the ill parent in Family 8, described letters she was writing for her daughter to open on her 18th birthday and high school graduation. She described her letters as “difficult but important to write.” Barbara, the ill parent in Family 5, lamented that her 14 year old son did not know her and may never know her. She requested a copy of the transcript to help him know her better after her death.

Adolescents and well parents described pictures and video tributes as meaningful ways to remain close to the ill parent after death.

Ill parents and their adolescents described non-tangible ways of remaining close to each other after death. Gene, a well parent in Family 6, gave this example:

Well, I’ve seen her mom talking to her. I’ve overheard her reassuring her, if I’m not here in body, I’ll be here in spirit.

In the same family, the ill mother promised she would be with her daughter all the time, especially in her dreams. The daughter said she would pray to her mother, and when she encountered a problem she would remember what her mother would do. In this way the mother would continue to provide guidance after her death. Thinking about the ill parent brought comfort to the adolescents. They emphasized they would never forget the ill parent. The adolescents talked a great deal about remembering happier times prior to the advanced cancer diagnosis.
Making it better. Just as the adolescents undertook specific efforts to make it better for the ill parents while they were alive, the ill parents did specific things to make it better for their adolescents after the ill parent’s death. Their attempts to plan their adolescent’s future were important to them in their parenting role. For example, ill mothers and fathers discussed college plans with their adolescents and made financial plans for them. Several ill mothers identified a specific woman or group of women to serve as surrogate mothers after their deaths. It was important to these mothers to be sure that their children would continue to know them better through the surrogate parent who had known the ill parent well. Another ill mother made sure custody papers were completed for her husband, who was not the biological father, to take custody of her daughter after her death. Several ill mothers spoke to their daughters about their current boyfriends. The mothers made it clear that they approved of these boys as potential spouses.

Whereas the ill parents talked about planning for the adolescent’s future after his or her death, the adolescents talked about the present and how difficult it was to think about a future without their parents. The adolescents described helpful advice from their ill parents such as “stay in school” and “apply to college.” Peter, an ill parent in Family 2, described the importance of preparing his son for his death:

Let them know you’re not afraid. This is like I said before. This is not you dying. This is just a passing. You’re passing from here to there. And that’s it. And if you can make them understand that, which I think they do, they’ll feel much more at ease, you’ll feel much more at ease, ya know.
Although the ill parent did specific things to make it better for the adolescent, the adolescent may not be willing to accommodate the parent’s suggestions. Colleen, an adolescent in Family 8, explained:

She is trying to, I don’t know, I guess help with whatever she can before it happens. But she doesn’t like saying the word die around me, and I probably wouldn’t like hearing it. But it is a reality. And she always tells me to save my money and to start thinking about what I’m going to do and looking at colleges. She just tries to advise me on how, what I’m going to do because I, she doesn’t, I don’t know. And she knows I don’t know what I’m going to do. And she’d like for me to be more prepared and stuff, but I’m not. And I probably won’t be until it happens. So, I don’t know. She keeps just trying to push me to do whatever she can do before it happens, before she dies.

The ill parents continued to try to make things better for the adolescent even when the adolescent did not want to face the reality of death. When the ill parents did things for the adolescent to make it better after their death, the parent also felt better.

*Giving Up Our Time Together to End Suffering*

Although the majority of adolescents talked about not being ready for their ill parent to die, maintaining hope the parent would get better, a few narratives revealed the adolescents’ readiness to have their time with their parent end because it meant that their ill parent’s suffering would also come to an end. The adolescents who talked about wanting their parent to die introduced the idea in an apologetic way by saying “I hope that doesn’t sound bad like I want her to go, but I think it would be easier if she just kinda did because don’t like looking at her like that. “

The suffering was often too difficult for the adolescent to watch. Karen, the adolescent in Family 9, described it this way:
It’s hard to see her in the bed she in and she knows it’s hard for me to see her like this when she don’t want to be like this… I don’t want to see her go, but it’s just too hard.”

The two daughters who were ready for the suffering to end described their mothers as very independent women. Although the women could communicate, they were bedbound and dependent on others for most of their needs. The adolescents talked about how they took care of their mothers. One of the adolescents added that, since her mother does not take care of her anymore, it feels like she is already gone. Neither of the women’s spouses nor the adolescent son talked about suffering or being ready for the ill parent to die. Diane, an ill parent in Family 9, described that she and her daughter would cry together when she said she would not be here forever. These adolescents were ready for the suffering to end for their mothers and themselves. The daughters did not want their mothers to die and would choose an alternative to death if there were one.

Two adolescents described being ready to give up their time with their ill parent, while one ill parent talked about being ready to die at any time, but did not talk about suffering. Three adolescents and two ill parents described not being ready, but they expected to be ready sometime in the future.

In summary, the findings of this study suggest a nonlinear model that depicts the adolescents’ and the ill parents’ responses to the realization that their time together will be limited by the parent’s impending death. The adolescents and ill parents responded by spending more time together and extending their time together by making plans to maintain their relationship after the parent dies. A few adolescents were ready to give up their time with their ill parent to end the suffering. The model
explicates specific ways the ill parents and adolescents choose to spend their time together to maintain their relationships. Spending time together while the parent was alive was beneficial to the adolescent and both parents because the parents could rely on the adolescent to help with household chores, and the adolescent felt good about being helpful. Planning to maintain their relationship after death was also beneficial to the adolescent and ill parent because it allowed them to extend their time together. The few adolescents who were ready to give up their time with their parent expressed feelings of sadness and suffering that were becoming very difficult to bear. Death was perceived as the only way to end this suffering.
CHAPTER IV
DISCUSSION

The findings of this study of the narratives of 7 parents with advanced cancer, 9 spouses, and 10 adolescents add to knowledge about parent-adolescent interactions as they responded to the parent’s limited life expectancy. Knowledge of individual family members’ responses was also expanded. The findings add to the literature by describing the processes that parents with advanced cancer and their adolescent children use to respond to the parents’ limited life expectancy and to plan for subsequent lives without the parent. Participants in this study described their experiences as direct responses to the parent’s impending death. That is, these responses would probably not have occurred if time were not limited. Limited time together was the core concept that led to spending more time together and extending their time together after the parents’ death.

The impending death of a parent has been shown to have a significant impact on an adolescent’s life (Heiney et al., 1997; Siegel et al., 1992; Welch et al., 1996). When the parent was diagnosed with advanced cancer, the family usually had time to recognize that death was imminent; changes often occurred within the family over this period of time. While scholars have written about parental death among adolescents, most of the research has been done after the parent’s death. Few researchers have
described the complex and dynamic psychological processes of families who are living with and responding to a parent’s limited life expectancy. In this study, the researcher attempted to illuminate and explicate the complexities inherent in the individual responses, and interactions between the ill parent and adolescent when each realized that their time together would be limited by the impending death of the parent.

The major purpose of this study was to develop a theoretical framework to describe interaction patterns between parents with advanced cancer and their adolescent children. Related goals included an exploration of how parent-adolescent interactions change as the cancer progresses and identification of strategies parents use to prepare their children for their lives after the parent’s death.

Grounded theory methods were used to illuminate the processes ill parents and adolescents used to manage their lives within the context of the parent’s impending death, and to respond to changes over time. Data included transcripts of ill parents’, adolescents’, and well parents’ interviews, and the researcher’s memos. The resulting theory is one perspective of reality that offers explanation and understanding about the interactions between parents with advanced cancer and their adolescent children.

Maintaining normalcy and eliciting support were found to be very important to the adolescents in the current study. Earlier studies have suggested that adolescents elicit support from their parents, friends, relatives, and siblings (Berman, Cragg, & Kuenzig, 1988; Christ et al., 1993; Christ et al., 1994; Gray, 1987). Children especially benefited from talking with others whose parent was dying or had died. The current study supports previous findings and adds teachers and school counselors to the list of helpful supporters. Previously, researchers have suggested that going to school and
spending time with friends distracted the children from their parent’s illness and provided balance and normalcy in their lives (Christ et al., 1993; Hymovich, 1993). It became more difficult, however, for children to get away from the realities of the parent’s illness, to be happy, and to live “normally” as the parent’s illness got worse (Christ et al., 1993). These findings were supported in the current study. Adolescents reported hiding their emotions in public; some described their feelings in personal diaries.

Researchers have found that the adolescents’ intense involvement with friends distracted them from their parent’s life threatening illness, but they were hesitant to confide in their friends about their parents’ illness because they feared rejection (Christ et al., 2000). Previous researchers have suggested that children whose parent was dying undergo a loss of peer contacts outside of the classroom, and extracurricular activities (Christ et al., 1993; Christ et al., 1994). In the current study, staying involved in these activities was very helpful to adolescents in maintaining normalcy and support.

Several new findings were identified in the current study. Adolescents who brought their friends home to spend time with their ill parent sincerely appreciated their friend’s visits because the friends were very comfortable with the ill parent and were supportive to the family.

The Framework: Making the Most of the Time We Have Left Together

A theoretical framework emerged from the data from the narratives of the 26 participants. The model suggested that parents with terminal cancer and their adolescent children respond to their limited time together through a process of “Making the Most of the Time We Have Left Together.” The process begins with
“Coming to Know Our Time is Limited,” moves to “Spending More Time Together” and “Extending Our Time Together.” For some adolescents, the process culminates in “Giving Up Our Time Together to End the Suffering.” The components of this model largely support findings about parental death among adolescents in earlier studies. There were also some new findings.

**Coming to Know Our Time is Limited**

The theory’s first phase, Coming to Know Our Time is Limited, is the unavoidable first step in the process of Making the Most of the Time We Have Left Together. Coming to Know inherently involves a realization by the adolescent about the ill parent’s declining health and impending death. Adolescents shared stories about how they were told and the changes they saw in their parents that indicated declining health. The narratives revealed a discrepancy between what was told and what was known; even when the adolescents had not been explicitly told, they knew their parents’ health was declining and that the parent was going to die. In some cases, their parents did not believe the adolescents understood the severity of the illness. Based on the realization of limited time, adolescents and their parents developed strategies to make the most of the time they had left together by spending more time together.

**Spending More Time Together**

The second phase of this theory was labeled Spending More Time Together. In the current study, ill parents and adolescents spent more time with each other than before the cancer diagnosis. At the same time, each tried to maintain normalcy. These findings were consonant with those of earlier studies (Elmberger et al., 2002; Elmberger et al., 2000; Shands et al., 2000) in which adolescents described conflicting
feelings of wanting independence from their mother with cancer, yet also knowing she may die and wanting to spend more time with her (Huizinga et al., 2003).

In the current study, participants talked about feeling anxious, scared and worried, consistent with what has been described by parents and adolescents in earlier studies (Heiney et al., 1997; Huizinga, et al., 2003; Siegel et al., 1992; Welch et al., 1996; Worden, 1996; Zahlis, 2001). As expected with this stage of most cancers, fatigue was reported by the ill parents in the current study, as well as in earlier studies (Christ et al., 1993; Christ et al., 1994). Both anxiety and fatigue were common barriers to Spending More Time Together.

The results of the current study suggest that adolescents and their ill parents became closer to each other by spending more time together. These findings were consistent with those of earlier researchers (Elmberger et al., 2000; Elmberger et al., 2002). These findings contrast the developmental tasks of adolescents such as withdrawing emotionally from their parents, achieving emotional independence, and being accepted by their peers (Blos, 1962; Christ, 2000; Fleming & Adolph, 1986). Researchers have also suggested that adolescent girls became closer to their ill mothers while boys tended to separate from them (Christ et al., 1994). In the current study, most of the adolescents became closer to the ill parent. Becoming closer was not related to gender or relative gender, but rather to the relationship between the adolescent and ill parent prior to the cancer diagnosis. Those who were close to each other before the diagnosis became closer. Those who were not close did not become closer. This finding contradicts an earlier study in which it was suggested that adolescents often use emotional detachment to manage their intense empathic feelings.
toward the ill parent (Christ et al., 1993). Rather, the preexisting relationship suggested whether or not parent and child became closer.

The current study suggested that adolescents made concerted efforts to make life better for their ill parents. Although the well parents sometimes needed to coach the adolescents on things that would be helpful, most of the time the adolescents were proactive and accurate in identifying what needed to be done and doing it. The adolescents talked about anticipating their ill parent’s wishes and needs before they were spoken. Helping their parents made the adolescents feel good about themselves as an individual and as a contributing family member. These findings support earlier studies in which it was suggested that helping their parents distracted the children from their parent’s illness and provided balance and normalcy in their lives (Christ et al., 1993; Hymovich, 1993).

*Extending Our Time Together*

The third phase of the current theory was labeled *Extending Our Time Together*. The second and third phases are nonlinear and may be concurrent. They complement each other by enhancing the possibilities for maintaining the adolescent-parent relationship through illness and beyond death. This phase includes the concurrent, interactive processes of remaining closer and making it better. Adolescents and ill parents made plans to remain close, (that is, connected), after death. In addition, the ill parents used specific strategies to make life better for the adolescent after death.

Although physical proximity to the parent becomes impossible after death, psychological proximity, that is, a continued relationship following the death, has been shown to be beneficial to the child (Field et al., 2005). The child remains close to the
parent, even after death, by cultivating the parent’s comforting presence and seeing the parent as a role model.

The ill parents in the current study made a concerted effort to remain close to their adolescents after death by writing letters to them, and by giving them other tangible objects by which to remember them. Other ill parents promised to visit in their dreams and to look after them. Earlier studies support this concept. Mothers in Elmberger and colleagues’ study (2000) study set up a mechanism for maintaining their relationship with their children in the future by preparing videotapes for their children to play during specific times during their lives after the mother’s death.

Researchers have suggested that ill parents and their children were unlikely to engage in interactions that would provide a foundation for remembering the parent after death, because these interactions would undermine coping strategies that relied on a denial of the parent’s impending death. One previous report of ill parents who took an active role in creating a specific legacy, such as a letter or video for their adolescents, did so because others prompted them (Saldinger et al., 2004). None of the ill parents in the current study spoke of prompting from others.

Elmberger and colleagues (2000) found that mothers perceived themselves as failures in their mothering role because they might not see their children and grandchildren grow up. The findings of the current study suggest that finding ways to extend their time together may counteract feelings of failure. The findings suggested the importance of continuing the parenting role by making life better for the adolescent after the ill parent’s death. The ill parents in the current study made plans for their adolescents’ financial security, college, and psychological support. The mothers in the
current study shared the names of specific women to serve as guides and role models for their daughters after the mother’s death. They described women who knew them well and could pass on the ill mother’s values to their daughters. In some cases, the mother and daughter reported two different women. The findings of Elmberger (2000) affirmed the importance of planning for the child’s care after the parent’s death.

*Giving Up Our Time Together to End the Suffering*

The fourth and final phase was labeled *Giving Up Our Time Together to End the Suffering*. The model culminates in this phase for some, but not all adolescents. This phase was only described by adolescents who found it excruciating to watch their mother’s suffering. These adolescents made a concerted decision and specific efforts to avoid being in the parent’s presence, because watching the mother’s suffering was too difficult. The mothers, however, did not absent themselves from their daughters. To the contrary, they worked to maintain not only the relationship, but specifically the parenting role as long as they could, and even extending the relationship beyond death.

*Making the Most of the Time We Have Left Together*

The core category, labeled “*Making the Most of the Time We Have Left Together,*” unified the categories found in the study and reflects the importance of maintaining the adolescent/parent relationship. This theoretical framework illustrates the active and interactive processes that counter the individuation that is usually the hallmark of adolescence. That is, the ill parents and adolescents are making active steps not only to be as close as possible in the present, but to develop ways to maintain a connection after death. Individuation as a result of physical separation by death was an inevitable eventuality for these families. The families in this study chose to
strengthen their relationships prior to death in recognition of the absence of future opportunities for this closeness.

As this review of relevant literature suggested, this current study’s theory supports previous findings on the strategies adolescents and ill parents use to maintain their relationships. One of the advantages of the current study is that it is prospective. Previous studies have been limited by retrospective interviews after the parent’s death. The model reflects the dynamic process of how adolescents and ill parents continuously adapt their relationship to make the most of their time together. The study is important because the theory emerged from the narrative data of the current experiences of the participants.

Implications for Clinical Practice

Several implications for clinical practice are suggested by this study. The interventions are suggested for Caucasian parents with advanced cancer in hospice and their adolescent children, although others may benefit from the interventions. Generally, the adolescents need guidance in traversing this new and unexpected experience of facing their parent’s impending death from clinicians who convey empathy and understanding.

The findings from the current study suggest strategies for adolescents to make the most of their time with their ill parent. An intervention program could be designed to include all of the strategies, allowing the adolescent to decide which ones are best. The hospice nurse or social worker could present the strategies during a home visit and facilitate helpful strategies. Pragmatic strategies include running errands, making meals, doing the laundry, and caring for younger siblings. Comfort oriented strategies
include backrubs, manicures, pedicures, hugs, and kisses. Another strategy is collecting special pictures of the ill parent and adolescent or putting together a video with the pictures. Because adolescents who had specific goals such as learning more about their ill parent tended to want to spend more time with their ill parents, providing a list of potential questions may help adolescents to begin a conversation with the ill parent. Legacy journals are available in bookstores, hospices, and online to give the adolescent ideas about ways to construct their own questions. Finally, visiting with the ill parent in their dreams and talking with them after death can also be helpful strategies.

Friends are a major source of support for the adolescents. Clinicians should appreciate their contributions by including friends in adolescent support groups and encouraging adolescents to bring their friends home to spend time with their ill parent. Being open to the ways friends are helpful could shed new light on interventions from an adolescent perspective.

Adolescents also drew strength from school counselors and teachers. Findings from this study should be disseminated to them locally through school-based workshops and nationally through the American School Counselor Association. Because school nurses, pediatric nurse practitioners, primary care physicians, pediatricians, and bereavement counselors also interact with these adolescents, they would benefit from the findings of this study.

The findings from several studies have suggested that interventions that guide parents as they interact with their children throughout a terminal illness and after the death of the parent were helpful (Adams-Greenly & Moynihan, 1983; Siegel, et al., 1990). The findings from the current study suggest specific strategies for parents with
advanced cancer in a hospice program to extend their time with their adolescents after death. The nurse or social worker may facilitate conversations between the ill parent and adolescent about how they plan to extend their time together after the parent’s death, or the conversations may include only the ill parent or adolescent if they prefer not to talk about it together. One strategy is writing letters to the adolescent with words of advice or encouragement that focus on a particular day. The letters are given to the well parent, or another adult, with instructions about when they should be given to the adolescent such as the adolescent’s birthday, high school graduation or wedding day. Another strategy is to identify a proxy parent who knows the ill parent well and can answer the adolescent’s questions about the parent after death such as “Would Mom like this prom dress?” The proxy parent is the same gender as the ill parent and may also serve as a role model for the adolescent. Finally, the ill parent can provide the adolescent with tangible treasures such as a favorite piece of jewelry and intangible treasures like advice to continue their education.

Limitations

There are several limitations in this study. Although transferability was used to provide a detailed description of the participants, lack of diversity in ethnicity and religious affiliations limited generalizations of the findings. In the current study participants were Caucasians and African-Americans with Christian religious affiliations. Annual family income and education, however, varied widely in the current study; annual family income ranged from less than $10,000 to more than $90,000, and education ranged from seventh grade to 4 years of college. In the
majority of previous studies, participants reported annual income of greater than $50,000 and at least some college education.

All of the participants were from one hospice. Participants from other hospices might have contributed different perspectives. This particular hospice is one of the largest in the United States and offers services to patients and families that may have been unavailable in other smaller hospice, such as art and music therapy. The researcher had limited access to the sample and only had knowledge of the potential participants who were referred by the hospice staff.

The adolescents seemed to have a good relationship with their ill parents. Adolescents without a good relationship may have responded differently.

Although subjectivity occurs in qualitative research, collaboration with experts in qualitative research and palliative care and continuing review contributed to objectivity. Some participants may have fabricated their narratives to receive the $35 participant reimbursement, but this was rarely the case. Although only one participant may have initially agreed to participate for the money, the narrative was very similar to those of the rest of the family suggesting it was not fabricated. All of the participants seemed sincere, and perhaps of greater importance, each participant indicated gratitude for the chance to participate in the study.

Finally, all of the ill parents died before there was an opportunity to collaborate with them in constructing the theory. A second interview would have been helpful to clarify responses. Feedback from the participants may have validated the theory.
Future Research

Based on the findings of this study, several areas of future research are suggested. Longitudinal studies are needed to determine the efficacy of the adolescents’ responses to the parents’ limited life expectancy, and to explore how parent-adolescent relationships change over time. In addition, given the specific efforts of families in this study, it will be helpful to explore how the adolescent perceives the relationship extending after death. Further research is warranted to describe the interactions between adolescents and their parents with advanced cancer who are not enrolled in a hospice program.

Empirical studies using larger samples are needed to validate and expand the theory. Specifically, studies are needed to develop an instrument to identify positive strategies to prepare adolescents for their parents’ imminent death while the parent is alive.

Empirical studies are also needed to test the efficacy of intervention programs aimed at facilitating positive strategies to prepare adolescents for their parent’s death from advanced cancer to provide evidence for practice.

In conclusion, the current study provided a model for understanding adolescents’ responses to their parents’ limited life expectancy and imminent death. By understanding the strategies the adolescents use to deal with their understanding, nurses and others can support and guide them through this very difficult time in their lives. It is crucial to begin these strategies while the parent is alive, and not wait until the parent becomes comatose or dies.
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APPENDICES
APPENDIX A

RECRUITER’S SCRIPT

Participant # _________

One of the goals of health care is to help patients and their families when they are sick. Denice Sheehan is a doctoral student in Nursing at Kent State University and the University of Akron. She is studying how people with cancer interact with their adolescent children. You may be eligible to participate in her study because you have advanced cancer and an adolescent child. Does this study sound like something you might be interested in? If you are interested, may Denice Sheehan call you?

What is the best telephone number to reach you? ____________________________

What is the best time to reach you? ____________________________

May she leave a message on an answering machine about the study? Yes No

Participant’s name ____________________________

Recruiter’s name ____________________________

Recruiter’s agency ____________________________

Social Worker’s name/telephone number ____________________________

__________________________________________

__________________________________________
APPENDIX B

FLYER: PARENTS AND THEIR CHILDREN NEEDED FOR A STUDY ON PARENT/CHILD INTERACTIONS

If you
• are a parent with advanced cancer
• have an adolescent child (12-18 years old)
we invite you to participate in this study

PARTICIPATION INVOLVES:
• A 30-60 minute confidential, one-on-one interview
• $35.00 per interview for your time
• Convenient interview locations
• Your stories will help health care professionals help others

For more information and to sign up, call our confidential, telephone number:
(216) 990-xxxx

This is a research dissertation study conducted by Denice Sheehan, PhD(c), RN, and has been approved by the Kent State University Human Subjects Review Board: (330) 672-xxxx.
This is Denice Sheehan. I am a nurse and a doctoral student at Kent State University and the University of Akron. This is a confidential line. Thank you for your interest in the study: “Parent/Child Interactions”.

At the beep, please leave your name, number, and the best time to reach you, or indicate how I might otherwise contact you. I will return your call within 24 hours. Thank you for considering participating in the study.
Hello, my name is Denice Sheehan. I am a doctoral student in Nursing at Kent State University and the University of Akron. (Name), your nurse/social worker from Hospice, said this would be a good time for me to call you to talk about my research study. Is this a good time for you to talk with me for about 5 minutes? Yes ______ No, ask about a better time to call back __________

May I tell you some information about the study?
The purpose of this study is to learn how parents with advanced cancer interact with their adolescent children. If you are a parent with advanced cancer with a child between the ages of 12 and 18 years you are invited to participate in this study. Participation in the study consists of an interview about your interactions with your adolescent that I think will last 30-60 minutes. You do not have to answer any question with which you feel uncomfortable. You may stop the interview at any time. The interviews are confidential.

The interview might be tiring. The topic of advanced cancer can be sensitive and might bring up thoughts or feelings you could find distressing. We do think participants might help others with a similar illness. Do you think you might be interested in participating in this study? Yes ____ No ____

Because you are interested, I need to ask you a few questions to be sure you meet study criteria and that this is a good time to do an interview. May I ask you a few questions? Yes ____ No ____

- Have you been diagnosed with cancer? Yes ____ No ____
- Do you have a child between the ages of 12 and 18? Yes ____ No ____
- Do you write in English? Yes ____ No ____
- Do you feel strong enough to talk with me about your interactions with your adolescent for about 30 to 60 minutes? Yes ____ No ____
Met criteria:  Yes ___  No ___
[If no, thank them for their time; if yes, proceed with setting up the interview]

I would very much appreciate your involvement in this project. Do you have questions about the study? [Answer questions and ask if still interested.]

I would like to set up a time and place to talk with you.

<table>
<thead>
<tr>
<th>Place</th>
<th>Day</th>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>_____</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>Hospice House</td>
<td>_____</td>
<td>_____</td>
<td>_____</td>
</tr>
<tr>
<td>By Telephone</td>
<td>_____</td>
<td>_____</td>
<td>_____</td>
</tr>
</tbody>
</table>

I am also interested in your family’s perspective about how they think your cancer affects your interactions. This is not a requirement for YOUR participation, however. I would interview them separately from you, although we could schedule the interviews “back to back” or they could be scheduled at different times.

Would your husband/wife/partner be interested in participating?  Yes ___  No ___
Would you invite them to call our telephone number to schedule an interview or should I call or send them study information? Will call __ Researcher will call __ (best day/time _____) Send information ___

Would you like to invite your adolescent to participate?  Yes ___  No ___
Would you like to schedule an interview for your adolescent now?  Yes ___  No ___
[If no] Would you or your husband/wife/partner like to call our 800 number to schedule an interview for your adolescent or should I call or send them study information? Will call __ Researcher will call __ (best day/time _____) Send info__

Thank you for agreeing to talk with me. I will meet you at (place) on (day/date) at (time).
I will meet your son/daughter (child’s name) at (place) on (day/date) at (time).
If you need to contact me in the meantime, my telephone number is 216-990-0665.
APPENDIX E
AGENCY'S POLICY ON HOME VISITS

<table>
<thead>
<tr>
<th>TITLE: Safety Based Policy and Guidelines</th>
<th>POLICY AND PROCEDURE</th>
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<tbody>
<tr>
<td>EFFECTIVE DATE 1994</td>
<td>NUMBER HOWN 1</td>
</tr>
<tr>
<td>REVISION DATE 9/97</td>
<td>PAGE 1 OF 2</td>
</tr>
<tr>
<td>REVIEWED DATE 9/02</td>
<td></td>
</tr>
</tbody>
</table>

It is the policy of to maintain reasonable and prudent safety measures for agency staff who are making a house visit in an area or in a home they believe may be unsafe. Because safety is subjective, each team member must determine their team leader the measures needed for their safety. Education and awareness are the best tools in supporting that process. Dialogue with the staff member's supervisor along with these tips and guidelines will assist in determining various safety options.

Safety tips:
- Avoid driving in the dark lane
- Walk with purpose and confidence
- Be aware of the environment around you
- Lock doors
- Wear clothing that allows freedom of movement
- Keep all unnecessary belongings and valuables secure while at work
- Do not bring unnecessary cash or valuables to work
- Take enough cash out of your purse or wallet to carry with you while at lunch or on tasks
- When out of your office, lock your door if there is no one working in the office or area
- Be sure to lock your door at the end of each day
- If someone unfamiliar or suspicious is in your area, ask if you can help him/her with directions or information. Report anyone who is loitering in the building or on the property, who looks suspicious, or fails to identify him/herself
- Headquarters: If you are in the building after business hours or on weekends, you must notify security when you arrive and when you leave. You should present your employee identification badge to the security personnel
- Sites: If you are at the site after business hours or on weekends, keep the exterior doors locked at all times. Do not admit any unauthorized individual(s)
- Do not admit unidentified individual(s) to any building/facilities. Notify the appropriate security personnel
- If you are leaving the building after hours and want an escort, call on-site security and give them at least 15 minutes notice
- Where available, make sure building security systems are activated at the end of the day
- Do not prop open fire exit doors and/or any door that is normally kept locked
- Check to be sure that all lights and equipment (i.e. coffee pots) are turned off and that the area is secured at the end of the day
- Do not answer questions or over the phone from unidentified persons
- Do not give home telephone lines or whereabouts where they are readily visible or accessible to the general public or unauthorized personnel
- Never give out staff phone numbers or pager numbers without approval by the supervisor or supervisor on call
- Hang up immediately on obscene phone calls and notify your supervisor and security if they persist
- Do your part to protect patients, fellow workers, and yourself by following all safety and security rules

100
- Report and document all incidents of threats or aggression
- Avoid secluded or isolated areas
- Avoid wearing expensive jewelry

**Alternatives to escorts:**
- Utilize resources such as maps and other team members familiar with the area that you are traveling
- Be familiar with the locations of Police and Fire Stations
- Identify the safest route/alternate routes
- Call the patient/family to arrange your time of arrival and where to park
- Ask a family member to watch for your arrival
- Take a mobile phone with you (especially if patient has no phone)
- Drive by and return to the office for assistance if you have safety concerns
- Make joint visits with another team member

**Using escorted visits:**
- Escort visits must be arranged through team leaders or on-call supervisor
- Discuss with your team leader the safety concerns and options you may have to ensure safety
- Escorts will meet the staff member at the designated location
- Escorts may accompany a staff member into the patient’s home if the safety concern is in the home
- Every effort must be made to ensure the patient’s and families’ confidentiality and privacy when using an escorted visit
- Team leaders shall be available to discuss safety issues

In the event appropriate guidelines are not able to be followed or do not cover a particular situation, it is our policy that employees may use their judgment not to make a visit due to safety concerns until they are able to reach their Team Leader (or the Team Leader on call) for assistance.
I am a nurse and a doctoral student in nursing at Kent State University and the University of Akron. I am exploring ways in which parents with advanced cancer interact with their adolescent children. The goal of this study is to assist professionals and others who work with people with cancer and their families. I would like to invite you to participate in the study.

The interview will last approximately 30 to 60 minutes. I will ask you about your relationship with your adolescent child and how your interactions have changed since you were diagnosed with cancer. I have worked with many people with cancer and their families. The interview will be audiotaped and later transcribed. The audiotape will be destroyed after transcription. I may contact you sometime after the initial interview to ask for clarification of some information that you provided, to inquire about any additional thoughts you might have had, or ask you to review a summary of the results of the study.

You may experience some discomfort or painful emotions while discussing this sensitive topic with a stranger, especially if you have not had the opportunity to discuss your experiences before. You may also become tired during the interview. You may answer only those questions you wish to answer; you may stop this interview at any time. If you would like to receive information related to support services, Denice Sheehan will be happy to provide that for you. If you decide not to participate in this study, it will not affect your health care in any way.

Some people find it helpful to discuss their experiences. In addition, I believe what you tell me will help improve care for cancer patients and their families. Information you provide will be kept confidential within the limits of the law.

Results will be reported for the group as a whole, although descriptions of your experiences and your quotes may be used as examples. Your identity will be concealed in any reports. You will be given $35.00 today to compensate you for your time and travel.
If you want to know more about this research project, please call Denice Sheehan (Tel. 216.990.xxxx) or her advisor, Dr. Claire Draucker (Tel. 330.672.xxxx). The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice Provost and Dean, Division of Research and Sponsored Programs (Tel. 330.672.xxxx). You will receive a copy of this consent form.

**Consent**

I agree to take part in this project. I know what I will be asked and that I can stop at any time.

____________________________________  _____________________
Participant’s Signature                      Date
APPENDIX G

CONSENT FORM FOR ADOLESCENT PARTICIPATION (PARENT)

Participant # _________

I have read the Adolescent’s Consent Form and agree to allow my adolescent child to take part in this project.

Child’s Name ________________________________________

__________________________________________________  ______________
Parent’s Signature                        Date
I am a nurse and a doctoral student in nursing at Kent State University and the University of Akron. I am exploring ways in which parents with advanced cancer interact with their adolescent children. The goal of this study is to assist professionals and others who work with people with cancer and their families. I would like to invite you to participate in the study.

The interview will last approximately 30 to 60 minutes. I will ask you about your spouse’s relationship with your adolescent child and how those interactions have changed since the cancer diagnosis. I have worked with many people with cancer and their families. The interview will be audiotaped and later transcribed. The audiotape will be destroyed after transcription. I may contact you sometime after the initial interview to ask for clarification of some information that you provided, to inquire about any additional thoughts you might have had, or ask you to review a summary of the results of the study.

You may experience some discomfort or painful emotions while discussing this sensitive topic with a stranger, especially if you have not had the opportunity to discuss your experiences before. You may answer only those questions you wish to answer; you may stop this interview at any time. If you would like to receive information related to support services, Denice Sheehan will be happy to provide that for you. If you decide not to participate in this study, it will not affect your spouse/partner’s health care in any way.

Some people find it helpful to discuss their experiences. In addition, I believe what you tell me will help improve care for cancer patients and their families. Information you provide will be kept confidential within the limits of the law.

Results will be reported for the group as a whole, although descriptions of your experiences and your quotes may be used as examples. Your identity will be concealed in any reports. You will be given $35.00 today to compensate you for your time and travel.
If you want to know more about this research project, please call Denice Sheehan (Tel. 216.990.xxxx) or her advisor, Dr. Claire Draucker (Tel. 330.672.xxxx). The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice Provost and Dean, Division of Research and Sponsored Programs (Tel. 330.672.xxxx). You will receive a copy of this consent form.

Consent

I agree to take part in this project. I know what I will be asked and that I can stop at any time.

_____________________________________________        _____________________
Participant’s Signature                                  Date
APPENDIX I

CONSENT FORM (adolescent)

Participant # __________

I am a nursing student in the College of Nursing at Kent State University and the University of Akron. I am doing a research project to understand how parents with advanced cancer communicate with their adolescent children. This information will help us improve care for families in which someone has cancer.

The interview would last approximately 30 to 45 minutes. You will be asked several general questions about your relationship with your ill parent and how your interactions have changed since the cancer diagnosis. Denice Sheehan will interview you. She is a nurse who has worked with many people with cancer and their families. The interview will be audiotaped. Later, the words on the tape will be typed/word processed, and the tape will be destroyed. I may contact you sometime after the first interview to ask you to help me better understand your thoughts. I may also ask you about any more thoughts you might have had, or to read a summary of this study.

Some people find it difficult to discuss these topics, especially with someone they don’t know. You do not have to answer any question you don’t want to, and you can stop the interview at any time.

Some people find it helpful to talk about what it has been like for them since a family member has had cancer. The information you provide can help us care better for other families.

You do not have to participate in this interview. If you do participate, I will not tell anyone what you say to me unless you say something that makes me believe that you would hurt yourself or someone else. If you take part, you may stop at any time.

Results will be reported for the group as a whole, although descriptions of your experiences and your quotes may be used as examples. I will not identify you in any reports. You will be given $35.00 today to compensate you for your time and travel.
If you want to know more about this research project, please call Denice Sheehan (Tel. 216.990.xxxx) or her advisor, Dr. Claire Draucker (Tel. 330.672.xxxx). The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice Provost and Dean, Division of Research and Sponsored Programs (Tel. 330.672.xxxx). You will receive a copy of this consent form.

**Consent**

I agree to take part in this project. I know what I will be asked to and that I can stop at any time.

__________________________________________         ____________________
Participant’s Signature                     Date
APPENDIX J

AUDIOTAPE CONSENT FORM

Participant # _________

I agree to audiotaping at ______________________________ on ____________________.

_____________________
Signature

_____________________
Date
APPENDIX K

DEMOGRAPHIC DATA

Participant # ________

Age: ________

Gender: 
Male/Female

Race (circle): 
White
African-American
Hispanic
Asian
Other ______________________

Zip Code: ______________

Occupation: __________________________________________

Partner status (circle): 
Married
Partnered
Divorced
Separated
Widowed
Single/never married

Ages of children: _______________________

Religious affiliation: ___________________
Education (Enter letter here): ________
A. Completed 8\textsuperscript{th} grade
B. Completed 12\textsuperscript{th} grade
C. Completed 2 years of college
D. Completed 4 years of college
E. Completed more than 4 years of college

Annual household income (Enter letter here): ________
A. $10,000 or less/year
B. $10,001 - $30,000/year
C. $30,001 - $50,000/year
D. $50,001 - $70,000/year
E. $70,001 - $90,000/year
F. $90,001 or more/year
APPENDIX L

INTEREST IN FINDINGS (PARENT, SPOUSE, PARTNER)

Participant # _________

Are you interested in receiving a copy of the research findings from this project?

Yes _____  No _____

Are you interested in receiving correspondence regarding this project?

Yes _____  No _____

Are you interested in participating in future research on this topic?

Yes _____  No _____

If you answered yes to any of the questions, how/where should we send the information?

Name: ______________________________________

Street/Box: __________________________________

City: _______________________________ State: _____ Zip Code: ____________
APPENDIX M

INTERVIEW GUIDE (PARENT)

Participant # _________

1. Please tell me about the first time you were diagnosed with cancer.

2. How old was (adolescent’s name) at that time?

3. Tell me a little bit about (adolescent’s name).

4. Tell me about your relationship with (adolescent’s name).

5. Have you told (adolescent’s name) about your diagnosis?

6. Have you thought about talking with (adolescent’s name) about what the diagnosis means? What does your child understand about the prognosis?

7. Please describe some interactions you have had with (adolescent’s name) since you have been sick that stick out in your mind.

8. Please describe a typical interaction with (adolescent’s name) related to your illness.

9. Please describe a particularly pleasant interaction with (adolescent’s name) related to your illness.

10. Please describe a particularly difficult interaction with (adolescent’s name) related to your illness.
11. What is (adolescent’s name) understanding of the course of your illness? Have you spoke to him/her about the future? If yes, please describe how you are doing that.

12. What advice would you give to other parents in your situation?

13. Is there anything else you would like to tell me?

14. How has this discussion been for you?
APPENDIX N
INTERVIEW GUIDE (SPOUSE/PARTNER)

Participant # _________

1. Please tell me about the first time your wife/husband/partner was diagnosed with cancer.

2. Have you told your adolescent (adolescent’s name) about your husband/wife/partner’s diagnosis? If yes, please tell me about the time your child learned about the cancer diagnosis.

3. Please describe some interactions you have observed between your husband/wife/partner’s and (adolescent’s name) related to the illness that are typical.

4. Please describe some especially pleasant interactions you have observed between your husband/wife/partner and (adolescent’s name) related to the illness.

5. Please describe some especially difficult interactions between your husband/wife/partner and (adolescent’s name) related to the illness.

6. What is (adolescent’s name) understanding of the course of your husband/wife/partner’s illness? Have you spoken to (adolescent’s name) about the future? If yes, please tell me about how you are doing that.
7. What advice would you give to other parents in your situation?

8. Is there anything else you would like to tell me?

9. How has this discussion been for you?
APPENDIX O

INTERVIEW GUIDE (ADOLESCENT)

Participant # __________

1. What is your understanding about why I’m here?

2. Please tell me a little bit about your mom/dad. (parent with cancer)

3. Please tell me about your relationship with your mom/dad.

4. What do you think is happening with your mom/dad?

5. How old were you when your mom/dad was diagnosed with cancer?

6. Please describe some interactions you have had with your mom/dad since she/he has been sick that stick out in your mind.

7. Do you talk to your mom/dad about the illness? What are these discussions like?

8. Please describe a particularly pleasant interaction with your mom/dad related to her/his illness. Do you have good times together that happen because of the illness?

9. Please describe a particularly difficult interaction with your mom/dad related to her/his illness. Do you have really bad times together because of the illness?

10. What do you think is going to happen to your mom/dad?

11. What advice would you give to other adolescents in your situation?
12. Is there anything else you would like to tell me?

13. How has this discussion been for you?

14. If after the interview you feel upset or would like someone to talk to, who on the hospice team would you feel most comfortable talking to?
APPENDIX P

HUMAN SUBJECTS APPROVAL LETTER

TO: Denice Sheehan, College of Nursing
FROM: Katherine Light, Research Subjects Administrator
DATE: July 7, 2005
SUBJECT: 05-607 “Interactions between Parents with Advanced Cancer and their Adolescent Children”

I am pleased to inform you that the contingencies requested by Kent State University Institutional Review Board (IRB) at the June 22, 2005 meeting have been met and your Application for Approval to Use Human Research Participants received final approval on July 7, 2005.

This approval is good for one year from June 22, 2005 through June 21, 2006. HHS regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB further requests an annual progress report and a final report at the conclusion of the study. A Periodic Review form will be sent prior to the renewal date of June 21, 2006, but please be aware that timely annual reviews are ultimately the responsibility of the Principal Investigator.

If you have any questions, please contact me at 330.672.2704. (klight@kent.edu)
You may begin collect data. Good luck with your research project!
<table>
<thead>
<tr>
<th>Family</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Partner Status</th>
<th>Primary Cancer Site</th>
<th>Occupation</th>
<th>Religious Affiliation</th>
<th>Education Completed</th>
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<td>Tonga</td>
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<td>Colos</td>
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