UNTIMELY PASSAGES: YOUNG ADULT DAUGHTERS SHARE THEIR EXPERIENCES OF PARENTAL CANCER

by

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Abstract

Parental cancer during young adulthood is often unexpected and potentially disruptive to the developmental goals of this period. This study explored how young adult women experienced a parent’s cancer diagnosis and treatment. Five young adult participants, who had a parent receiving cancer treatment, were interviewed for this research. The interactive interview format, derived from an autoethnographic approach, allowed the researcher to include her own experiences of her mother’s cancer in the data and analysis. Themes arising from the data included: (1) time, (2) the meaning of cancer, (3) coping, (4) relationships and interaction, (5) family relationships, and (6) spirituality and hope. Although parental cancer presents numerous challenges, the experience appears to become a learning opportunity incorporated into development. Overall, young adult daughters demonstrated resiliency and adaptability in response to their parents’ illnesses, and managed to negotiate their own needs while continuing to provide support to their parents and families.
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Introduction

Each week in Canada, an average of 2690 people are diagnosed with cancer and 1296 Canadians will die from the disease (National Cancer Institute of Canada, 2003). According to the Institute, the prevalence of cancer increases as people age, with the number of new cases in adults between the ages of 50 and 59 more than double the number of diagnoses in the 40 to 49 age group. Adults in this older age bracket are likely to have children who are in their twenties. While it is now widely acknowledged that cancer impacts the entire family, little is known about the effects of parental cancer on young adult children. This exploratory, qualitative research project aimed to reveal how young adult women experience parental cancer.

Personal Interest

My research question arises directly out of my own experiences with parental cancer. In my early twenties, my mother was diagnosed with metastatic breast cancer. At the time I am writing this, she has been living with this incurable disease for over three years. Coping with my mother’s illness and prognosis has been the most significant and challenging experience of my life thus far.

Throughout my mother’s illness, I have struggled to find meaning in these circumstances. Examining my own experiences from an academic perspective has allowed me to find some purpose in this situation that seems unfair and undeserved. I must emphasize: only gradually was I able to explore my experiences in an academic context. Originally, my research question for my Master of Social Work thesis addressed a completely different subject area. However, as my former research question solidified, I found myself thinking, “I want someone to do a research project about my experiences. I
want someone do a study that I could be in.” It did not occur to me that I could be that “someone.” My undergraduate studies in psychology emphasized conventional, quantitative approaches to research. Consequently, I previously believed that it was inappropriate for me to research a subject area in which I was emotionally immersed.

Before committing to this research topic, I spent a considerable amount of time discussing this idea with colleagues and research advisors. Although I received strong encouragement to pursue this question, I felt hesitant to explore such an emotionally laden topic. It concerned me that choosing this research question could negatively influence my emotional well-being. I would be unable to distance myself from my subject—I am living the experience I am examining. As a result, I wondered whether devoting so much energy to this particular topic could have detrimental consequences for me, especially if my mother’s health deteriorated while I was working on this project. After much contemplation, I reached the conclusion that this research project would provide me with valuable insight into my own experiences, and I was motivated knowing that my research could potentially benefit my participants and other young adults dealing with parental cancer. My preliminary review of the literature revealed that I could contribute to a neglected area of research.

I feel uniquely qualified to research this subject area and privileged to have an opportunity to examine my experiences in this context. Within a creative qualitative research framework, I have been able to explore my story while it continues to evolve. By explicitly examining my own relationship to my subject area throughout this thesis, I aim to reveal the particular impact my experiences may have on my research outcomes.
Literature Review

In my review of the literature, I will first discuss Rolland's (1999) Family Systems-Illness Model which provides a framework for exploring the impact of parental illness on a family. I will then provide an overview of development during young adulthood. I argue that the developmental stage of children determines the meaning and experience of parental cancer. I will explore the literature on young adulthood with the aim of demonstrating that young adulthood is a transition period with specific developmental goals, and that this over-looked age group is uniquely impacted by serious parental illness. I will link my overview of development to my discussion of cancer with a brief section about the timing of illness in the life cycle. Next, I will consider the literature examining the impact of cancer on the family in general. I will then narrow my focus to critique the specific literature on parental cancer, and the impact of parental cancer on daughters. Throughout, I will identify the strengths, gaps and limitations in this research.

The Family Systems-Illness Model

Many articles examining cancer and the family make reference to family systems theory, which originated with Bowen (1978). In this perspective, family members are viewed as part of an interdependent system in which the situation of one member influences the condition of the others. The stress of an illness in the family disrupts the balance or equilibrium in the system, sometimes resulting in family conflict (Faulkner & Davey, 2002; Lewis, 1986).

Building on family systems theory, Rolland, a physician and psychiatrist, developed the Family Systems-Illness Model (1999). This model provides a systemic
way of conceptualizing the relationship between illness and the family, and a framework for evaluating families dealing with illness. The comprehensive model accounts for the changing demands of an illness over time and emphasizes the fit between the demands of the condition and the strengths and vulnerabilities of the family. In the model, Rolland describes his unique psychosocial illness classification system and illness timeline. This useful classification system acknowledges that illnesses vary in terms of onset, course, outcome, level of incapacitation and degree of uncertainty. The timeline accounts for the dynamic course of illness, positioning the condition at either the crisis, chronic or terminal phase.

Rolland's (1999) model is particularly relevant to my research question because it places the parent's condition within a developmental perspective that considers the interactions among the illness, individual, and family life cycles. Rolland explains that the family life cycle can be viewed as varying between phases that require more cohesion and bonding, and times when personal independence is emphasized. In addition, transition periods can be particularly vulnerable because of changes in roles and family patterns. As I will elaborate in the next sections, young adulthood can be characterized as a transition period in which families typically become less cohesive.

Similarly to Rolland, in their book *Cancer and the Family Life Cycle*, Veach, Nicholas and Barton (2002) consider the impact of different phases of cancer at each stage in the family life cycle. The authors identify six stages in the clinical course of cancer: diagnosis, treatment, rehabilitation, survivorship, recurrence, and terminal. While six phases of the family lifecycle are also discussed, for the purpose of my research, I will limit my attention to their discussion of families at the launching stage (i.e. the stage...
when children typically leave the family home). When illness and family development are considered together in an integrated framework, the challenges that may result from the interaction between these factors can be anticipated. The contributions of Veach et al. (2002) will be discussed in more detail later in this literature review.

A number of articles support the use of a life span developmental perspective when examining the impact of parental cancer on children (Compas, Worsham, Ey, Howell, 1996; Faulkner & Davey, 2002; Lewis, 1986; Spira & Kenemore, 2000). Parental cancer is experienced by individuals of all ages, and it is necessary to explore how developmental differences impact on the coping and adjustment to the illness (Compas et al, 1996). A developmental perspective is a longitudinal view of human functioning that focuses on stages of change, stability and transition over the life course (Bocknek, 1980). Within this perspective, young adulthood is not a fixed state but rather a period or transition within the broader life span.

Defining Young Adulthood in a Developmental Perspective

While disagreement exists about the age range that constitutes young adulthood, the vast majority of definitions fall somewhere in the range between 18 to 30 years of age. Definitions of young adulthood vary by culture, ethnicity, socioeconomic status and gender (Carter & McGoldrick, 1999), which contributes to inconsistency. While contemporary descriptions of young adulthood are somewhat scarce, over the past decade, the focus on young adulthood has grown, and recognition of the significance of this developmental period has increased (Shulman & Ben-Artzi, 2003). Young adulthood is often referred to in the literature as the 'launching stage,' at least from the perspective of the parents (e.g., McGoldrick & Walsh, 1999).
Evolving Theories of Young Adult Development

Psychoanalyst Erik Erikson, one of the first writers to use the term ‘young adult,’ made a major contribution to developmental theory with his conception of eight critical stages in development, each marked by unique identity conflicts (Bocknek, 1980). These periods are structured in terms of opposing psychosocial conflicts that individuals face in their continuing personality development (Erikson, 1982). A conflict is specific to a particular life stage and must be resolved if the individual is to achieve appropriate developmental growth. In Erikson’s theory, the core issue of young adulthood is intimacy versus isolation. Intimacy refers to the ability to develop close interpersonal relationships, while isolation refers to the potential for remaining unconnected and for viewing others as alien and dangerous (Erikson, 1982). It is difficult to translate Erikson’s abstract idea of psychic conflict into concrete developmental tasks, but his model raises the question of whether it is necessary to resolve certain developmental goals at a particular phase in the life course.

Thomas and Kuh (1982) offer a composite framework of early adult development that combines the works of three popular theorists from the seventies. In this model, the stage from age 22-28 is termed “novice adulthood” (Thomas & Kuh, 1982). The authors highlight the key developmental tasks of this stage. Novice adults must identify life goals and form relationships with people who are supportive of these objectives. During this stage, young adults are actively pursuing the “one right way to be,” (Thomas & Kuh, 1982) as guided by family and societal expectations. Novice adults are torn between their conflicting needs for intimacy and for experimentation. During these years, personal and career goals are identified, and adults establish a home base separate from family of
origin. While it was published over 20 years ago, overall, Thomas and Kuh’s (1982) description of novice adulthood remains pertinent today.

Fulmer (1999) offers a more recent definition of young adulthood. He explains that economic trends have a strong impact on the ability of young people to support themselves financially, and that decreases in real wages and increases in education requirements mean that young adults are taking longer to become self-supporting. The term “economic adolescence” has been used to describe a period of employment without being able to support a family (Fulmer, 1999). Although the majority of young adults leave home during these years, it has become more common for young adults to return to the family home after living away. Young adults of all socio-economic backgrounds continue to depend on their parents for tangible and emotional support as they “prepare for productivity” (Fulmer, 1999). In terms of relationships, Fulmer proposes that young adults must learn to become as attached to a few select others as they are to their family members. At this time, young women are more likely than young men to feel a sense of continued obligation to their families. Fulmer’s economic perspective illustrates the need for young adults to receive ongoing practical support from their parents, and highlights how developmental norms reflect larger socio-economic variables.

Similar to Fulmer (1999), Shulman and Ben-Artzi (2003) distinguish between achieving “psychological” and “practical” independence. In previous decades, achievements associated with adulthood, such as marriage and economic self-sufficiency, occurred earlier in the life cycle. A sense of “psychological” independence was linked to and driven by these “practical” markers of adult status (Shulman & Ben-Artzi, 2003). Today, the elongation of the transition to adulthood means that these developmental
accomplishments can occur independently, rather than driving one another. A study with Israeli teens and young adults found that the psychological aspects of adult status, such as competent decision making, were deemed by participants to be more important than practical aspects of independence, such as financial self-sufficiency. These findings are encouraging in the context of parental cancer because they suggest that young adults can obtain a sense of adult status even if the achievement of practical markers of adulthood is delayed.

McGoldrick and Carter (1999) define early adulthood as approximately age 21 to 35. They propose a number of tasks to be addressed during these years. Young adults must increase their abilities to care for themselves, develop awareness of their own sexuality, acquire discipline for work and relationships, and learn to focus life goals. McGoldrick and Carter (1999) state that during this developmental stage, young adults must continue to negotiate evolving relationships with their parents and families, increase their abilities to nurture others physically and emotionally, and develop the skills to support their own children. The authors provide a current and wide-ranging definition of early adulthood; however, their proposed age range seems overly broad. As well, this model does not give enough weight to the changing nature of young adults' relationships with their parents or to the implications of leaving home.

Arnett (2000) introduces the concept of "emerging adulthood," which he defines as the years between ages 18 and 25. In the industrialized world, broad demographic changes over the past decades have transformed late adolescence and the early twenties from a brief period of transition into adult roles into a distinct phase of development. Arnett (2000) describes these years as the most "volitional" period of life, marked by
relative independence from social roles and normative expectations. In fact, heterogeneity can be viewed as a characteristic of this age period. For most people, emerging adulthood is a period of variability; through exploration of life possibilities most gradually arrive at lasting decisions in work, relationships and worldviews. Arnett advises that this period is culturally constructed and not all young people have opportunities for exploration of available options. Arnett’s conception of emergent adulthood contrasts with the model developed by Thomas and Kuh (1982) who propose these years are guided by social expectations.

Reflecting changes in economic, demographic, and educational trends over the past decades, young people are taking longer to become financially independent, and most are delaying marriage and parenthood. Consequently, young adulthood has emerged as an increasingly significant developmental stage. To summarize the commonalities from the previous theories, the developmental goals of young adulthood are to: delineate life and career goals, become independent and self supporting, develop intimate relationships external to the family of origin, and establish one’s own home. During this stage, relationships with parents continue to evolve, and young adults benefit from the ongoing support provided by a stable family of origin.

*Off-Time Illness*

Somewhere in the forties, social conversations begin to include the question ‘Are your parents still living?’ We do not ask people in their twenties. (Hagestad, 1996, pp. 215)

Parental illness during young adulthood is disruptive because it occurs “off-time.” As Rolland (1999) explains, when illnesses happen earlier in the lifecycle, they can interfere with the possibilities for meeting normal developmental goals. Hagestad (1996)
elaborates on this concept when she discusses how her experience of cancer revealed the socio-cultural construction of time. She explains that humans have a fundamental need for predictability and continuity, finding it extremely trying to live with uncertainty. In Western countries, the expectation of an 80-year lifespan has become a map for the anticipated life course. When facing a life threatening illness, individuals (and their family members) are forced to give up the illusion of a predictable future (Hagestad, 1996). In future-oriented societies, the perceived loss of a future can make it difficult to live in the present.

*Cancer and the Family*

In the past two decades, strong evidence has emerged documenting the dramatic impact of cancer on the family. Lewis (1986), a pioneering and prolific researcher in this area, identifies 11 separate stressors for families dealing with parental cancer. Emotional strain is highly prevalent with a cancer diagnosis, and family members commonly report feelings of anxiety, fear, anger, helplessness and injustice (Lewis, 1986). The physical demands of care provision can cause stress, sleep loss, and health problems for caregivers; feeling unable to physically help the patient contributes to a sense of powerlessness. Lifestyle and role changes often result in significant stress for family members, especially in the case of parental illness. A sense of uncertainty about the prognosis, recurrence, and the course of the disease can overwhelm a family, especially early in the diagnosis and at advanced stages of the disease. Living with this lack of certainty threatens the family’s sense of control, and regardless of the stage of cancer, families are fearful of the patient dying (Lewis, 1986). The diagnosis of cancer in a family member often raises a sense of personal vulnerability and existential concerns for
other family members, especially adult children (Lewis, 1986). Other problems experienced by families may include financial concerns, a lack of knowledge about support services, sexuality changes, and conflicting needs between family members and the ill individual.

Leedham and Meyerowitz (1999) explain that cancer is a unique stressor for many of the reasons identified by Lewis (1986), but also because of the hereditary nature of some cancers and the intensive and invasive nature of the treatment. Cancer also may result in the progressive deterioration of quality of life.

Lewis, Hammond and Wood (1993) developed an explanatory model to describe the effects of maternal breast cancer on family functioning. In a later work, Lewis (1996) describes the outcomes of four studies that tested this model. She and her colleagues found a recurring pattern of results that were consistent with their theoretical model. The pattern is as follows: higher levels of illness demands increased depressed mood in the mother which negatively affected the quality of marital relationships. This led to decreased coping behaviour in the parents and an overall decline in household functioning. While this model focuses on families with young children and adolescents, it is helpful in illustrating the systemic effects of cancer on the family and sheds light on the mechanisms of the disruption.

Veach et al. (2002) discuss the impact of cancer on families at different stages of the lifecycle, and contribute to the small body of literature that examines the impact of cancer on families launching children. During this time, families are changing dramatically, and the crisis of cancer presents a direct conflict to the developmental goals of this phase in the family life cycle. Adult children may have to alter their life plans. If
children decide not to leave home, or to return home, the authors caution that developmental delay can occur. Additionally, as illness progresses, cancer can become embedded in the family system. If developmental tasks are not resumed after crisis periods, development can be further stalled. Throughout different stages of illness, young adults may struggle to balance their own developmental needs for independence, and the needs of their families.

Due to increased awareness and research interest over the past few decades, it is now widely acknowledged that a cancer diagnosis represents an emotional crisis for all family members (Wellisch, 1998), and that cancer impacts the functioning of a family in many capacities.

*Parental Cancer: Impact on Children*

A growing body of research describes the impact of parental cancer on children. The majority of the literature addresses the psychological impact on school-age children and adolescents. Of the few studies that included young adults, two are related (Compas et al., 1994; Compas et al., 1996). The first study by Compas et al. (1994) measured markers of psychological distress in cancer patients and their family members. This cross-sectional study included cancer patients, their spouses, and their young adult, adolescent, or pre-adolescent children. The findings revealed that levels of psychological symptoms in the children of cancer patients depended on the ages and genders of the children, and whether it was their mothers or fathers who were ill. Anxiety and depression symptoms were higher for young adults and adolescents than for children, which likely reflects developmental differences in stress responses, as well as a possible response bias among younger children. For adolescents and young adults, stress
symptoms were greatest for daughters who had ill mothers and for sons who had ill fathers. The highest levels of distress were measured in adolescent daughters whose mothers were ill, although one third of young adult women also reported significant levels of distress.

The second study is also a cross-sectional study and examined the relationship between cognitive appraisals, coping strategies and psychological distress in children whose parents have cancer (Compas et al., 1996). In traditional models of coping, a perception of control is equated with more positive coping (Compas et al., 1996). Regardless of age, children in this study perceived very little control over their parents’ illnesses. This study aimed to identify whether children used problem-focused coping or emotion-focused coping strategies in response to their parent’s illness. Adolescents and young adults were more likely to use emotion-focused coping strategies, such as avoidance, than were preadolescents. This finding is troubling as emotion-focused coping strategies are considered to be relatively ineffective in managing emotional distress, and are associated with greater symptoms of anxiety and depression (Compas et al., 1996).

While these previous studies represent an important contribution to the field, the cross-sectional nature of these studies provides little understanding into the distinct problems faced by each age group. These studies may have been more useful had they focused on a specific age group, as opposed to a cross-sectional design. As well, the second study raises questions about the utility of distinguishing between problem-focused and emotion-focused coping without more attention paid to the context and purpose of these strategies.
These previous studies are a sample of the increasing body of research exploring the impact of parental cancer on the children. More research is needed both to understand the lived experience of children and the specific complications of parental illness for young adult children.

**Impact on Daughters**

Many studies have shown that cancer impacts children differently depending on their gender, and the research indicates that daughters generally experience more distress than sons in response to parental cancer (Compas et al., 1994; Faulkner & Davey, 2002; Leedham & Meyerowitz, 1999; Spira & Kenemore, 2000). A number of studies have examined the impact of breast cancer on daughters; because of the potential for inheriting breast cancer risk, daughters express concerns about their own susceptibility to the disease (Faulkner & Davey, 2002; Spira & Kenemore, 2000). Spira and Kenemore (2000) interviewed adolescent girls whose mothers had breast cancer. The participants expressed fears about recurrence of their mothers’ disease and the loss of their mothers. The adolescent girls were also apprehensive about their own physical and sexual development in light of their mothers’ diagnoses.

Role changes precipitated by parental illness can cause a great deal of anxiety for everyone in a family, but especially for daughters, who are most likely to take on a caregiving role (McGoldrick & Walsh, 1999; Spira & Kenemore, 2000). In addition to caring for the parent with cancer, daughters often take on the responsibilities of the ill parent, which may include caring for other children and family members (Edelman, 1994; McGoldrick & Walsh, 1999). Adolescent girls find themselves torn between their desires to support and spend time with their mothers, and their developmental needs to separate
from their families (Faulkner & Davey, 2002). As well, girls at this age have difficulty managing their feelings of anger and resentment.

Maternal cancer has been found to impact daughters to the extent that they develop symptoms of post-traumatic stress disorder (PTSD) (Boyer et al., 2002). Although their study of PTSD is quite technical in nature, Boyer et al. highlight the traumatic nature of the illness. They found that 92% of women with cancer and 94% of their daughters viewed breast cancer as a trauma. Of adolescent and adult daughters participating in the research, 13% had symptoms of PTSD, while 85% percent of daughters met criteria for two out of three PTSD diagnostic symptom clusters.

A retrospective, cross-sectional study by Wellisch, Gritz, Schain, Wang and Siau (1992) measured psychological and emotional functioning, and health care behaviours in a sample of women whose mothers had been diagnosed with breast cancer. The study included women who were children, adolescents and adults at the time of their mothers’ diagnoses. Half of the women’s mothers had died from the disease. Across all comparison groups, daughters shared the common perception that their mothers’ cancers had altered their life plans. The authors suggest that lack of emotional resolution around this issue may further influence daughters’ life plans. At the developmental level, adolescents and children may develop a problematic self-representation as they integrate the image of their ill and potentially dying mothers into their own emerging senses of self. This issue would likely be less significant for young adults or adults who have a more developed self-concept. For adolescents who are undergoing physical maturation at the time of their mothers illness, sexual development may become associated with illness or death. This research identified adolescent daughters of mothers
who died of breast cancer to have the highest risk of adverse emotional outcomes and psychological distress later in life.

In a later chapter focusing on the psychological well-being of women with a strong hereditary risk for breast cancer, Wellisch, Hoffman and Gritz (1996) emphasize that the needs of daughters of breast cancer patients have been significantly under-addressed, given the significant size of this population. In general, the psychological functioning of high risk women is considered to be adequate, and these women revealed a tendency towards incorrectly estimating their own risk for the disease. This chapter focuses on a highly specific population but highlights the lasting impact maternal breast cancer can have on daughters.

In their related retrospective studies, Leedham and Meyerowitz (1999), examine whether women who were adolescents when their parents were diagnosed with cancer experience a lasting impact in adulthood. All study participants recalled strong negative reactions to their parents’ diagnoses and significant family difficulties. Unexpectedly, these difficulties were often in their relationships with their healthy parents. Nearly all the participants reported eventual positive changes in their general outlooks, social relationships and attitudes towards cancer. The authors remark that many of these changes were too subtle to be reflected in psychological measures, which provides support for a qualitative methodology in future research. These studies found that negative effects tended to be of a short duration, and that parental cancer does not appear to cause later psychological problems. This finding contrasts with the work of Wellisch et al (1992) that indicates adolescent daughters of breast cancer patients are at the highest risk of later psychological difficulties. While Leedham and Meyerowitz (1999) provide...
considerable insight into long-term adjustment to parental cancer, a retrospective interview provides a different perspective on the experience than an interview conducted during the illness.

This research reveals that parental cancer, especially in the mother, has a significant impact on adolescent and adult daughters. The increased distress in daughters seems to relate to their care-giving obligations and to fears about their own susceptibility to cancer. More inquiry is needed to shed light on why parental illness leads daughters to experience more distress than sons, or whether daughters and sons simply express distress differently.

The Impact of Parental Illness and Loss During Young Adulthood

Surprisingly, the literature about death and the family provides the most insight of the experience of living with serious parental illness as a young adult. In my opinion, Edelman's (1994) influential book *Motherless Daughters* provides the most accurate portrayal of the interaction between parental illness and developmental stage. This book is based on interviews and surveys with women whose mothers have died. The work is highly relevant to a discussion of cancer because, depending on the diagnosis, the death of the parent from the disease is either anticipated or a definite possibility. Edelman portrays the experiences and consequences of mother loss at different developmental stages.

During young adulthood (the twenties), a successful launch from home depends on having a secure base to return to in times of stress (Edelman, 1994). When a woman loses her mother (or her mother becomes seriously ill) at this time, “it touches every

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1 This perception may be skewed by my own experience of parental cancer and, as a consequence, may not be representative of the experiences of other young adults who have a parent with cancer.
base" (Edelman, 1994, pp. 55). In young adulthood, a daughter is often in the process of moving out and beginning a career, but she may have to return to her family home to take on caregiving responsibilities. Although she is no longer dependent on her mother physically, she continues to need emotional support. Loss at this stage is challenging because young adult daughters have the capacity to anticipate future losses: “twentysomething daughters often leap ahead to imagine the secondary losses—no one to help plan a wedding, no one to consult about child rearing, no grandmother for the kids—they envision as long-term effects of mother loss” (Edelman, 1994, pp. 58). Edelman provides considerable insight into the lived experience of coping with parental illness or loss for women in their twenties.

In their chapter examining the consequences of death at different stages in the family life cycle, McGoldrick and Walsh (1999) emphasize the significance of parental illness/loss during young adulthood:

It is remarkable that so little attention is given to the impact of loss in young adulthood...given the tendency in our society to deny the importance of family ties at this phase, the impact of loss of a parent for young adults may be underestimated by them, their families, their friends and even their therapists. (McGoldrick & Walsh, 1999, pp. 188-189)

The authors outline a number of reasons terminal parental illness can be particularly challenging for young adult children. At this time, the young adults have often moved away from home and are invested in developing careers and intimate relationships. As a result, they are conflicted between their own aspirations and their sense of obligation to their families. Illness may lead parents to become more dependent on their adult children which can be threatening and frightening to young adults still establishing their own self identities. Another source of concern results when young adults are forced to abandon or
put on hold their life goals to care for family members. McGoldrick and Walsh propose that prolonged caregiving can prevent forward developmental progress. In this chapter, the authors clearly illustrate the concrete consequences of parental illness or loss for young adult children.

**Conclusion and Research Question**

Rolland’s (1999) Family Systems-Illness Model provides a useful framework for conceptualizing the impact of parental illness on a family, especially in terms of the interactions between the illness and the developmental stage of family members. Although there is some disagreement about the exact age range of young adulthood, it is a time period when individuals usually develop intimate relationships, become more independent and self-sufficient, and establish a home and a career. Parental illness can be particularly disruptive at this time because it is so unexpected—it is occurring “off-time.” Strong evidence documents the profound impact of cancer on the family. While research into the specific effects of parental cancer on children is increasing, there is a paucity of research examining how parental cancer influences young adult children. A significant amount of research indicates that parental cancer causes more distress in daughters, but more inquiry is needed into this area.

The purpose of my study is to illuminate the lived experience of young women who are coping with parental cancer. My specific research question is: **how do young adult women experience a parent’s cancer diagnosis and treatment?**
Methods

Methodological Approach

An experience of loss shatters the meaningful world people have assembled for themselves. Often, we have a strong desire to understand, manage, and recover by creating an account that makes sense of loss and puts the pieces back together. (Ellis, 1998, pp. 49-50)

Carolyn Ellis, a preeminent writer of autoethnographic inquiry, captures the desire of many individuals to make sense out of emotional life events. My research question arose directly out of my own desire to understand and find meaning in my experience of my mother's cancer. In doing this research, I hoped to explore my own story as well as the experiences of other young adult women in similar circumstances. When I began planning this project, I was uncertain how to situate myself in my research. Reading Ellis’ work on autoethnographic inquiry (Ellis, 1995; Ellis, 1998; Ellis & Berger, 2003) encouraged me that personal experiences were a legitimate focus for academic inquiry, and she offered a methodology that allowed me to genuinely and meaningfully include myself in the research.

An autoethnographic approach is often used for loss or illness narratives, and these narratives frequently begin with the personal experiences of the researchers (Ellis, 1998). This mode of inquiry combines the autobiographical “gaze inward” with the ethnographic “gaze outward” (Neumann, 1996, p. 173). Uniquely suited to my research goals, this approach “blurs distinctions between…the researcher and the subject,” and allows the researcher to “occupy the dual interactive roles of researcher and research participant” (Ellis, 1998, p. 49).

Various approaches to interviewing are consistent with an autoethnographic approach. Collectively, these approaches are referred to as “collaborative interviews”
(Ellis & Berger, 2003). The interview types relevant to my research goals are reflexive dyadic interviewing and interactive interviewing. In a reflexive dyadic interview, the researcher asks the participant prepared questions on a specific subject area. This format is unique because the interviewer discloses her personal experiences related to the subject being discussed, and she shares her perspectives on the interview process. An interactive interview usually takes place in a small group in which the primary researcher acts as both the researcher and as a research participant. In this format, each participant is given space to share her story and all stories are given equal weight in the analysis. Attention is also given to the emerging relationships between the participants. My interview format combined elements of both interview formats. Similar to a reflexive format, my interviews occurred in dyads, and I shared my thoughts on the prepared topics for discussion. Consistent with an interactive format, I took an active role in the interviews and included my contributions in the analysis.

Prior to initiating this research project, I had met other young women who also had a parent living with cancer. In these conversations I found understanding and connection. I hoped to establish this atmosphere in an interview setting. Collaborative approaches to interviewing reflect the dynamics of relationships:

As conversations where one person’s disclosure and self-probing invite another’s disclosures and self-probing; where an increasingly intimate and trusting context makes it possible to reveal more of ourselves and to probe deeper into another’s feelings and thoughts; where listening to and asking questions about another’s plight lead to greater understanding of one’s own; and where examination and comparison of experience offer new insights into both lives. (Ellis, 1998, p. 58)

This interview methodology allowed for natural and conversational interviews. By sharing my personal experiences, I minimized some of the power differences often embedded in a typical interview relationship. Additionally, creating an interview situation
that could be beneficial to my co-investigators\(^2\) was a central concern in my research design. Participating in collaborative interviews has been found to have positive therapeutic benefits for both the researcher and the research participants (Ellis & Berger, 2003).

Research that includes personal accounts of the investigator has been denounced for lacking academic merit. Ellis’ account of her partner’s death from emphysema, *Final Negotiations: A story of love, loss, and chronic illness* (1995) was criticized as “self-therapy” (p. 308), and often rejected as “therapeutic” (p. 308) rather than academic. Ellis challenged this dichotomy, arguing that personal accounts *could* possess intellectual value and substance, explaining that the “therapeutic and scholarly” are not “mutually exclusive” (Ellis, 1995, p. 308). While non-traditional approaches to academic inquiry should continue to be developed, utilized and defended, researching personal topics is not a substitute for professional, therapeutic support. Consequently, these approaches demand increased self-awareness from the researchers. The researcher must acknowledge the distinction between the therapeutic aspects of research and psychotherapy.

As the researcher, I recognized the importance of developing self-awareness before conducting this type of research. Attending regular counselling sessions prior to and throughout the research process contributed to my abilities to approach this personal topic with academic rigor. Because my counsellor specializes in the area of cancer and the family, I was able to discuss issues that arose during this research process and receive input on methodological issues. Counselling has provided me with insight into and

\(^2\) The term ‘co-investigator’ is an alternative to ‘participant’ and acknowledges the participant’s active role in creating data in a qualitative interview. As well, it suggests an ongoing dialogue between the researcher and her participant (e.g. Hermans & Bonarius, 1991).
awareness of my own experiences, and has allowed me to recognize which aspects of my experience were appropriate to disclose during the interviews.

**Sampling**

An illustrative or evocative sampling approach was used to select study participants. A statistically representative sample and broadly generalizable data are not the intended outcomes of this sampling approach. Instead, this sampling strategy seeks to provide a “flavour” (Mason, 2002) of the phenomenon being examined. In this study, I intended to capture the stories of a small selection of young adults who are living with parental cancer.

The age range of study participants was significant because my research question addresses a specific developmental stage. While no consensus has been reached regarding the age range that constitutes young adulthood, I limited my sample to participants who were between the ages of 20 and 29 when they received news of their parents’ cancer diagnoses or recurrence. This age range is consistent with most definitions of young adulthood.

To capture the everyday experience of a parent’s cancer, I gave preference to participants whose parents were currently undergoing cancer treatment. To ensure a sufficient number of participants, I accepted women whose parents had received treatment within the past five years. While I did not distinguish between types of cancer or the severity (staging) of the illness, all of the women who took part in the study or who expressed interest in participating had parents with advanced forms of cancer. This likely reflects the greater impact of more serious disease. Daughter’s caregiving roles and their level of involvement with their parent’s illness were not specified. Bereaved participants
were excluded from this study because this presents issues distinct from those explored here. Women unable to converse fluently in English or unable to provide informed consent were excluded from participation in this study.

Participants

A total of five women, including myself, participated in this study. All participants lived in the Greater Vancouver area. Details about the participants' characteristics are summarized in Table 1, and brief descriptions of the participants follow. Pseudonyms have been used to maintain the anonymity of the participants, with the exception of myself, the researcher.

Table 1: Characteristics of Participants and their Parents (N=5)

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age at interview</th>
<th>Parent with cancer</th>
<th>Age at parent’s diagnosis/recurrence</th>
<th>Parent’s diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amanda</td>
<td>21</td>
<td>Mother</td>
<td>16/20</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>Kate</td>
<td>32</td>
<td>Mother, Father</td>
<td>27</td>
<td>Lymphoma</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>32</td>
<td>Lymphoma</td>
</tr>
<tr>
<td>Melissa</td>
<td>24</td>
<td>Mother</td>
<td>21/23</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>Rachel</td>
<td>26</td>
<td>Father</td>
<td>22</td>
<td>Kidney cancer</td>
</tr>
<tr>
<td>Jenny</td>
<td>24   (researcher)</td>
<td>Mother</td>
<td>21</td>
<td>Breast cancer</td>
</tr>
</tbody>
</table>

Amanda

Amanda was finishing grade 11 when her mother was first diagnosed with breast cancer. The same day that her mother was diagnosed, her grandmother was diagnosed with a recurrence of breast cancer. While Amanda’s mother went into remission, her grandmother died of the disease after three years of treatment. A few months after her grandmother passed away, Amanda’s mother experienced a recurrence of cancer. At the time of the interview, her mother was still being treated for the disease and Amanda was living with her mother and step-father, on leave from post-secondary studies. She was
planning to begin a nursing program in the near future. Amanda identified herself as a practicing Christian. Since the interview, her mother's health has deteriorated.

Kate

When her mother began having health problems, Kate was 27 and living with her parents. She had just finished her teaching degree and begun her first teaching job. After seven months and a number of misdiagnoses, Kate’s mother was diagnosed with lymphoma. While Kate’s mother is now in remission, Kate feels her mother’s personality changed as a result of her treatment for brain metastasis. At the time of the interview, Kate was living with her long-term boyfriend and completing her Master’s degree in education. A month or two prior to the interview, her father was diagnosed with lymphoma and he had recently begun treatment. Kate identified herself as Christian but was not particularly observant. Her father’s current health is unknown.

Melissa

Melissa was 21 when her mother was first diagnosed with breast cancer. At the time, she was in her fourth year of her undergraduate program and living with her mother and step-father. Initially, Melissa’s mother responded well to treatment. However, the cancer returned last summer. At the time of the interview, Melissa was living with her boyfriend and working full-time. She had just learned that her mother’s cancer had metastasized. Melissa’s mother’s health continued to deteriorate, and she died two months after the interview. Melissa is exploring her religious beliefs.

Rachel

Rachel was 22 when a tumor was found in her father’s kidney. He was diagnosed with metastatic cancer. At the time, she was running her own business and in a long-term
relationship. Shortly after his diagnosis, her relationship ended and her business collapsed. While Rachel did not live with her father, at one point during his illness, her father moved in with her, leading to severe financial difficulties. At the time of the interview, Rachel was in a new relationship and working full-time. Rachel identified herself as Jewish. Her father has died since the interview.

Jenny

When my mother was diagnosed with breast cancer, I was in the final year of my undergraduate degree and had recently moved back to my family home after a few years away. Shortly after my mother’s initial diagnosis, liver and bone metastases were identified. I spent the first year of my mother’s illness in Toronto for graduate school. After the first year, I took leave from that program and returned to Vancouver to be with my family. I am completing my degree in Vancouver. Despite a brain metastasis last fall, my mother continues to respond well to her treatment. I am Jewish and moderately observant.

Interview Procedures

After receiving ethical approval from the Behavioural Research Ethics Board at the University of British Columbia, I began recruiting participants for this study through posters in the British Columbia Cancer Agency and through word-of-mouth. Potential participants initiated contact with me by email or telephone. After ensuring that they met the participation criteria, I explained consent procedures and introduced my interactive interview format. When a potential participant agreed to take part in the study, interviews were arranged at the time and place of her choosing. The participants provided consent before the interviews began.
After discussing interview procedures in more detail and answering any questions, I began interview sessions by explaining that the topics for discussion (see Appendix 1) arose from my own experience of parental cancer and reflected areas I hoped to explore. This served to locate myself as both a researcher and a participant.

While I provided my co-investigators with the choice to begin with their stories, all chose to hear about my experiences first. Consistent with an autoethnographic approach, the interviews were designed to be relatively unstructured and conversational in nature. In addition to asking direct questions, my interview format used self-disclosure to prompt participants and to introduce topics. I believe my self-disclosure allowed me to develop a genuine rapport with participants, increased the richness of my data, and served to provide transparency about aspects of my experience which guided my interpretation of the data.

The majority of interviews lasted approximately 90 minutes. With the permission of the participants, each interview was tape recorded and transcribed in its entirety. I was not interviewed separately (i.e. I was not asked the questions I had prepared by another interviewer), as a separate interview was not indicated by my methodology, and my disclosure during the interviews was sufficient to capture my experiences. All quotations that are discussed later in this thesis, including mine, were taken from these transcribed interviews.

Data Analysis

While Ellis (1995, 1998; Ellis & Berger, 2003) writes extensively on creating data through interactive interview formats, she provides less instruction on analyzing the data created in these contexts. Consequently, my approach to data analysis borrows from the
categorical content perspective, with awareness paid to the role of my participation in the interviews and to the dynamics of the conversations. Content analysis “focuses on the content of narratives as manifested in separate parts of the story” (Lielbich, Toval-Mashiach, & Zilber, 1998, p.16) with less emphasis placed on the story as a whole. The goal of analysis is to create themes or categories that capture patterns across the data (Merriam, 1998). While developing themes is “largely an intuitive processes” (Merriam, 1998, p. 179), the study’s purpose, the researcher’s theoretical framework and the content of the data all guide the development of themes. Merriam (1998) emphasizes that creating categories is data analysis, and this analysis occurs concurrently with data collection. In fact, the “simultaneous collection and analysis of data whereby both mutually shape each other” (Sandelowski, 2000, p. 338) is a defining attribute of qualitative research.

While I informally analyzed data throughout the interview process, I began formal data analysis with thorough readings of the transcribed interviews. I highlighted recurrent and particularly salient statements. Through comparison within and between transcripts, I began to identify recurring topics of discussion. Next, I grouped related statements under broad categories and reorganized the statements within the categories to generate sub-themes. From this process, I defined themes that seemed to capture the experience of parental cancer.

Consistent with an interactive interview format (Ellis, 1998), my experiences as they were shared during the interviews are included in this analysis. I analyzed my contributions the same way I evaluated the words of other participants. I aimed to identify themes represented across the data rather those that were exclusive to my experience. However, creating categories is a subjective experience (Merriam, 1998); the
categories I identified were inevitably influenced by my own experiences and the theoretical perspectives that informed my research design.

Validity

Due to the nature of qualitative research, validity cannot be determined through objective measures or statistical tests. According to Maxwell (1996), the key to developing rigor in qualitative research is to identify the potential validity threats before beginning data collection. Prior to beginning interviews, I identified my own emotional investment in the research topic as the most significant threat to validity. To address this threat, before beginning data collection I made my motivations for doing this research explicit, and I considered some of the ways in which my own experiences could influence my findings.

Data analysis is an interpretive process; however, the validity of data analysis is threatened when a researcher imposes her own interpretation on the data without understanding the meanings expressed by the participants (Maxwell, 1996). I recognize that in the context of qualitative research, the collected data always represents the product of the interactions between the researcher and the participants. In a collaborative interview, this co-creation of knowledge is explicitly acknowledged in the methodology. Throughout this research, I have reflected on the process of participating in and analyzing this data. Being aware of my own assumptions and the meanings I have ascribed to my experiences are steps to address these validity threats. My biases should become apparent because I interpreted my own story alongside my participant’s words. Including my own experiences in my analysis forced me to deliberately acknowledge similarities and discrepancies between my story and my co-investigators’ stories.
Member checking, the process of requesting a participant's feedback regarding data and research findings, is extremely important in assuring that participants' meanings have not been misinterpreted (Maxwell, 1996). My interactive interview format addresses some of the potential for misinterpretation because the participant acquires a more active role in the interview process. Once I completed data analysis, I summarized my findings and emailed or delivered this information to participants, soliciting feedback. Two participants provided input on the findings. Both agreed that the themes I had identified accurately captured their experiences. One participant asked to review which excerpts of her interview I used in the analysis. I shared a draft of my findings with her and she was satisfied with how I had used and interpreted her words. The other responded that her mother's health had deteriorated significantly since our interview and that the issues of time and self-care had recently become more relevant to her. A third participant was unable to provide feedback due to a personal illness, and I was unable to contact the final participant.
Findings

A diverse range of issues were discussed by participants. From the interview data, six main themes and numerous sub-themes emerged. The themes are (1) time, (2) the meaning of cancer, (3) coping, (4) relationships and interaction, (5) family relationships and (6) spirituality and hope. The themes can be further grouped into two broad categories: abstract ideas and concrete issues. The more abstract ideas encompass the concept of time, the meaning of cancer and spirituality. The concrete issues include discussion of relationships, both within the family and external to the family, and the issues related to coping. For the purpose of this section and the discussion section, rather than further divide the themes into these two broad concepts, I sequenced the themes to capture the actual experience of parental cancer: these abstract and concrete issues are not separate, rather they are entwined and integrated. Together these themes create a powerful picture of the complex experience of parental cancer for young adult daughters.

The quotations in the following sections are taken directly from the transcribed interviews. When necessary, these excerpts have been slightly edited for clarity and conciseness.

Time

Time was revealed as a central theme in the interviews, and was represented in both abstract and more concrete forms. Sub-themes under time include (1) unexpected timing, (2) uncertainty/waiting, (3) being present, (4) concerns for future, (5) acceleration of time, (6) illness progression and (7) holidays. Most of these sub-themes were discussed at various points in the interviews.
Unexpected timing

The unexpectedness of critical parental illness during young adulthood was a prominent sub-theme in the time category. All of the women interviewed recalled feelings of shock when they learned of their parents’ diagnoses. Participants describe this as a time of “chaos,” a “blur,” and even as “ground zero.” From the moment of diagnosis, time was disrupted—as Melissa explained: “Time stopped for like two weeks and I was just a ball of tears, just like the entire two weeks.” Most of the participants discussed the timing of their parents’ diagnoses in comparison to the expected timing of serious parental illness.

I think losing a parent is hard on anyone regardless of what age they are...I think it’s difficult to deal with it whenever, but I think it’s easier to deal with it when you’re in your forties, because it’s expected. Like, your parents are old! They’re supposed to die when they’re old. But because we’re so young, there’s still so many things that haven’t happened in our life that our parents are supposed to be a part of. (Melissa)

Rachel too found herself unprepared to be dealing with her father’s cancer.

Most of my friends were, and still are, in their mid to late thirties, early forties. But still they had never dealt with this before, I mean it just usually doesn’t happen until you’re married and have kids of your own and you’re in your early fifties and your parents are in their mid seventies...(Rachel)

Uncertainty/Waiting

The challenge of living with uncertainty is a predominant sub-theme under time, and possibly even defines the experience of having a family member with cancer. This category reveals how cancer disrupts the sense of a predictable future and in turn, the ability to make plans:

I guess the uncertainty is the hardest part because that means you can’t plan anything...I can’t think beyond a couple weeks or a month, because I just don’t know where I’m going to be or what [will be] happening. (Jenny)
The uncertainty pertaining to a parent’s health made a few participants feel as if their lives were on hold:

Like I said before, it feels like a lot of stuff that you should be going forward with in your life gets a little bit—even though I keep denying it—gets kind of put on hold, or at least there’s always a question about how it’s going to go. (Kate)

For participants, such as myself, whose parents had advanced forms of cancer, more than one expressed a strong desire for any sort of structure or certainty, even if it meant knowing when their parent would die:

I’ve sort of started to feel like if somebody could have just have given us a date, said your mom’s gonna live 3 years, make the most of it. Your mom’s gonna live 1 year. Your mom’s gonna live 6 months. But it’s just, preparing for her not to be alive, and for it to keep going for so long, it’s just such a draining place to be in. (Jenny)

Rachel, whose father’s health was deteriorating rapidly at the time of the interview, expresses her need for any predictability.

My dad has just been in such a precarious situation for the last few weeks, it’s totally been occupying all my time...I’m really thinking how long can this go on for. Like how long? Cause kinda you have to think about yourself too. It’s terrible, terrible...I just pulled his oncologist aside...I said like how long? Like weeks?...she was like it’s a matter of weeks. At the rate he’s going down it could be as quickly as 2, 3, 6, maybe if we stabilize him in some way he could go for like 8, maybe 10. And in a way, I was almost relieved because at least I had some definition in my life. You know my contract ends here at the end of March. They want to give me another job...when can I start this job? Do I start April 1st? Do I start May 1st? You know. I’ll take a week off for shiva and I’ll take another week to clear out my dad’s apartment. And like now I’m just going to start and take 3 weeks off? So at least like having that window of time was like there’s an end date for the relationship with my father and a start date to the rest of my life. Everything that I’ve been neglecting, unable to commit to, I’ll really live fully. (Rachel)

Rachel’s words reveal the numerous ways time plays a roll in the experience of illness.

Inherent in living with uncertainty is the sense of waiting for something to

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3 The weeklong Jewish ritual of mourning immediately following a death.
happen, the feeling of being in limbo. As Rachel explains: “You never know when they
are going to take a turn for the worse.” Kate describes the challenge of not knowing what
to expect:

I want to know either way...Like, you talked about all the waiting. I just want [to]
know if he’s going to die, OK, we can prepare for that. If he’s not, awesome, we
can all relax and I don’t have to feel guilty about stuff anymore. (Kate)

Rachel reveals that the anticipation of what might happen can be terrifying: “He’s
just going down so quickly and...I have no idea who I’m going to have to be and what
I’m going to have to do. No idea! And that’s really scary.” In light of this uncertainty,
when something happens, even if it is illness progression, it can feel like a relief:

We found out in November that she had a brain tumor, and in some weird way it
was this strange feeling of relief because...it was that limbo you talked about
before, [those are] exactly the word[s] I’ve used, living in limbo, like everything
is overshadowed by this. That whole year I was [away for school], I was waiting
for that phone call ‘Jenny, you need to come home.’ Like that whole year,
and...when [they found the brain tumour] it was kind of like, something’s
happening! In a weird way, it was this bizarre sense of relief... (Jenny)

When illness is prolonged, uncertainty becomes the norm:

I’ve gotten so used to uncertainty. Like, uncertainty is normal now for me...And I
guess life is always uncertain, you know? We just had this illusion of having more
certainty at some other point. (Jenny)

Being present

The sub-theme of being present, rather than future-oriented, was expressed as
both a coping mechanism and as a challenge. Amanda explains how learning to be
present-focused and developing appreciation for the present are positive outcomes of her
mother’s illness:

I think it just sort of makes you appreciate living more. I mean obviously I have
days where I lose that perspective, but yeah, it makes you appreciate the small
things in life, just like...the uncertainty of life for everybody, really. I mean, you
never really know what’s going to happen. You’re not invincible. You’re not here forever. (Amanda)

Amanda is thankful for the time she does have with her mother.

You want to just be thankful that you have this time that you have, however long it is. You know, if it’s six months or ten years, you have time. And to just appreciate that time, and get the most out of it...especially if you know that you don’t have a lot of time, don’t spend that time sort of feeling sorry for yourself. (Amanda)

I describe how I became so focused on the present that I rarely thought about the future.

I actually had that realization a couple months ago...‘I don’t [feel like I] have a future anymore.’ I got really good at being in the present, because it was the only way I could deal with this, and I didn’t even let myself [think about the] future. (Jenny)

Despite the circumstances that led me to this insight, I feel privileged to understand the value of being present-oriented at my age.

Just being able to be present, to know what it is to live your day like it’s your last...I think that’s really important because I know so many people who are living six years in the future. I think this experience has really forced me to be present, which is good and bad in some ways, but I think to have that knowledge at this point in my life...I guess [that’s one of the] positive things. (Jenny)

As evidenced by these previous statements, living with a parent’s cancer prognosis required the participants to refocus their awareness to the present time.

Concerns for future

All of the women who participated in this research expressed concerns for the future. Some of these concerns related to fears about their own susceptibility to cancer.

Most of my co-investigators felt certain they would get cancer themselves, especially when there was a strong family history:

Well, I sort of decided after my mum had it – ‘cause my grandmother died of cancer too, and my dad’s dad died of cancer – and especially now that it’s both of [my parents], I’ve just decided that I am going to get cancer...and I think I’ll feel OK about it when I find out. Or else it’ll still be shocking, because maybe I’m
telling myself that I’ll have it, but I’m not really believing it. I don’t know. But I’ve just decided that I just am. (Kate)

Amanda becomes fearful of doing breast self exams:

When [my mom] got cancer, it was a shock, whereas for me, I just assume this is something that’s going to happen to me. And in fact I’m so paranoid, you know? I almost don’t want to do monthly [breast] self-exams because every time I do them, I’m like, ‘I’m going to find something! There’s going to be cancer there!’ My doctor tells me I’m crazy, he’s like, ‘You’re only 21, actually you don’t have to worry about it.’ But then you read about these freaky cases “24-year-old Girl Gets Cancer.” I think the youngest one I’ve seen is like 26 or 27, but even still… that’s a little close for comfort. (Amanda)

Other worries for the future related directly to the loss of the parent. I had to give up some of my expectations for my future:

I think one of the hardest things for me was giving up that idea of what my mom would be part of in my life. Getting used to the idea that well, my mom’s probably not going to be part of a lot of important events in my life. (Jenny)

Amanda worried about raising children without her mother’s advice:

How am I supposed to know how to be a mum if I don’t have my mum to phone? Who am I going to call at 3 o’clock in the morning [when] my baby’s screaming and I don’t know what to do, if my mom’s not there? And that’s not to say that you don’t have friends and like, close family friends who’ve had kids and whatever. But just no one seems to be able to replace [her] in the same way. (Amanda)

The participants also expressed sadness for their parents, in that they would not be able to be part of significant life events.

They’re supposed to be grandparents to our children. They’re supposed to be there for our weddings. And they’re supposed to be there to meet the man that we fall in love with…and it’s so scary that they aren’t, that they might not be able to see those fabulous parts of our lives that they are supposed to see before they die…Basically, they need to see those things to know that their kid is going to be OK. (Melissa)
Acceleration of time

Most participants considered accelerating events in their lives so that their parents could be part of these important occasions. While they were aware of the impracticalities of rushing into major life events, three participants who were in relationships expressed a desired to get married sooner:

My boyfriend and I have been dating for over a year, and every once in a while, I sort of think, you know, if [my mom] comes back with really bad news, we have to get married now, so that she could be there. I mean those sort of things go through my mind, but I don’t think I’d go through with something so crazy.

(Amanda)

Despite her boyfriend's reluctance, Melissa felt pressure to get married because of her mother's illness:

I want [my boyfriend] to hurry up and propose to me so that my mom can be there at my wedding. I mean...she’s one of the most important people to me. It just wouldn’t be the same if she wasn’t there at my wedding. And [my boyfriend is] totally holding it off...he’s just got this stupid thing about how he’s got to be settled. He’s got to have a life for himself...which makes a lot of sense but at the same time I’m like, well wait a second you know, we’ve got a timeline here.

(Melissa)

Kate shares her thoughts:

It’s kind of the time when you’re trying to get your career going, your relationships going, you wanna maybe have a baby, you want to move where you want to go, and suddenly, everything’s shut down. Or you want to race it along. Suddenly I’m thinking, ‘Oh, my God. Is my dad going to be able to walk me down the aisle? We gotta get married right now. We gotta have a baby right now.’

(Kate)

Kate identifies the tension of “having life things either put on hold or needed to be sped up, and not done when you would’ve liked them.” Changes to the perceived pace of time are also revealed in Kate’s previous statements. Time felt further accelerated when daughters had to take on increased responsibility for their parents:
You’re suddenly thrust into a position of being their parent earlier than you should have to and...worrying about having to figure out things, like financial things, or the ‘What do I do when?’...suddenly I feel like I’m going to have to take over control of the family somehow. Like, it’s almost having to grow up too fast even though we are grown up. But suddenly a lot of responsibilities are on you that shouldn’t be yours yet. (Kate)

**Illness progression**

Time is structured by the progression of the illness and treatments. In a concrete sense, time is structured by medical appointments: “My mom’s had chemo like, every three or four weeks for three years straight, basically” (Jenny). When waiting for test results, participants became acutely aware of the passing of time:

Once the MRI was done, it was just agonizing, because nobody knew what he had. And...nobody could get him a biopsy. Finally, there was a cancellation. And we also ended up taking him into the [hospital] a couple of times and they wouldn’t admit him. They barely even listened to us, like, ‘well, if there’s nothing wrong right now, then what’s going on?’ We’re like, ‘well, it’s been wrong for two weeks!’ (Kate)

The interviews revealed that time becomes measured in terms of the illness progressing towards the terminal stage:

So the doctors said we’ve gotten to the point where we’re going to treat it, not to cure, but treat it so that it just alleviates the pain and makes it a little more manageable and prolongs the life, right, but we’re pretty much past the point where it’s curable. (Melissa)

Time starts being measured in terms of firsts and lasts:

He’s just getting so weak so fast, and there’s always firsts, you know? First time he can’t walk. There’s always lasts and firsts... The last time he drove his car, last time he pulled through, the last time he saw a movie, the last time... And then there’s always firsts, you know? First time he couldn’t walk. I had to bring a wheelchair and push him around in the wheelchair. I’d never pushed anyone around in a wheelchair before. It’s hard. (Rachel)

Reaching these points on the illness timeline is significant because daughters are reminded that the illness is progressing and time with their parent is running out. “That feeling of, time is limited. I think that sort of overshadows everything. And...right now
that’s what I’m dealing with. How do I make this time meaningful?” (Jenny) The overshadowing question of ‘how much time is left,’ may be the essence of the experience of a parent’s cancer.

_Holidays_

Holidays and birthdays often take on increased significance when a family member has cancer. Special occasions that occur annually are reminders of time passing, and can become especially difficult. I reflect: “Holidays are always brutal...because they’re so symbolic of everything.” On occasion, to avoid the emotional intensity of holiday celebrations with my family, I made alternative plans:

Especially around holidays...everything is so emotionally laden, like is this the last New Year’s together? Is this the last Passover? Is this the last–something? And it’s just like stuff gets so intense...I have chosen not to be part of it once or twice, like feeling really horrible for that, but just not being able to be there. (Jenny)

Melissa reflects on how her family’s Christmas traditions were influenced by her mother’s illness:

We always go for a walk on Christmas day, like we’ll enjoy a really nice Christmas dinner, wake up in the morning, open all our gifts, have a nice brunch and then right after the brunch, we’ll go for a really nice walk, and um this year we couldn’t go for the long walk because my mom had a lot of pain in her legs and lower back and...when we decided to go for a way shorter walk, everyone was thinking, ‘Oh God, it’s because of mom.’ (Melissa)

A parent’s illness can overshadow other special events, like birthdays or a friend’s wedding. Kate remembers her 28th birthday, shortly after her mother was diagnosed with cancer:

My mom was in the hospital, and I went up and I saw my family and they were all so distressed for me...They sort of made me a [birthday] cake and were all tiptoeing around me, and then there [was also] my friend’s wedding and everyone’s kinda going ‘err, we’re sorry’ and uh, I remember coming home, I think I came home on my birthday, my mom had asked my dad and my aunt to go
get me gift certificates to places because she didn’t get me presents and...I knew
she’d done that but nobody gave them to me till like four days after my birthday,
it was like in [the movie] Sixteen Candles when nobody remembers the birthday.
And I was sort of sitting around on my birthday kind of going ‘(sigh)–great
birthday.’ (Kate)

I reflect on how my 22nd birthday was influenced by my mother’s treatment:

I’d decided to have a barbeque for [my birthday]...but um I remember the night
before that we’d found out that like, how we understood [it] the chemo was
not working and so that was just like debilitating. So that whole birthday party
thing was not a good experience for me. I think I got really drunk! (Jenny)

Families deal with holidays in different ways. Melissa’s family tried not to let her
mother’s cancer influence the holiday celebrations.

I think my family...when we’re in those kind of situations, like Christmas or
whatever, we just choose to basically forget about [her illness] and...just enjoy
the holidays as if she wasn’t diagnosed with cancer...I don’t know if that’s good
or that’s bad or just a way of coping...but it’s the last thing I really want to think
about on a holiday. (Melissa)

Rachel and her father coped with holidays and birthdays by not placing too much
emphasis on them:

I just choose not to put so much significance on it, and just [not] romanticize
everything. Like, I didn’t even give my dad a present on his last birthday. It was
just like, ‘whatever, Dad!’...we had many birthdays together. It just doesn’t
matter. You know what? It doesn’t really matter if I give you [presents]...in some
ways because it’s just he and I, we can make that consensus easily. If I was part of
a whole family where everyone has different...emotional systems and stuff like
that, that’d be really hard. (Rachel)

Even though holidays could be challenging, some participants had special memories of
those times:

My mother being sick allowed my dad and I to have...some special memories...
that are sort of yucky memories in some ways, like the Christmas that she was in
the hospital. And people invited us over, but we didn’t want to go. We just made a
little Christmas dinner together and had our little presents together, and that really
was special to me, having time like that with my dad. (Kate)
Meaning of Cancer

Common meanings ascribed to cancer are explored in the second theme. While over time participants' understandings of cancer evolved, when they described their reactions to their parents' diagnoses, widespread perceptions about the disease became clear. These reactions were often similar. Melissa shares her response: “Just hearing that somebody’s found a lump you just like immediately think ‘Oh my God, cancer equals death.’” Amanda also equated cancer with death:

And then all of a sudden, ‘Oh, my mom has cancer!’ and I think I didn’t really completely understand what was going on ‘cause automatically I thought, ‘She’s dying.’ That was the first thing I thought, was, ‘She’s going to die’…that was my automatic response…(Amanda)

Amanda also felt that she should be reacting to her mother’s illness in a particular way:

When she was first diagnosed, I had so many ideas in my head about what it meant for someone to have cancer and what it meant to be dealing with that. And so I thought I was supposed to be emotional all the time. And I remember telling my best friend…that my mom had cancer. I remember thinking, ‘I can’t just tell her. I need to make sure I get myself good and upset so that I’m crying about it when I tell her because then she’ll care more if I’m crying about it!’ I remember specifically thinking that. (Amanda)

As participants became more familiar with the cancer experience, they found some of their perceptions changing. Reflecting on an article I read, I describe how I became more aware of the reality of cancer treatment:

Right after this first happened, I read this article – it was called Welcome to Cancerland. And it was about this woman who…was a science writer, and she had been diagnosed with [breast] cancer. And she was just kind of critical of all, all the pink ribbons and everything. Like, it didn’t work for her… that title’s kind of stuck with me, that Welcome to Cancerland because it’s a whole other world. Like, you don’t even know it’s there, but there’s…all these people whose lives are scheduled around their chemo and everything. (Jenny)

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4 I am referring to the article Welcome to cancerland: A mammogram leads to a cult of pink kitsch by Barbara Ehrenreich published in Harper’s Magazine, November 2001.
Once Amanda became more aware of the nature of cancer, her perspective also changed:

People sometimes will say, ‘Oh, it must be so horrible, your mom having cancer,’ and I’m like, ‘Well, most of the time life just goes on,’ you know? Sure, she needs to have a nap every day, and some days she’s just more tired than others, but for the most part, life goes on. And she’s still here, and I guess you just sort of get used to it. Like, if you’ve never had anyone in your family — especially someone that’s close — have cancer, you’d probably look at the situation and think, ‘Oh, that would be terrible! How would I live with it?’ But when you’re actually going through it, it just becomes your life. (Amanda)

Amanda is not denying or minimizing the impact of the disease on her family but rather acknowledging the inaccuracy of common perceptions about cancer, and speaking to the ability of people to adapt to difficult circumstances.

Through her involvement in her father’s medical care, Rachel found her perceptions of doctors changed:

Suddenly, doctors become like God, you know. They knew everything...what [will we] do doctor? Will he live? Will he die?...You know they were just like God. You know the first people you encounter when you come into this world [of cancer] and the last people you encounter when you leave...I mean the medical system’s really harsh, and f**ked up and hard to get around. (Rachel)

While most participants did not convey similar impressions of the health care system, Rachel was also the only participant who identified herself as her parent’s primary caregiver.

Cancer is a disease that is defined by treatment protocols. Study participants shared their thoughts on cancer treatment. Rachel powerfully describes a treatment her father received: “At one point, he went on Interferon, which is just like liquid poison from the pits of hell, this drug.” I reflect on Rachel’s comment:

Since this started happening, I’ve always been wondering, what is it about cancer that makes it so unique and so horrible. And I think that’s what you’re saying, the fact that it’s the treatment that makes you feel so awful as opposed to the cancer. My mom...had liver cancer, you know, metastasized cancer and she didn’t know it...[but] as soon as she started having treatment she was really, really sick. I
mean every three weeks, every month she has to choose to go and get this treatment which makes her feel crummy. (Jenny)

Like with many other aspects of coping with a parent’s illness, there are still positive outcomes from unpleasant experiences like chemotherapy:

Whenever I think my mom and I, or our family, were in a really low point...we’d be at the cancer agency, which I kind of think of as...the great equalizer, like everyone’s there, regardless of where they are in life, you know? We’ve been there and there’s people who haven’t had lunch that day [because they couldn’t afford food]. We’ve been there and there’s people who – like I remember one situation, I would sit there with my mom while she gets her treatment and in the other chair it was the other way around. It was a girl who was pretty much my age. She had breast cancer, double mastectomy or something! And it’s just like, wow! You know? [Compared to that] we don’t have anything to complain about. (Jenny)

Coping

Coping, the third theme, refers to the process of adapting to and dealing with an ongoing stressor. While many aspects of cancer contribute to a family’s stress, coping with the ongoing, day-to-day demands of a family member’s illness can be draining. Kate illustrates this in her response to the question: “What is the hardest part of dealing with a parent’s cancer?” She answers:

I don’t know. I mean I feel like I should be saying, ‘the thought of losing my dad’ – but it’s more like all of the things around it in your daily life, I think. But I don’t know. I feel like I should be saying something much more tragic that’s the hardest part, but...maybe not. (Kate)

More specifically, some of the issues the participants in this study faced included (1) physical changes (in their parents) (2) distance (3) emotions and (4) self-care.

Physical changes

Both the disease of cancer and the treatment result in physical changes. The young women interviewed for this study were troubled by physical signs of illness in their parents. While some participants were not surprised when their parents lost their
hair following chemotherapy or radiation, others were shocked. I ask Melissa if she has seen her mother without hair. She replies: “Once. And it was pretty traumatizing.” Kate describes when her father lost his hair:

That was freaky too. They shaved his head because his hair was falling out and they thought, ‘Forget it. There’s hair everywhere!’ And my dad’s hair hasn’t really gone grey and he hasn’t really lost it – and he’s [almost] seventy. He’s at an age where most people have lost quite a bit of hair and stuff so having his head shaved, suddenly his hair is grey, like the little bits that are growing suddenly are grey and not having the hair, he really looks older. It’s really distressing. My young in-control dad – well, ‘young’ – suddenly looks like an old man. And that’s kind of scary… Or, upsetting too. That’s really unfair! (Kate)

Hair loss is distressing because, as Kate reveals, it is a constant reminder that a parent is ill and vulnerable. Witnessing a parent in pain was particularly difficult for participants.

She got like this pretty intense radiation done on her legs because that’s where most of the pain was, in her legs and everything, and the SCI joint. It was five super strong treatments, and they said that she might feel some extra pain just because of the tumors swelling or something for the first two weeks after the radiation. But, um, but… today is the two week point and she’s still in excruciating pain, so she came over to my place last night… she just was all crunched over, it was just not pretty at all, and it was just like super hard to see her that way. (Melissa)

Amanda felt frustrated that her mother had to contend with unexplained pain and side-effects, in addition to her cancer treatments.

It’s just some sort of added burden… it’s hard to see that. And I don’t know how much of it is related to the cancer, or how much of it is, you know, maybe related to a drug she’s taking, or whatever, but it’s been kind of frustrating, ‘cause you think, ‘Ok, isn’t it bad enough?’ (Amanda)

For Rachel, her father’s deterioration following a hospital admittance forces her to realize that it is unlikely he will recover.

For the first few weeks I was like you know, ‘When are you getting up Dad? We brought you in here for the leg and that’s dealable, like we can take care of that, I mean why aren’t you getting up?’ And then kinda just realizing s**t he’s not going to get up. Like this is it. (Rachel)
Emotions

Life threatening illness in a parent is by nature an emotionally difficult experience. Learning to accept and deal with unpleasant emotions is part of the process of coping with a parent’s cancer. In this study, commonly identified emotions were anger and guilt. Kate remarks: “I think with the whole parents with cancer thing there is a lot of guilt, just around everything.” Rachel also identified feelings of guilt: “Just because I’m my dad’s primary caregiver, I mean... I kinda feel guilty, about putting him in hospital... He didn’t like it there.” Especially when participants had previous experience with cancer in their families, the often reacted with anger to another diagnosis. Amanda describes her reaction when her mother developed a recurrence of cancer:

I was so mad because you don’t expect it. You think, we’ve been through this once, you know, we went through the whole Nana dying thing, it’s over. So, yeah, I was way more upset the second time than I was the first time. (Amanda)

Kate had a similar reaction to her father’s diagnosis with cancer, years after her mother was diagnosed: “I’m finding that [with] my dad sick, I’m still really ticked about it. It sounds sort of silly, like, I should be saying I’m sad or whatever. But I’m angry. Cause we went through this with my mum already. Enough!”

Participants also described feelings of fear and anxiety, which they attributed to their parents’ illnesses. Rachel shares her concerns: “you know my dad’s really my only relative... who’s like in the city or just part of my life and just the fear of being alone is so overwhelming.” Rachel attributes some of her fear to a lack of information about what to expect around death:

I think the more information I get the less scared I am, because it doesn’t make it so... ‘This is the first time it ever happened, this is uncharted territory,’ you know? ... But not having any understanding, not knowing what’s coming next is really tough. And I think it fuels fear. (Rachel)
I discuss my feelings of anxiety:

[I] have more anxiety now. Things like, driving freaks me out more than it used to, partly because I’m just like, if I got into an accident, my family can’t deal with that right now, you know? We just don’t need anything else happening. I definitely do have a bit more anxiety and I do think it’s related [to my mother’s cancer]. (Jenny)

Amanda reflects on her emotions around her mother’s illness and how she expresses these feelings.

I don’t really get emotional about it that often. It’s sort of like, ‘Oh, my mom has cancer and she’s having chemo, and blah, blah, blah, and this is what’s going on.’ And my best friend said to me ‘What do you feel about it?’ You know? ‘Aren’t you upset?’ ‘Don’t you need to express things?’ And, I don’t know, I sometimes have days where I sort of have a mental breakdown, and I’m freaking out, and I just want to be comforted, but... I’ll have this like, strong face or whatever you want to call it. Like, for me it’s so, ‘this is how it is, this is my life.’ If I get upset about it, it doesn’t really help. (Amanda)

While at times it seemed preferable to avoid dealing with negative emotions, participants, including myself, acknowledged the need to recognize and express their emotions.

I mean I’ve dealt with this a lot in my head, like, you’ve said you’re really emotional and for me the challenge was trying to process this in an emotional place and realizing that you can’t analyze everything and think about everything. I mean, you can, but at some point you have to process it on an emotional level. (Jenny)

Rachel also distinguished between “logical” and “emotional” reactions to her father’s impending death. While emotions can seem overwhelming at times, during crises, shock seems to suppress emotional reactions. I speculate:

But I think [at] first you’re in shock, it’s not like you immediately have this emotional reaction. Like, I think we have this protective mechanism – going into shock – that lets you deal with things. Like, you deal with stuff after. My mom had this thing with her brain. That was pretty intense. And for the whole week that that was happening...we were just in shock and doing what we needed to do. And like, you know, a couple of months after we started feeling [more]. (Jenny)
Distance

Physical proximity was closely related to emotional involvement in a parent’s illness. Kate describes her guilt when she was unable to be physically present for her parents: “I also felt like everything that I did had to be focused around going to visit [my mom], or going to the hospital, and if I wasn’t at the hospital, then I was a bad daughter and I didn’t love her.” Physical proximity is particularly significant during young adulthood because this is the stage when children typically leave the family home.

I basically was making the transition towards moving out and becoming independent. And then once my mom was diagnosed...I went back home and we all kind of had to get back together and had to plan everything in terms of what’s going to happen to my mom. And...at this time in your life, I think that’s one of the things that are kind of unique: you’re supposed to be separating, but then you’re just drawn right back into everything. (Jenny)

For Rachel, the instability of her father’s health prevented her from living in a different city. She describes how her instinct was to “run” from her father’s cancer.

One thing I remember when my dad was diagnosed is I just went into a tailspin. I just went completely self destructive, particularly in ending my relationship which was really good. I mean I devastated [my boyfriend]. Shocked everyone around me. I started smoking more, drinking more...I wasn’t one of those people that just stopped smoking, oh my God, OK I get it now, no, I just like chain smoked, just go f**k cancer...But then it took me, you know, about a year, I [realized that] I was just running. I realized there’s not a nook, a cranny in this world that you can hide from cancer. Whether that grief or that knowledge or that reality, you just can’t hide, it’ll find you...I was just trying to...escape. (Rachel)

Apparently this is a common response to a parent’s illness: when asked what advice they would give to someone else in their situation, both Rachel and Amanda advised staying present, physically and emotionally.

Don’t run. Definitely don’t run. I’m shocked at how many people run and don’t come back. Like move to Toronto and don’t come back, they come, you know, the week their parent is dying. But they just can’t be present through the whole thing. I remember somebody told me: ‘you can only do this once.’ And you really
It’s so true. And you know, I can only do this once with my dad and I’m not gonna f**k it up. I’ve wanted so badly to move to a different city. ‘Oh Dad, I got a great job in Toronto’ or whatever. Knowing he’ll be so happy for me, he’s not gonna say ‘no, stay here and take care of me.’ You know, it’d be the perfect excuse, there’s so many excuses I could come up with, to be here and not to have been here for this many years...(Rachel)

Similarly, Amanda offers this advice:

I’d say just to not detach yourself as much as possible. Sometimes it’s hard to stay in the game, or whatever. To stay. But, yeah, to be involved as much as possible and, I guess, to be informed. To be aware of what’s going on. And just appreciate what you do have. (Amanda)

Coping with a parent’s cancer can be overwhelming. Separating one’s self physically was helpful for participants, including myself.

Being away [for school] was really important for me. I think it allowed me to sort of process things... and just recently, in February, I moved out of my parents’ house, and there were sort of a lot of reasons... It just sort of got, ‘I can’t live here anymore’ and I think everyone was pretty shocked that all of a sudden I just moved out. But for my own, you know, sanity, I needed to not be there anymore. (Jenny)

When Kate’s father was in the hospital, she felt obligated to be there constantly. She was relieved when a cold prevented her from visiting.

Being away from it is really helpful... When my dad was first sick and in the hospital, I was there every day. And then luckily I got a cold and so I couldn’t go, so I didn’t have the guilt of not being there, but I got to go out and do other things, and I just felt so much better. Like, I just felt like I was going to go home and cry every night after the hospital. And when I wasn’t there. Ahhh! Everything was wonderful. (Kate)

I reflect on how living in my own apartment allowed me some distance from my mother’s illness.

It’s sort of amazing to me how much that distance does, like that – out of sight out of mind – it really does help. I’m so much happier when I’m not at home, just because I don’t have to deal with this all the time. (Jenny)

Amanda recently realized that she avoided being at home:
I think I sort of remove myself from the situation sometimes too...I'm really busy, you know? And I'm not home that much. So, I think that's something I've become more aware of lately, I'm like, 'Am I just avoiding things?' Because I like being busy so much of the time that I'm not home and I don't have to see? (Amanda)

Although Amanda expresses her desire to spend time away from home, when her mother is out of town she is uncomfortable:

I find another thing really funny, is that as much as I am not home that often, I get really upset if my mom goes away. My dad, in the last couple years, has traveled more with work. And because she's not been working, she's able to go with him. So they'll go away for a week or two down to the States or whatever, with his work, and I get really upset. I don't like the idea that she's leaving. You know? I don't like the idea that she's going away and leaving me alone. It's sort of like I'm attached to her. But when she's here I want my own space. But when she's gone, I just don't like the idea that she's not here. (Amanda)

Despite the seemingly common instinct to avoid being involved with a parent's illness, staying involved can be incredibly rewarding. Rachel poignantly describes her experience of being present through her father's illness:

I would never regret staying, ever, ever, ever, ever. The exchanges that we have... just like the amount of love that you experience going through this experience is just massive, it's infinite, it is so tangible. I'm sure you've experienced [it], like just the feeling of the love you share, in a glance, in a touch, that just envelops you, you just swim in it. I'm so glad I've experienced that with my father. In some ways...I think your grief is like equal to the amount of love that you share. Um, I'm scared of the grief. I'm really scared of the grief. And I know that like, [when] my dad dies there's nobody that's going to love me like that ever again, ever. And that's so hard to deal with. I'll have a husband, I'll have children, you know but it's just [not] like that love... (Rachel)

Self-Care

Especially when daughters were primary caregivers, it became a challenge to balance their own needs with the needs of their families and parents.

I took him...for the blood clot, to the Cancer Agency. They said it was a serious clot. They put him on blood thinners. Gave him an option of going home or going to hospital...It [was] the most inopportune time. I was hanging on by my fingernails. Doing like sixteen hours a day [at work]. Thinking, my father at home
Rachel describes the impact of her father’s illness on her own well-being:

I have to take my dad to 2, 3 doctor’s appointments a week. You know how long they take. They take a half a day, easily. It’s just tough, being in two places at one time. You just can’t. Like there’s no time for me to, look at me, like, I’m tired, I’m pale, I’ve gained tons of weight. I’m just f**king tired. (Rachel)

While I am not the primary caregiver for my mother, I too struggled to find balance:

I think one of the things I’ve had to learn is just sort of balancing what I need, like, moving out...I needed to do that for me...It’s sort of trying to figure out taking care of myself versus taking care of my mom. And like, I felt really guilty about [moving out] for a long time...‘Ok, who’s going to cook my family dinner?’ But I think that’s one of the things that you do have to figure out, is how can I be healthy and take care of myself and be there for my mom enough, but also take care of myself. (Jenny)

Self-care was complicated by the desire of daughters to support their parents. Amanda explains: “it is hard because I don’t want her to feel like she’s alone. But I also need to know that I have my own time. That my life is still mine.” As an only child, with two ill parents, Kate felt tremendous pressure:

My mom just seemed to really need me. And...if I just turn up there for the afternoon for some reason, my mom’ll be like – because she doesn’t ask me to come over, she doesn’t say she needs me – but when she sees me, she goes, ‘Oh, when I came home and saw your car I was just so relieved!’ And like, I think that’s her way of saying, ‘I really wish you were here all the time.’ And so, you’re just like, ‘oh my God!’...And then there’s my poor mom, like, 24-7 taking care of [my dad] at the hospital...I’m an only child, so I feel like I should be picking up as much slack as my mom....And I don’t have any brothers or sisters to support me or to deal with the paperwork if somebody dies or support my mom. It’s just me, and it’s so frustrating. (Kate)

Despite the challenges of coping with the ongoing stressor of cancer, participants were able to find positive outcomes in their experiences. Melissa reflects: “well, we have some
baggage now, you know? Like, that’s what makes people people, and the experiences that happen to them in their lives make them better people.”

Relationships and Interaction

The fourth theme addresses relationships and interpersonal interactions, which were discussed at length during the interviews. The sub-themes in this category include (1) connection and disconnection, (2) disclosure and reactions, and (3) intimate relationships. Family and parental relationships are considered separately (in the next theme) because the issues are distinct.

Connection and disconnection

Following their parents’ diagnoses, participants found themselves searching for connection. I share my experiences:

That summer [after she was first diagnosed]...was just such a weird, bad time. I didn’t really have a lot of friends around. I sort of felt like I needed so much, and just needed someone, and sort of finding myself attracted to all these disgusting guys at work and...hanging out with them because I just needed something, and just feeling like, I don’t know, sort of at loose ends, lost, upset, whatever. (Jenny)

In some situations, participants found themselves making choices they would not have made in other circumstances. One participant “hooked up” (became physically/sexually involved) with the family member of another cancer patient, another with a doctor treating her parent. This was attributed to the “desperate” need for connection.

Participants often described feeling isolated from their friends and peers. This was closely related to whether participants felt others understood their experiences. Rachel explains: “I don’t think people around really understand unless they’ve gone through it...Oh my God. I’ve just been high maintenance...totally alienated from all of my
friends.” Rachel was surprised by the extent to which her father’s illness influenced her relationships:

I had no idea of just the immediate impact [my father’s diagnosis] would have. It isolated me from a lot of my friends because they just couldn’t relate, you know. They would just say ‘oh, I can’t imagine yadda, yadda, yadda.’ (Rachel)

Amanda found that she related better to people who had experienced similar challenges:

I guess I find it...harder to relate to people who haven’t really lived with anything really stressful in their lives. Like, I...almost resent them. And I find that I’ve become closer to people that have gone through something similar, or at least...something bad has happened to them in their life. My best friend and I are really close, and probably because we can relate. It wasn’t her mom, but her grandma died of cancer...she’s really close to my mom too, so that relationship has really grown, I guess, through this experience. Because she’s really been able to share with our family, and share with my mom, and we’ve been able to be really close and talk about it. Like I said that she complains that I’m never able to get emotional about it, but I do – I am able to talk to her more than I am to other people. Most of my other friends, even though I’ve been friends with them a long time, I just feel like they can’t understand, so why bother? I sort of don’t get into a lot of details with them...or they feel really bad for you. And I hate that! I hate that when people are like, ‘Oh, that must be so terrible! Oh! Oh!’ (Amanda)

Illness became so central to the experiences of some participants, including myself, that at times it became difficult to relate to friends: “you can’t relate to what these people are doing anymore, because you’re just so involved with what’s happening to your mom.” (Jenny). Amanda felt disconnected from her friends’ interests and “annoyed at people’s priorities in life.”

While participants reported feeling disconnected from some friends, other relationships became closer. As well, some participants felt that their experiences with their parents’ cancers allowed them to connect with new people: “it opens you up to people that...you would’ve never met otherwise”(Melissa). The experience of having a parent with cancer made participants feel better equipped to support other people dealing with similar circumstances:
I feel more comfortable talking to people about [cancer]...one of my friends, her mom was diagnosed with breast cancer, and I just felt like...[I knew] what to say...I felt like I could talk about it frankly and not be walking on eggshells...And she actually was willing to talk to me, where [with] other people, she may be unsure about it. But I was the one person she would tell because she knew that I'd [gone through] it too. And that’s kind of nice. Being able to connect that way and share that way. I guess. (Laughs) Is that really nice? I don’t know! But it sort of is. It’s being able to connect on a deeper level than you would’ve otherwise. Not just talking about clothes! (Kate)

Like Kate, I also am more confident in my abilities to support others:

I think it’s given me a capacity to give to people more in a way. Even though I have so much less to give, I just don’t have as [many] resources. I think...if anything tragic happened to someone else, I feel like I could help them more than I could [before]...it gives you a different way to connect with people, on a much deeper level...knowing what it’s like to deal with suffering and pain and stuff. (Jenny)

Disclosure and reactions

Disclosing a parent’s illness to others can be difficult. Melissa preferred keeping the details of her mother’s illness to herself:

I’m one of the most open people. (Laughs) Like, I’m too open sometimes. But with my mother’s illness, that’s one thing that I really keep to myself and I know that a lot of people know about it, because when something’s happening that’s too much for me to emotionally deal with... I’ll tell people. I’ll tell people at work, ‘Oh my God, my mum got re-diagnosed with cancer!’ You know? And then they’ll be like, ‘Oh my God, that’s horrible!’ But then I won’t talk about it ever, ever, ever again, and they won’t ever, ever, ever ask. And that’s fine with me. I’d rather that they just don’t know anything about it. (Melissa)

For months, I experienced great difficulty sharing my mother’s diagnosis with anyone other than close friends:

Because I know for me...I couldn’t tell people...I couldn’t physically tell people what was going on until I’d say [almost a year after my mother’s diagnosis]. And even then, it’s so gradual...that I’ve been able to tell people, like new people I meet. I think in the last few months I’ve made a lot of [progress], like I can tell people just sort of in passing, ‘Oh, my mom has cancer,’ because I’m doing my research on it...it makes it a lot easier for me to say that. (Jenny)
Reluctance to share a parent’s diagnosis was often attributed to the uncomfortable reactions of those receiving this news, which is revealed in the following excerpt from the interview between myself and Melissa.

Melissa: I met [my boyfriend] after my mom had been diagnosed. Cause my mom had been diagnosed in February and then, in September I met [him], or August… I don’t think I told him right away, but I think I told him maybe two months in, and I think I told him once things were going well for her. And um, you know it was something that I was happy about, I was joyous about, and wanted to include him in that. Do you want to hear something really, I don’t know if it’s disgusting of me?... I didn’t like the way that he responded.

Jenny: Oh, yeah. I totally know what you mean.

Melissa: Now I’ve just realized that that’s just the way people respond and they just don’t know how to respond, right? And you just have to know that people are going to respond in the exact opposite way that you’d want them to. And if they respond in the right way, then you are like so pleased, you know?

Jenny: And I guess this is really why you choose whether or not to tell people.

Melissa: Exactly. And I just prefer not to tell anybody because I just don’t want them to respond in a way that I don’t want them to.

Another reason study participants were reluctant to disclose this information was a perceived need to protect other people. Melissa explains: “I don’t want to burden other people. And it’s not something that I can just be open with people [about] because then they have to say something.”

Participants were often asked about their parents’ health. Sometimes, participants found themselves feeling annoyed at being asked this question so frequently; however, when acquaintances neglected asking about their parents’ health, they felt hurt. Kate reflects on being asked about her father’s health:

Right now I don’t know how my dad’s doing. He’s doing sort of OK for someone who’s in the thick of chemo, but I really don’t know what to answer. I’m glad they ask me. At the same time I wish they wouldn’t because I feel like if I say, ‘oh, he’s fine!’ then that sounds like, ‘oh, he’s getting better and everything’s
going to be fine.’ And then I feel like it somehow gives that other person permission to think that you’re OK too now, and everything’s fine...whereas if they think that something’s wrong, they tend to remember that, every now and then, you might act funny or not show up to something, or be having a bad day or something like that. So if I say it’s fine, suddenly I don’t feel like I have leeway to have a bad day anymore...so I find that question hard. (Kate)

Amanda explains that her answer depends on who is asking about her mother’s health:

“You don’t get into details of things with people who you feel like they’re just asking to be nice or whatever. And so I think it definitely depends who you’re with.”

*Intimate relationships*

In intimate relationships, participants sought support in dealing with their parents’ cancers. Melissa describes her desire for her new boyfriend to understand her circumstances:

When [my boyfriend] and I were pretty early in our relationship and I was thinking, ‘Oh, God! Is this guy going to be able to give me the support that I want, that I need? And in fact, he’s not really responding to this in the way that I think he needs to if we’re going to be having a relationship.’ And I thought to myself, ‘Something needs to happen of equal or more proportion to the magnitude of what has happened to my family...for him to understand!’ And a month later his mother was diagnosed with cancer. (Melissa)

Melissa questions whether her boyfriend would have been able to provide her with appropriate support had he not experienced a parent’s cancer diagnosis as well.

I often wonder, if his mother hadn’t gotten cancer at the time that she did, [would we] still be together? That’s just a horrible thought...[If his mother wasn’t diagnosed] I don’t think that he would’ve been able to give me that emotional support. Now he knows that he’s just supposed to be the shoulder to cry on and just hold me, you know? Be protective. And that’s great for me. (Melissa)

Like Melissa, I also found my mother’s illness seemed to influence what I was looking for in relationships:

Well, it’s just weird...this event affects you on every level, every single part of my life is affected by this, whether I like it or not. Just my ability to deal with things, and for some reason it comes up a lot in me being in, looking for romantic
relationships...like this idea, ‘Could his mother be a replacement for my mother?’ That kind of thing. And that was a big deal, one of my boyfriends...he wasn’t close with his family at all, and that was sort of a problem for me, I think. Just ‘cause I don’t want just the boyfriend, I want his family too, you know? (Jenny)

Amanda sought emotional support from her boyfriend:

With my boyfriend, I almost feel bad for him. He’s the one that sees the good days and the bad days....he sort of sees me on the days that I’m just sort of acting crazy and I don’t know why. Or the days when I feel like crying, and I have no idea [why] and I’m just upset. And he’s the one who sort of has to comfort me, or just tolerate me when I’m being sort of psycho, you know? So, yeah. I think I put him through a lot, ‘cause I just go way up and down...I find some days I’m super emotional, and some days I’m really fine. And so, obviously I see him probably the most in my life other than my mom, and he’s the one who sees all of that, so... yeah, I think definitely it affects our relationship. (Amanda)

While Kate feels her parents’ illnesses have brought her and her boyfriend closer: “in a lot of ways, [it has] been good for my relationship. It’s helped us look at questions that we wouldn’t have even thought of otherwise,” she is also concerned that at some point her boyfriend will become tired of dealing with the situation:

With my boyfriend, who’s really been understanding, but I feel like if I call again and say, ‘I’m staying [with my parents] another night.’ Like, what’s going to be the breaking point for him when he says, ‘Fine! Stay there forever!’ Um, which, won’t happen, but... (Kate)

Because of her parent’s illnesses, Kate is concerned that she will be diagnosed with cancer in the future. She has discussed this fear with her boyfriend:

I talk to my boyfriend about it and I tell him, you know, all kinds of horrible things that are going to happen. And my dad stayed with my mom. And you know... that’s been a big concern in my relationship where I wouldn’t have been concerned about that before. Like, I wanna know that you’re going to be there for me no matter what’s happening, no matter how disgusting it is, no matter how embarrassing and, you’re going to [stand by] my side like my mom stood by my dad’s side. He says he will. (Kate)

While some participants found their parents’ illnesses enhanced intimacy in their relationships, there can definitely be negative impacts:
Within that week [of my father’s diagnosis], I broke up with my boyfriend of four years. Totally devastated [my boyfriend]. He went away on a scheduled business trip while all this was going on and... he went away on a three week business trip, a four week business trip and... I just needed him so much and he wasn’t there. (Rachel)

Finally, I reflect on how my relationships have been positively and negatively influenced by my mother’s illness.

I mean it’s very hard because... all my significant relationships have happened after my mom was sick, and I don’t think that’s a coincidence... Like, I had some counselling. I’m still getting some counselling occasionally, and I think it forced me... do some work [so] that I was able to be in relationships. But at the same time, it’s part of every relationship. And in one of my previous ones, you know, I was looking for someone who would help me deal with my mom dying. I wanted someone who’d be there. And then my most recent relationship, this guy was like, ‘You know, you weren’t open enough with me!’ Which I didn’t expect... And he thought he could save me – but that was maybe what I was looking for... It’s just very complicated, trying to find someone who understands this, and who can be there. I’ve sort of decided... it’s a bad time in my life to be in relationships and bring people into this. I mean, they’re coming in at this awful time in my life. This guy I was just seeing, I met him the first time the night after I found out my mom had a brain tumour! And our whole relationship was overshadowed by this! So of course it didn’t work out. (Jenny)

Family Relationships

Participants discussed family relationships, the fifth theme, at length. The statements in this theme were difficult to categorize due to the complexity of the feelings expressed around these primary relationships. Changes in relationships with ill parents and non-ill parents\(^5\) were common. Participants also discussed resulting changes in family dynamics.

Relationship with ill parent

Most participants became closer to their ill parents as result of their cancer diagnoses. When asked about changes in her life since her mother’s diagnosis, Amanda

\(^5\) I am using the terms “ill parent” and “healthy/non-ill parent” for succinctness and clarity. Otherwise, I would not define an individual by his or her health status.
responds:

It definitely changed my relationship with her. I never, ever would’ve said she was one of my friends when I was in high school. But now she’s one of my good friends. She’s the person that I talk to probably more than anybody else, about my life, and she shares with me. It’s totally changed our relationship. So in a way I’m almost glad that it happened, because I don’t know if I would’ve ever had that strong relationship with her otherwise, but obviously you don’t wish that...

(Amanda)

Kate found that that being involved in her mother’s physical care required them to become closer:

I probably have a bit more of a comfort level with my mom from her being sick, just the embarrassing things that happened to her, or that I had to help her with. Which on the one hand I wish I didn’t know anything about, but on the other hand, there’s not much that I don’t know about her now, which is sort of a bonding thing, I guess! (Kate)

Rachel found that her father’s illness profoundly influenced her relationship with him. I asked her what she had gained from the experience:

Wisdom. Definite wisdom...I think I really gained a father, you know? We’ve really taken our relationship to such a level that it will be with me always. It’s just such a strong connection. Such an important relationship. (Rachel)

While most participants became closer to their parents, there were also times of awkwardness, discomfort or distance. In response to the question about changes since her mother’s diagnosis, Melissa answers:

Just you know, the way you are with your family, just that sometimes you’ll break into tears and you’re worried about what you have to say to your mom. When I was talking to her last night, I felt like I couldn’t be as open with her as I have been...like I feel bad talking to her about stupid, trivial things that are going on in my life and, but those are things I’ve always talked to her about and she’d always work these things out with me and you know she was kind of like my personal, problem worker, but now I feel like I can’t really trouble her and if I talk to her about it, it’s like, why am I talking to you about this?...I should be talking to [her] about really important things. (Melissa)
Rachel’s relationship with her father has ultimately been enhanced because of his illness, but she also describes difficult interactions:

> We can get argumentative and stuff like that. Sometimes you know if I do get short with him it’s because it’s like, ‘don’t make this harder than it should be on me,’ you know. I get upset when he’s difficult with nurses or rude to doctors, which he has the tendency to be and it’s just like f**k, ‘why are you doing this?’ And I get mad at him and he gets mad at me...When he takes me for granted I get upset with him...but now I feel guilty because...all the arguments we’ve had in the past six months, [are] due to the cancer. I kinda see that, like it’s his memory. He’ll ask me to go and get him a specific kind of juice or something, and I’ll go get it and bring it back, and he’ll get mad that it’s the wrong one. But I’m like ‘what are you talking about? You told me to get this,’ [and he says] ‘no I didn’t, take it back.’ (Rachel)

In this previous excerpt, Rachel alludes to the difficulty of coping with cognitive changes related to cancer or the treatment. Kate too witnessed personality changes in her mother as a result of her treatment.

> They tried this treatment that is like chemo, and it goes across the brain barrier, but the next day they have to do an antidote or it’ll kill you...And it seems to have gotten [the cancer]. But, it also took away a bit of my mom. Like, she can’t get the words out that she wants to get out. She can’t write as well as she could...she’s a very different person, and I don’t, unfortunately, completely remember the person she was before, and that’s really frustrating. (Kate)

As Kate illustrates, adjusting to personality changes can be painful and upsetting for family members.

> Which parent is ill

For participants who had both parents or step-parents involved in their lives, there was considerable discussion about whether their mother or father was ill. Some participants considered how their experiences of parental cancer may have been different had their other parent been ill, instead. Melissa reflects on what it would be like if her father was ill instead of her mother.
There's so much of my mother in me, that I think that I would hear her, you know? Like, always, even if she wasn't around I'd hear her. Whereas I don't know. I don't know if I'd have that with my dad. (Melissa)

For Kate, because both parents have had cancer, this topic took on a different meaning:

I remember I did the, ‘Who could live without who more easily?’ And we decided it would be my dad. And then it's funny because now we see the proof of that. That it would be my dad... Who knows? Like, if he'd actually lost my mom, who knows how it would've been. But we figured that he'd just keep going to the golf course and he'd have a jolly old time. His place'd be really messy and gross. And he'd never shower, but he'd be OK. (Kate)

Having experienced both of her parents' cancers, Kate reflects that her father's illness was more awkward for her:

Maybe the hardest part with my dad, maybe it's not the same with my mom, has been knowing how, I don't know what the right way to say it is, I'll get around to it in a hundred words, with my mom, she was female. I was born to her. You know, if there are going to be weird things that happen or uncomfortable moments or they're going to be taking her gown down to check something, we already knew what our relationship was there. But then, suddenly, with my dad it was very uncomfortable. Do I hold his hand because I think he's worried, or not? Because in our family we don't really do that, right? Do I leave the room when they're gonna examine him? Or is it OK if I stay? (Kate)

Kate goes on too describe an extremely uncomfortable experience when her father, while in the hospital, had fallen in the bathroom. Kate was unsure how to help him:

I'm questioning myself, I'm like, ‘Oh God, I thought I could help and I thought I could be really useful, and what's wrong with me’ and all the mixed feelings and questioning yourself and, I guess just the parameters of the relationship are a little bit hard to figure out. Or, even if I go to their house to visit and I happen into their bedroom, should I knock first? I don't want to knock because I might wake him up, but if I don't knock, what if he's in the middle of trying to do something in the bathroom or something and I walk in... So that's awkward, because I can't do all the things for him or with him that I would've with my mom. (Kate)

**Family dynamics**

Cancer impacts and threatens the essence of the family unit. When a loss is anticipated, family members grieve the potential changes that will occur in their families.
I explain: “I guess that’s sort of what I’m dealing with emotionally...wanting so much to preserve my family as it was, kind of, in past tense, and like, sort of preserve what we...have now.” If the family is understood as a system in which the actions and emotions of each family member influence the system as a whole, it is understandable that a parent’s illness will influence the dynamics of other relationships in the family.

Amanda experienced tension in the relationship dynamics between herself, her mother and her step-father. I explain how my mother’s mood influences the rest of my family:

My mom’s always [said] she doesn’t want to be alive at any cost. She has a very hard time being happy when she doesn’t feel great. And luckily she feels a bit better now because she’s off these steroids, but when she doesn’t feel good, she’s not very pleasant to be around, and I don’t really blame her. But sometimes I sort of wish she would just, you know, put on a happy face ‘cause it just affects everyone else in my family so much. It’s like whenever she’s upset, my dad’s all agitated, and then I get mad at my brother, and...it just sort of, there’s like a cycle, or a system or whatever. (Jenny)

In some cases, a parent’s cancer seemed to significantly influence a participant’s relationship with her healthy parent or step-parent. Amanda describes her frustration and anger with her step-father who she feels doesn’t understand or accept the reality of her mother’s illness:

Definitely it’s frustrating, because my dad sort of, I don’t know if he just is oblivious or purposely is oblivious, and... my mom will be in agony over her neck pain or whatever, and he just sort of goes about his life like everything’s normal. And I think that’s frustrating, because, I’m like, ‘Do you not see what’s going on?’ And it’s not like she’ll get mad at him, because she just sort of tolerates her pain. But it’s me that’s angry at him, whether or not I actually say anything. It depends on the day. But...it frustrates me that he just sort of doesn’t, he just ignores it, or... So I mean it does create some tension. (Amanda)

Melissa worried about her relationship with her step-father if her mother died:

My relationship with my step-father is something that I really worry about, just because, you know he does mean a lot to me but, you know, how much will he mean to me after my mom is gone, or if my mom is gone, you know. And, I
don’t know. That’s a thought that I keep to myself, that I don’t really talk to my family about too much. (Melissa)

Kate’s mother was considered to be in remission when her father was diagnosed. Kate discusses issues in her relationship with her mother following her father’s diagnosis:

It’s been a bit of a battle between us too. A little bit of, ‘Who cares more?’ and ‘Who’s this going to affect more?’ because mom... was saying like, ‘Oh, you don’t need to be here for this. You don’t need to be here for this.’ And she keeps saying, ‘He’s my husband. So I’m losing my partner. You know, you’re not losing your partner. So this is harder for me.’ And I’m like, ‘It’s my father. You can get another partner! I don’t have another father...’ I don’t know how you say who it’s harder for. But I see her case because that is true. Like, I knew one day I would lose my dad and that’s the way it goes and they get older and you survive it...But, luckily she one day said, ‘You know what I realized: it’s just as important for you to be here as it is for me, so you do whatever you want!’ (Kate)

**Spirituality and Hope**

Spirituality, the final theme, was not an intended focus of this research, yet the topic arose spontaneously in the majority of interviews, often in response to the question: “What has helped you deal with your parent’s cancer?” In this section, I also examine hope, because, as revealed in the words of a participant, it is closely related to spirituality.

**Examining Beliefs**

All of the participants found that their parents’ cancers led them to examine or question their belief systems. For some participants, their parents’ diagnoses made issues of spirituality more important. Melissa explains: “I think one of the biggest things that’s happened to me since my mom’s diagnosis is I have really been paying attention to the idea of God.” Melissa attributes her increased sense of spirituality to signs of a divine presence:

I was an Atheist before all this happened, but it’s just made me, like, the way that my mother found the lump was because she felt that she should do a breast exam, and she never did breast exams, but she just felt like she should! Something was telling her. And she told me that, and since then I’ve really been paying attention
to those kinds of signs, and now it’s just sort of really turned something in my head. There is something more divine out there. And I think that’s really positive...because that is something that I was really missing before. (Melissa)

Although Melissa is still exploring her religious beliefs, spirituality has clearly taken on a significant and positive role in her life because of her mother’s illness:

I’m still searching for what I want to believe in, but it’s my religious awareness or whatever of something all-powerful, I don’t think it’s a Christian God necessarily, but just that there is something that’s overseeing us, that’s sort of in a little bit of a way protecting us, guiding us…it’s become so profound. (Melissa)

Amanda, who felt a strong sense of faith before her mother became ill, describes her satisfaction in witnessing her mother’s faith grow following her cancer diagnosis:

We always went to church growing up, but it was never a big deal in our family, it was never really something we really talked about...when I was a teenager, I became more curious and more exploring ‘Why do I believe this?’ And really my faith was growing. And I saw a big change in [my mom] once she was diagnosed, and she started realizing that she had maybe not been relying on God so much in her life, and then her faith really became a huge part of it, and through her church and stuff, she’s got a prayer chain of people who she knows are always praying for her. And I think that has really brought her through it, and it has for me too. Like, just knowing that my life isn’t mine to control. And, you know, whatever is going to happen, is going to happen. And just trusting that we’re going to get through it. (Amanda)

While Amanda’s faith helps her deal with her mother’s illness, at times her feelings towards God are conflicted:

Sometimes I feel like my faith is really strong. Like, sometimes I’m trusting God with my mum’s life, and just feeling like He really has control over the situation, and just sort of saying, you know, ‘I’m not in control here and you are.’ And just feeling peaceful about it. And other times I just get so mad. I have days when I’m just like, ‘Why are you doing this to me? What did I do to deserve this?’ and ‘How come so many other people’s lives look perfect and I have to deal with this every day?’(Amanda)

Other participants also felt conflicted about their belief systems and religions, finding them both helpful and problematic. Kate’s reflects on her beliefs, prayers and
relationship to God:

Kate: We’ve decided we need religion lately…. my mom goes to church regularly, but we just don’t like it…but I feel sort of funny because, you know, you do that, um, ‘Dear God, if you let my mom live, I’ll never ask for anything ever again!’ Right? And then I’m like, ‘Hmmm, ring-ring. Hi! Me again. I know I said that if you let my mom live I’d never ask for anything again, but now it’s my dad, and uh, think you could just squeeze out once more?’ And then I feel like we’re doomed to have my dad die, because my mom didn’t. I feel like...

Jenny: Your luck’s kind of run out?

Kate: Yeah, exactly. Or my requests were answered before...It wasn’t, ‘Gee, I hope I get riding lessons for my birthday.’ It was a pretty big request! And it was cancer that she shouldn’t have survived. Just shouldn’t have! And so, to get it twice, I go, ‘No, there’s just no way!’ And…it does give you questions, because here I am sitting around asking questions to this God for whom I don’t do anything. Or I don’t go to his church. And I don’t follow his teachings or whatever. And so, do I even believe that there is one? And also the guilt of, ‘Oh yeah, I only go and ask,’ you know, I believe in God when I’ve got a problem and not the rest of the time!

Despite her mixed feelings about religion, ultimately Kate feels an increased sense of spirituality: “well, I sort of feel like, with all of the cancer that we’ve had, I…believe in faith a little bit more. Maybe not faith, but things happen for a reason.” Like Kate, I also found that this experience led me to question my beliefs. In the following excerpt from the interview between myself and Melissa, I describe how I have been feeling less connected to my religion and Melissa is responding to this comment. The following excerpt is also an example of the fluidity of roles in a collaborative interview.

Melissa: Well, I think it would make sense. I mean, if you were a spiritual person to start off with, and then something this horrible happens to you and your family, what kind of a God would, you know, let that happen to such a good family?...I can see that.

Jenny:...I don’t know if I’d ever call myself spiritual. That’s the thing. I think I’m religious. I would consider myself to have a religion but I think I’ve sort of moved away from that, I’ve moved away from that now, as opposed to closer.

Melissa: Is that it doesn’t seem that important to you now?
Jenny: I don’t know. I just…don’t know how it’s going to help me at this point…G-d is a hard concept. Like, it’s so abstract and difficult. It’s not like the G-d I believe in is something concrete that I can make an offering to.

However, despite my struggle with the concept of G-d, I reflect on the positive impact of prayer:

But then, on the other hand, a lot of people have been praying for my mom. Like, people in [a lot of different] countries, in all different religions have been praying, and on some level [it] makes a difference I think, too. (Jenny)

Mortality/Life after death?

A parent’s illness may force young adults to confront existential issues, such as mortality. Rachel describes the significant impact of her father’s diagnosis: “it pushed me into mortality. It was just kinda being an adult, you know?” Inherent in many spiritual belief systems are ideas about what happens to a person or to their soul after death. This issue was central to discussions of spirituality, and in participants’ mental preparations for the death of a parent.

I guess in terms of spirituality, it’s a question of what you believe about after people die. Because it’s worse to lose them, I think, if you think there’s nothing. But if you think that they’re going to go to something better, or something fun, or you’re going to see them again…(Kate)

Rachel reflects at length on her beliefs about the afterlife:

I read a book called Near Death Awareness…that really, really helped me. And it’s written by palliative care nurses and doctors. And when my dad was on [the chemotherapy drug] Interferon like, he almost died and he was experiencing, uh, experiencing it. Like, he saw his mom. He saw the people in his room, but he was just in a state of remembering. And I know that there’s something beyond that. You know? I knew that his spirit was going to pass. When I see… those people that connect to the spirit world, I actually believe it. And that really gives me comfort. [But my dad] thinks the light’s just going to go out. We talked about it a couple of days ago, you know? When he was getting a transfusion, I’m like, ‘Are you scared? Is it hard?’ I ask him questions like that. And then, yesterday in the hospital, I [said] to him, ‘So, you know, you’ll see auntie Lil soon, you’ll see so-

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6 In Judaism, writing the name of G-d is considered to be inappropriate.
and-so soon!’ He’s like, ‘What’re you talking about now?’ And I said, ‘Well, what do you think’s going to happen, Dad? It’s like, aunt Lil is going to be waiting there with her Scrabble board ready to go!’ (Laughs) ... He goes, ‘There’s just nothing. Nothing...’ he hasn’t told me he’s scared, or if he’s scared I don’t know. But he said, you know, if all those people are waiting to see him and he could be with them, then that’s not so bad. So I just kind of want to treasure that. (Rachel)

For Rachel, having faith helped her cope with her father’s illness. She elaborates on her definition of ‘faith’:

Just faith that there’s something on the other side, and there’s people that’ll welcome him on the other side. And that I’ll be able to, like, to feel him. And know that he’s there. And see him again, when my time has come. That makes me feel really good and it feels true, you know? ... And that kind of makes me feel like it’s going to be OK... It doesn’t make you feel happy. But it kind of makes it bearable. (Rachel)

Hope

When I asked my co-investigators about the role of hope in coping with their parents’ diagnoses, more than one responded that she had no hope, or that she was unsure if she did. However, when I introduced the idea of ‘reframining hope’, some of my co-investigators reacted positively to this idea. In the following excerpt, I explain how my own understanding of hope has evolved. Kate’s response follows:

Jenny: I always thought, I’m not hopeful! I don’t think my mom’s going to get better. Because right from the beginning, they told us pretty black and white, you know, she’s not gonna survive this. And I was like, ‘Well, you know, I don’t have any hope.’ And then I was talking to my [thesis] advisor about this. She’s done a lot of work on hope. And she says, ‘Well, you do have hope, it’s just for different things, right?’ Like, I hope that when my mom does die, I hope it’s not painful. Like, I hope it’s really quick. I hope she’s herself... I do hope for a lot of things. They’re just different. Right now, I hope she’ll be around until my graduation. That’d be really cool. I hope she’s around the summer, you know?

Kate: Oh, I hadn’t thought of it that way.

Jenny: It’s just sort of flipping perspective. And it’s like, you don’t have to hope for a cure to have hope for things. Although a cure would be nice, but... (Laughs)
Kate: Oh yeah, that would be really good, but...well I guess I’ll say a lot of the same things. My dad hasn’t seen, we painted a few rooms, he hasn’t even been here to see that...And I have some more wishes. I wish he could put some of his weight back on. I want him to go golfing. And I want him to be at my grad. I want him to be OK enough to come to my grad. Yeah, and I want him to be well enough to see me get married, and at least be there for when my baby’s born. If he doesn’t make it past that, OK! But, you know, at least be there for that. Um, be able to do his work. Be able to do my taxes, which he did, a good job. So yeah, I guess I do [have hope]. That’s interesting.

As Kate and I come to realize, hope can play a role in coping with a parent’s cancer, even if a cure is not realistic. Melissa, who had just learned that her mother’s cancer had metastasized at the time of the interview, found herself feeling hopeless:

Melissa: Well, it’s harder for me now because I was hopeful. And now it’s like, well what do I think now if I can’t think hopefully?...How can I be helpful to her with my thoughts? Because they do feel it, they do feel your hope. But she is so hopeless now... And my stepfather is still in this hopeful state where at least he puts on the facade of being hopeful, and it annoys her more than it helps her. And it’s...I don’t know where I’m going with this...

Jenny: Torn between how to feel...

Melissa: Yeah. Do I feel hopeful? Or do I feel like she’s going downhill and she’s not going to get better, or do I think well, let’s just do our best to try to prolong her life for as long as possible? And that is the way that I should be thinking, but because I’ve just been given this news, I’m thinking, ‘Oh, my God, my mother’s dying!’ So...right now I’m feeling hopeless and it’s a horrible, horrible feeling because I have been feeling so hopeful.

Cleary, hope serves an important purpose. These words of Amanda reveal the close relationship between hope and spirituality:

I mean, of course there’s part of me that does hope for a miraculous recovery. Like, ‘Yeah! One day all her tests are going to come back clear and she’s never going to have cancer again!’ And I’m not saying that that’s not possible – I do believe God is capable of miracles and these things do happen and it’s possible, but I also have this feeling that, well, it’s possible, but it won’t happen... I hope for [my mom] that she doesn’t suffer...Not that she isn’t suffering right now, because she is, even though she doesn’t talk about it a lot. But, I know for my Nana, she didn’t suffer very long. [The time that she was] really suffering, just before she died, was about six weeks. Which, considering that she had cancer for three years before that, wasn’t that bad...[I’m] not saying that any suffering is
good! But she was able to maintain a...mostly healthy life up until the very end. And I would hope that for my mom too, you know? That the end is far away. And that it wouldn’t be dragged out for a long period of time. (Amanda)
Discussion

This study aimed to illustrate how young adult daughters experience a parent’s cancer diagnoses and treatment. The findings drawn from the interviews create a complex, multifaceted picture of the numerous ways a daughter is affected by a parent’s cancer. Despite the obvious challenges and grief associated with a parent’s cancer, daughters managed to find some positive outcomes from their experiences. The love felt for parents and the commitment to family were undercurrents through all the interviews.

As mentioned earlier, the six primary themes that arose from the data can be further grouped into two categories, abstract ideas and concrete issues. In the findings section, the abstract and concrete themes were integrated to illustrate the nature of serious illness in the family: living with serious illness in the family is living with contradictions. For example, daughters were forced to find stability in uncertainty and to balance their hopes for the future with an appreciation for the present. In this section, each theme will be discussed in more detail and related to other findings in the literature.

Time

Time disruptions are a defining aspect of the experience of parental cancer. All of the participants in this study expressed feelings of shock and disbelief to be confronting the deaths of their parents during young adulthood; dealing with the reality of a parent’s mortality has been described as a “key marker of middle age” (Hagestad, 1996, p. 214). When participants recovered from the initial shock of their parents' diagnoses, they often found themselves in the phase of illness described as “living in limbo” (Rolland, 1999, p. 248). Living with this continuous uncertainty was almost intolerable for many of the participants. As a coping mechanism, participants were forced to acquire “the unenviable...
skill of developing a tolerance for ambiguity” (Carpenter, Morrow & Schmale, 1989, p. 102).

Facing a parent’s life-threatening illness during young adulthood is incongruent with the expected social timing of this passage. As revealed in the interviews, off-time or unscheduled transitions catch individuals unprepared and serve to highlight the pervasiveness of socially constructed timelines in guiding life expectations. However, social time schedules actually serve to reduce uncertainty by providing expectations about what events are likely and unlikely to take place during a given time in the life cycle (Hagestad, 1996). As indicated by myself and my co-investigators, a parent’s life threatening illness can result in the loss of “innocence about the normal expectations of life” (Frank, 1991, p. 39). Additionally, socially-structured life courses allow individuals to prepare for future challenges and contribute to a sense of belonging with same age peers. The off-time nature of parental cancer means that young adults may have limited social support because fewer of their same age peers are likely to have experienced similar circumstances. The potential sense of isolation resulting from this off-time experience speaks to the need for targeted support services or groups for this population.

Throughout the interviews, participants alluded to conflicts between “what they were supposed to be doing” during young adulthood, and the compromises required because of their parents’ illnesses. By considering the interplay between family and individual development, the impact of parental illness on family members can be understood (Rolland, 1999). Young adulthood is a transition period during which families become less cohesive. When serious illness occurs at this time and requires increased cohesiveness, the developmental goals of individual family members and of the family as
a whole can be disrupted (Rolland, 1999). The participants in this study described feeling that their “lives were on hold,” which highlights the potential challenges of trying to accomplish the developmental goals of young adulthood under the circumstances of parental cancer.

Participants also revealed their struggles to find balance between living in the present and anticipating the future. Rolland (1999) explains that with chronic conditions “the dimension of time becomes a central reference point” (p. 249) with family members challenged to remain focused on the demands of the present while preparing to deal with the unknown future. In the developed world, increased life expectancies have provided more certainty about the future, and consequently our society is increasingly future-oriented (Hagestad, 1996). When a parent is critically ill, young adult children feel unable to plan for the future, which can be a difficult adaptation and an isolating experience. Frank (1991) explains that because of his cancer diagnosis he was unable to make plans, and consequently felt he lost his sense of belonging. The experiences were similar for the young women in my study. However, developing an appreciation for the present was described as a benefit of the experience, a finding supported by Thornton’s (2002) review of positive outcomes from cancer. Practitioners working with this population can assist these young women in negotiating a balance between the present and future, and in identifying positive outcomes of their experiences.

In respect to daughters’ concerns for the future, nearly all participants in my study felt certain that they would develop cancer. As Tarkan (1999) explains, many daughters of mothers diagnosed with breast cancer become convinced that they too will develop the disease. Daughters often assume that what happens to their mother’s bodies will happen
to their own bodies (Takran, 1999). Consequently, they significantly overestimate their own risk and genetic susceptibility to the disease (Chalmers, Marles, Tatryn, Scott-Findlay, & Serfas, 2002). While none of the women in my study seemed paralyzed by this fear, this concern was widespread. Fear of illness can have serious consequences:

Amanda described her apprehension about doing breast self exams. Female relatives of women with breast cancer need personalized information about their own risk of the disease (Chalmers et al., 2002). Daughters of cancer patients may find solace in meeting with a doctor, oncologist, or genetic counselor to discuss their actual risk for the disease, ways to reduce their risk, and methods of early detection.

Knowing that their parents were unlikely to be part of significant life events deeply saddened and troubled many participants. Daughters were distressed that their parents might not be present at their graduations, weddings, or for the births of their children. Edelman (1994) found this anticipation of future losses to be typical. Although the topic of anticipatory grief has warranted extensive discussion and research unto itself, it is worth acknowledging that the feelings described by participants are consistent with this concept, a complex phenomenon of mourning, coping, interaction, planning, and psychosocial reorganization that occurs in reaction to the impending death of a loved one (Rando, 1997). The process of anticipatory grief can be therapeutic in facilitating preparation for death and in fostering increased intimacy, but it can be problematic if it leads to premature emotional separation from the dying family member. Young adult women can be assisted in understanding the phenomenon of anticipatory grief and supported in using this process to enhance their relationships with their ill parents.
Literature on the desire to accelerate time is scarce. However, this finding also seems related to anticipated losses. Perhaps the desire to accelerate life events arises from an attempt to compensate for the off-time occurrence of the parent's illness by creating congruency with the expected social timeline. Veach et al. (2002) suggest that when illness recurs and parents are seriously ill, they may encourage their adult children to meet developmental goals such as getting married, or establishing themselves in their careers. The authors explain that development may be accelerated so the parent can be part of the achievements of their children. While none of the daughters in my study described actually accelerating significant events, many considered the idea. The explanation of Veach and her colleagues is interesting because it suggests that parents may also feel this desire to accelerate events. This intriguing finding warrants further investigation.

While not discussed explicitly, participants made distinctions between various phases of illness that are consistent with those in Rolland's (1999) illness timeline. They described the time around diagnosis as a period of crisis. The chronic, ongoing stage of illness was identified as a time of "limbo," defined by uncertainty. Participants were also forced to acknowledge when their parent had reached the terminal stage of illness, when treatment was no longer intended to cure the disease. In the interviews, it became clear that illnesses change over time, and that different circumstances and demands accompany each phase of illness. It is essential for practitioners to consider the phase of illness faced by a family so that interventions and support can be targeted appropriately.

As expressed in the words of study participants, holidays and special occasions often become challenging and emotionally laden times when a parent has cancer. There
are two primary explanations for this difficulty: Holidays are symbolic of time passing, and holidays are times spent with family. Hendricks (2001) explains that holidays are conventions that help us ground the abstract concept of time. Since most holidays occur yearly, they represent the passing of time; consequently, holidays are markers by which we consider other events. Hagestad (1996) explains that holidays and annual events provide a predictable rhythm and sequence to time. She describes holidays as "punctuations" (Hagestad, 1996, p. 209) in calendar time that are experienced collectively. These interruptions in day-to-day life remind us that, despite the predictable sequencing of a calendar year, the future is ultimately uncertain. Holidays are also challenging because they are usually celebrated with family. Consequently, they are a time when the absence of a family member would be acutely noticed, and anticipating the holiday without a parent can be painful. As well, as Melissa explained, a parent's illness can interfere with or prohibit family traditions associated with a holiday.

Meaning of Cancer

Cancer and other illnesses are more than just physical conditions affecting the body; the human experience of being ill and the meaning of a particular illness is influenced by socially constructed beliefs and judgments (Kleinman, 1988; Sontag, 1978). Both Frank (1991) and Kleinman (1988) distinguish between illness and disease. They explain that diseases are the product of a biomedical perspective that seeks to identify measurable and 'objective' changes to the body. Illness is described as the experience of living through disease, an experience marked by fear and frustration (Frank, 1991). Kleinman (1988) defines illness as the human experience of symptoms and suffering. He explains that illness includes how people perceive, live with, monitor
and react to bodily symptoms, as well as their beliefs about how to best cope with disease symptoms.

Cancer, because it is still largely misunderstood, difficult to treat, and often fatal, is a particularly meaningful disease in our culture (Sontag, 1978). As expressed by participants in my study, a common assumption on hearing of a parent’s cancer diagnosis was that their parent would die. Koocher (1986) explains that “to many people ‘cancer’ is a synonym for death,” and that the public’s knowledge about cancer is complicated by the diversity of conditions known as cancer and by the rapidly changing treatments. Cancer has been described as the most feared disease in North America, yet Frank (1991) believes that this fear is not entirely explained by the actual incidence, mortality and suffering caused by the disease. Rather, societal beliefs have contributed to cancer’s construction as such a dreaded disease. In Sontag’s (1978) classic work *Illness as Metaphor*, the author proposes that when a disease is given meaning, the disease becomes a metaphor that is used to describe other things. The word “cancer” has been used to describe poverty, crime, drug abuse, corruption, decay and pollution (Frank, 1991; Sontag, 1978). Kleinman (1988) explains that cancer is a reminder of the unpredictability, uncertainty and injustice of life and symbolizes our lack of control over death and illness. These writers also discuss how the language of cancer treatment is that of warfare and fighting and that as a consequence, the body becomes the enemy. Given the negative and profound meanings associated with cancer in this culture, it is not surprising that daughters reacted intensely to a parent’s cancer diagnosis. Once participants were exposed to the reality of cancer through their parents’ illnesses, they sometimes realized that many societal meanings ascribed to cancer were inaccurate.
As revealed in the interviews, cancer treatment can seem worse than the disease itself. Cancer is an invasive disease and must be treated at a cellular level. Therefore, systemic, toxic treatments are standard (Koocher, 1986). As in my mother’s experience, the side effects of treatment are often worse than the early symptoms of cancer, and in some cases, as Kate alludes to, the treatment can prove fatal. Rachel describes her father’s treatment as “poison,” which is a common, and arguably accurate, view of chemotherapy drugs. This belief serves to reinforce the negative meanings attributed to cancer, as the treatment becomes implicated as part of the danger (Kleinman, 1988; Sontag, 1978).

Coping

Cancer is a topic well represented in the coping literature. A cancer diagnosis has been described as “a prototype of acute, extreme stress that confronts many families” (Compas et. al, 1994, p. 508). While a significant body of research has examined coping strategies used by cancer patients (e.g., Kershaw, Northouse, Kritpracha, Seafenacker, & Mood, 2004), fewer studies have examined coping in children of cancer patients, especially young adult children. This is a significant gap as Kershaw et al. (2004) found that the quality of life of women with advanced breast cancer was influenced by the coping strategies used by their family caregivers.

Participants reacted to physical changes and hair loss in their parents. Hair loss is almost synonymous with cancer treatment and has been described as the “visible sign most closely associated with cancer” (Frank, 1991, p. 92). Even though hair loss was expected, it served as a potent reminder of a parent’s cancer, which otherwise may have had few physical manifestations. While hair loss in a parent was distressing for some
participants, witnessing pain or signs of physical deterioration was particularly upsetting, especially when a parent seemed older, became frail or lost physical abilities. Watching a loved one deteriorate and feeling helpless has been described as one of the most difficult aspects of caregiving (Grbich, Parker & Maddocks, 2001). As Hersh (1997) explains, reactions to physical changes in a family member with cancer represent a form of grieving.

Participants identified negative emotions that arose during their parents’ illnesses. Emotional strain commonly accompanies cancer diagnoses, and this emotional strain has been reported by family members to be a difficult coping challenge (Yates, 1999). The emotions most frequently identified in my study included feelings of guilt, anger, fear and anxiety, findings supported by Grbich and colleagues (2001) in their study of families dealing with terminal cancer.

Emotions around a parent’s cancer are complex. While some emotions are common for the duration of the illness experience, other emotions are more likely to accompany different phases of illness. During the initial stage of diagnosis, feelings of shock, anxiety, confusion and despair are common (Sherman & Simonton, 2001). While emotional distress often decreases once treatment begins, anxiety about treatment outcomes and resentment of the disruption may occur. Levels of emotional stress in response to a parent’s cancer vary and depend on which parent is ill (Compas et al., 1994). Significant levels of emotional distress (depression and anxiety) have been identified in the adolescent and young adult daughters of mothers with cancer (Compas et al., 1994)
In my study, physical proximity seemed closely linked to the intensity of emotional reactions to a parent’s illness, and participants revealed that increased distance often minimized negative emotions. However, when daughters were not physically present for their parents they felt conflicted and guilty. As a coping strategy, physically distancing oneself from a situation is generally viewed to be an avoidant or maladaptive approach (Kershaw et al., 2004). Despite this view, as indicated by participants, some degree of separation was often necessary and beneficial. Kershaw and colleagues (1994) found that avoidant coping strategies, such as distancing, increased when a patient’s symptoms were higher, suggesting that avoidant coping strategies allowed caregivers to protect their own mental state by lessening their exposure to suffering in the patient. Rather than labeling coping strategies as adaptive or maladaptive, they must be considered in context. The sub-theme of distance further illustrates the tension between the developmental goals of young adulthood and the demands of a parent’s illness; since separating from the family is typical during this time, it can be particularly challenging for a daughter to remain physically involved with her parent’s illness.

Daughters found it challenging to balance their own needs with the needs of their families. Extensive research exists on caregiving and its impact on those providing care (e.g. Nijober et al., 1998). While my study did not measure the amount of caregiving provided by daughters, a parent’s cancer appeared to impact the physical and emotional well-being of daughters, regardless of the amount of care provided. Rachel, who identified herself as her father’s primary caregiver, described the most physical symptoms. As an only child, Kate also expressed significant pressure to provide support for her parents. Whether or not a daughter is providing physical care to her parent, she is
dealing with the ongoing stress of a cancer diagnosis. Providing emotional support for a parent or other family members can also be draining. A contradiction arises when a daughter is emotionally pulled into the family yet at the same time required to gain independence and responsibility earlier as a result of caregiving demands (Veach et al., 2002).

In previous decades, cancer was typically an acute disease that rapidly lead to death or deterioration (Nijober et al., 1998). Today, treatment advances mean survival time has increased, and cancer now has many characteristics of a chronic disease. As the course of the disease has changed, family members may be responsible for providing more care over a longer period of time, and have longer exposure to the stress and uncertainty that accompany cancer diagnoses. Consequently, more professional support may be needed to help families adapt to the long-term strain of cancer (Veach et al., 2002). More research is needed to understand how young adult children and their families cope with the long-term demands of cancer and the implications of ongoing parental disease for young adult development.

Relationships and Interaction

A parent’s cancer diagnosis impacted the participants’ interpersonal relationships and interactions in many capacities. Some of my co-investigators expressed surprise at the extent to which their relationships were influenced by their parents’ illnesses. In his classic developmental text, Erikson (1982) proposes that the central conflict of young adulthood is intimacy versus isolation. This conflict seems magnified by parental cancer. Shortly after their parents’ diagnoses, participants found themselves desperate for connection outside the family. Around the time of the initial diagnosis, families are
experiencing acute stress, and daughters seemed to seek support and stability elsewhere. In some cases, daughters found themselves becoming involved with people who they would have rejected under other circumstances. This could have negative consequences.

Parental cancer diagnoses made participants feel disconnected and isolated from some of their friends. Some felt they could no longer relate to the interests of their friends but more significantly, they felt that their peers were unable to understand their circumstances. As discussed earlier, the off-time nature of a parent’s illness during young adulthood means that fewer peers have experienced these circumstances and therefore are less likely to know how to react. Although many relationships prove to be supportive during a crisis, unfortunately it is common to lose some friends as a result of an illness in the family (Baker, 1999; Frank, 1991). Participants occasionally ceased contact with those people who seemed unable to understand how they were affected by their parents’ illnesses, and who were unreliable in providing support.

While some relationships disintegrated as a result of a parent’s illness, other relationships were enhanced. Some participants found that their parents’ diagnoses allowed them to form new relationships with people who had experienced similar life circumstances. As well, participants felt better equipped to support others, and more empathetic towards those facing crises.

Although participants expressed different levels of comfort around discussing their parents’ illnesses, many found disclosure to be uncomfortable. A parent’s illness is an emotionally loaded topic, and daughters in this study wanted assurance that if they shared this information they would receive a supportive response. Unfortunately, participants repeatedly found themselves disappointed and frustrated by others’ reactions.
As a result, they became more reluctant to share information. It seems likely, at least during early stages of the illness, that sharing a cancer diagnosis also reinforces the reality of the situation at a time when daughters are still adjusting to this news.

While research on disclosure among daughters of cancer patients is scarce, a study of disclosure and unsupportive social interaction in women with breast cancer provides some insight (Figueiredo, Fries & Ingram, 2004). The authors explain that disclosing concerns is a way of coping with a cancer diagnosis. Most women did not encounter unsupportive social interactions, though some women had experienced interactions that they felt either minimized the significance of the disease or created distance. Disclosure may have a significant impact on wellbeing; although the direction of the relationship is unknown, women who were less likely to disclose their diagnoses had less social support and experienced a greater number of unsupportive social interactions. They also expressed greater anxiety and emotional problems. The authors conclude that disclosure is important and must be considered in context of women’s support systems. A similar case could be made for the daughters of cancer patients. Because of the correlation with emotional wellbeing, the area of disclosure for family members of cancer patients warrants further inquiry. Social workers and other professional counsellors can assist and encourage daughters to appropriately disclose their parents’ illnesses, as this may increase their social support.

During young adulthood, intimate relationships become increasingly significant. All of my co-investigators were in committed relationships at the time they were interviewed. Parental cancer had both positive and negative impacts on their relationships. In some cases, a parent’s illness led to enhanced communication and
intimacy in relationships. For the most part, these intimate relationships became an essential source of emotional support. Sometimes, participants worried about the demands they placed on their partners, and were disappointed when they did not receive the support they desired. What daughters looked for in relationships was also influenced by their parents' illnesses. The literature on intimate relationships during young adulthood is limited, and little has been written about how these relationships may be influenced by parental illness. Because serious, long-term relationships are often formed during young adulthood, this is another area that should be explored further. Practitioners can assist daughters in understanding how their intimate relationships may be influenced by their parents' diagnoses, and provide suggestions for communicating about their support needs in these relationships.

**Family Relationships**

Family relationships are put under tremendous pressure when a parent is diagnosed with cancer. The potential loss of a family member threatens the essence of the family unit. Consequently, changes in family relationships are predictable. Rolland (1999) explains that illnesses generally make families closer, yet he cautions that they also carry the risk of creating distance and conflict. Sherman and Simonton (1999) propose that the ability of a family to respond to changes brought on by cancer depends on the openness of communication, the flexibility of the family structure, the personal meanings attributed to cancer, and the responses of family members to mortality issues.

Overall, study participants felt that their relationships with their parents became closer as a result of their illnesses. These findings are consistent with Leedham and Meyerowitz's (1999) research with daughters of cancer patients. When a parent has a
life-threatening illness, daughters may redefine their priorities and invest more effort and
time into their relationships with their ill parents. As well, in light of a serious issue like
cancer, more trivial relationship issues may be overlooked or fade away. Additionally,
many studies have shown that despite the stress associated with caregiving, it is
ultimately a rewarding and beneficial experience for many family members, and can
strengthen relationships (Barraclough, 1999; Grbich et al., 2001; Yates, 1999). While
most of the participants described positive changes in their relationships with their ill
parents, tension and discomfort were also reported. The relationship challenges were
related to frustration about caregiving and difficulty communicating. Cognitive changes
in parents were briefly discussed in the interviews. In this situation, family members
grieved the loss of the individual’s former personality and abilities. Participants in my
study also considered changes in their relationships with their healthy parents. Leedham
and Meyerowitz (1999) found that when daughters reported relationship difficulties,
problems were more likely to be with their non-ill parents than with their ill parents. This
was attributed to feeling distant from or resentful of the healthy parent, and finding the
healthy parent too demanding.

While it was common for participants to consider the implications of whether
their mother or father was diagnosed with cancer, this finding does not seem to be
discussed in the literature. When a parent is diagnosed with cancer, daughters spend
considerable time evaluating the impact of the illness on the family. Thinking about
which parent is ill may simply reflect the differences in a daughter’s relationship with her
mother and with her father, and be part of the process of adjusting to a parent’s cancer.
These thoughts may also reflect a daughter’s assessment of the quality of her
relationships with each of her parents, in light of a possible loss. Clearly, this is an area that is worthy of further investigation.

_Spirituality and Hope_

Over the past decade, spirituality in the face of illness has become a subject of increased academic interest, especially in social work. However, a lack of consensus exists on the definition of spirituality, a concept encompassing a broad range of ideas. In social work, spirituality is often understood as an individual’s search for meaning and a sense of purpose in her world (Canda, 2002). Sometimes, spirituality also refers to a person’s sense of wholeness or feelings of unity in relationship to herself, to others, to her environment and to a higher power (Woods & Ironson, 1999). Spirituality and religion are closely related but not necessarily the same. Religion generally includes organized systems of beliefs, values, practice and rituals shared by a particular community (Canda, 2002; Jenkins & Pargament, 1995). An individual’s sense of spirituality can exist within or outside of organized religion.

Cancer is a crisis that can bring into question spiritual issues for those diagnosed with the disease (Gall & Cornblat, 2002). People often become more religious, or, conversely, may lose faith in religion in light of life-threatening disease (Kendrick & Koenig, 2000). As revealed in my research, a parent’s cancer diagnosis raises the same issues for young adult daughters. While some daughters in my study found spirituality became more significant as a result of their parents’ diagnoses, others found themselves reexamining or questioning their belief systems. The spiritual issues explored by daughters in this study are similar to those expressed by women with breast cancer. Gall & Cornblat (2002) found that some women with breast cancer became more spiritual and
found solace in their faith in God. Other women found themselves wondering how God could help them cope with their illness and asked how a just, caring God could let them become ill and cause such suffering. Most women, regardless of their relationships with God, turned to a higher power for answers and peace. Kate mentioned that she only turns to God when she has a problem; during times of crisis or when circumstances seem beyond human understanding, it is natural to look to a higher power for support (Spilka & Hartman, 2000). Evidently, religious and spiritual beliefs can be strengthened by a crisis and can provide a basis for finding meaning in a difficult circumstances (Gall & Cornblatt, 2002).

The diagnosis of cancer in a family member often raises existential concerns about the purpose and meaning of life for other family members, especially adult children (Lewis, 1986). When a parent becomes ill, young adult children often experience a sense of mortality and vulnerability for the first time and must come to terms with the possibility of a future without their parent (Davis, 1997). In my study, mortality was sometimes discussed directly, and all participants alluded to an increased awareness of the fragility of life. For some participants, central to their discussions of spirituality were their ideas about what happens after death. Considering the existence of an afterlife and establishing a comfortable set of beliefs around this fundamental question are likely central to developing an understanding and acceptance of human mortality. When discussing spirituality with individuals who have incurable illnesses, Canda (2002) recommends that these conversations explore beliefs about what happens after death. This topic should also be discussed with family members of those with life-threatening health conditions. In my study, some participants were comforted by the idea that their
parents would reconnect with other loved ones after they died. Examination of beliefs around mortality and the afterlife may be an important step in helping young adults accept the eventual loss of their parents.

While a large body of research has examined the significance of hope for those diagnosed with cancer, there has been less research addressing the role of hope for family members of cancer patients. Hope is “a concept that is intuitively understood” but is “elusive to rigorous definition” (Bunston et. al., 1995, p. 81). Even if hope eludes definition, it is “an essential ingredient that supplies incentives to rise in the morning and look forward to the new day, regardless of circumstances...or the emotional pain” (Bunston et al. 1995, p. 97). Hope is described as “internal resource” (Baker, 1999, p. 205) that permits individuals to cope with the stresses associated with cancer. When hope is lost, coping ability is reduced. Hope typically changes over the course of cancer:

There is always hope, it just changes. First you hope that you don’t have cancer, then you hope that the cancer is curable or at least treatable. Then you hope for time and finally, you hope for a good going. If you lose hope you give up. (Baker, 1999, p. 205)

Until I introduced the idea of ‘reframing’ hope in the interviews, most participants described themselves as hopeless. Learning to remain hopeful can be important in coping resiliently with difficult circumstances. Daughters may benefit from recognizing that even when a parent’s cancer is incurable, they can still find hope.

In any interview, what was not said is often as revealing as what was expressed. In my study, financial problems were only discussed by one participant, and these concerns were related to the basic costs of living rather than to medical treatment. Had this research taken place in the United States, it is likely finances would have been a significant topic of discussion. While this may reflect the socio-economic statuses of my
participants, it also speaks to effectiveness and value of a publicly funded health care system. In the United States, financial burden is often cited as barrier to receiving cancer treatment, and is even related to increased mortality rates (Sherman & Simonton, 1999). As well, it was surprising that family dynamics were not discussed in more detail. For example, there was little discussion of siblings or of extended family relationships. While this is related to the fact that two of my co-investigators were only children and none lived with their siblings, it also suggests that young adulthood is a phase when individuals are still somewhat self-focused. Conversely, this may reflect the limited opportunities available for daughters of cancer patients to tell their own stories.

Summary of Discussion

For some participants, the experience of parental cancer began on the day of their parents' diagnoses. For others, it began earlier in frustrating months of symptoms and misdiagnoses. In both circumstances, daughters were shocked by the unexpected news. Participants found that their parents' illnesses distorted their perceptions of time; daughters faced overwhelming uncertainty and lost their confidence in a predictable future.

Coping with the ongoing stresses of cancer was physically and emotionally draining for participants. Daughters confronted their parents' treatment side effects, hair loss and pain. Emotions such as guilt, anxiety and anger were common. Sometimes, daughters struggled to balance their own aspirations with their feelings of obligation and desire to care for their parents and families.

Participants found their parents' illnesses influenced their relationships on many levels. Some felt isolated from their friends and sought support and connection
elsewhere. Difficulty disclosing a parent’s illnesses and disappointment with the
reactions of others were common. In intimate relationships, participants depended on
their partners for reassurance and support. Family relationships were also affected. While
daughters found their relationships with their ill parents generally improved, they
sometimes faced uncomfortable moments and awkwardness.

All of the young women in this study found their parents’ diagnoses led them to
examine their spiritual and religious beliefs. Daughters were forced to confront mortality,
and some explored ideas on the existence of an afterlife.

Despite these challenges, daughters demonstrated their resilience by finding
wisdom and meaning in their experiences. Even when a parent’s cancer was incurable,
daughters could still identify hopes for the future. Participants developed a deeper
appreciation for the positive aspects of their lives, the present time and the significance of
family relationships. As a result of their own experiences, daughters found themselves
more empathetic and better able to support others in crisis. Some participants developed
new relationships and felt deeper connections with other people who had faced similar
challenges. Other participants were gratified by their increased feelings of spirituality.
Significantly, most daughters found tremendous satisfaction in their relationships with
their ill parents, and were gratified that they chose to stay involved.
Limitations

Some limitations must be acknowledged. While the qualitative methodology provides a rich illustration of the experiences of this group of young women, the small sample size of this preliminary, exploratory study means that limited generalizations and conclusions can be drawn from the data. As with any research, the experiences of my co-investigators may have varied significantly from women who did not choose to participate. The women who participated may have been more involved physically and emotionally with their parents' illness and possibly coping differently than women who did not take part. Although my co-investigators came from diverse backgrounds, all were Caucasian and heterosexual. The definition of young adulthood used in this thesis represents a Western, individualistic perspective. Further expanding this study to explore the experiences of young adults from different cultural and ethnic backgrounds may reveal distinct findings.

Another issue to consider is the impact of my self-disclosure on the data constructed in the interviews. Most likely, different data would have been elicited by another interviewer or with a more conventional (i.e. more structured and less interactive) approach to interviewing. However, I am confident that my willingness to disclose my own experiences resulted in richer data.
Reflections

This thesis is the product of two parallel journeys: the journey of conducting research and the journey of adapting to my mother's illness. The research process began with an idea and a question, then wound through ethical review and a proposal defense, on to data collection, transcription and analysis, to result in outcomes and implications, and finally to end here, with reflections. Adapting to my mother's illness has been a longer, more challenging journey. It began the day of her diagnosis and will continue long after this thesis is complete. Here I reflect on both processes. I examine my dual roles of participant and researcher, consider the act of subjecting my own experience to academic inquiry, and ultimately, reflect on what I have gained from looking inward.

On Interviewing

Before I began interviewing, I could only anticipate how a collaborative interview methodology would work in practice. So much depended on uncontrollable variables such as rapport and my relationship with my co-investigator. Once I established the role and purpose of my self disclosure (i.e. to solicit responses from my participants and to create rapport), the interviews flowed smoothly. While this methodology allowed a conversational dialogue in the interviews, it forced me to choose between responding to participants comments or disclosing my own experiences. The extent of my disclosure varied in each of the interviews, depending on how much my co-investigator shared. As well, the fluidity of roles in the interviews varied. At some points, it is likely that an outside observer would have been unsure who was the researcher and who was the participant. My co-investigators felt comfortable asking me questions, which encouraged my self-reflection and allowed true dialogue.
Moments of genuine connection occurred. Participants often assumed I would understand their experiences, knowing mine were similar. Had I not disclosed my story, the participants and I would have been unable to connect over shared details of our experiences. For example, Kate and I discussed the cost of parking at the Cancer Agency (It should be free!); Melissa and I pondered the ages that we would have to start having mammograms (Is it 35? Or 45? Or...?). An email from a participant after our interview revealed that she also found the experience rewarding: “I felt really good doing it too - not only because I know that it will benefit others but just the relief of having it come out and connecting with you on that level was really positive for me, so thank you.” Mostly, I feel privileged that my co-investigators felt comfortable sharing their personal experiences with me, and to have had the opportunity to learn from them. The words of my participants have resonated with me, and helped me stay present in this illness experience.

On Data Analysis

By putting myself in this research, I took a risk. I lost my anonymity. My participants have the protection of pseudonyms. I do not. This research approach forced me to face my experiences with honesty and openness. Data analysis required me to read and re-read passages about times I would rather have forgotten, and to dissect the painfully familiar experiences of my participants.

When I began writing the findings and discussion, I started with the more abstract themes. The themes addressing relationships I put off until last. Reflecting on this, it seems obvious that these abstract themes were less personal and less emotional in
Fascinated by the concept of time as it related to parental illness, I wrote this chapter first. The irony of writing about time is the time pressure I feel to complete this thesis. On one level, I have the time pressure of the approaching deadline. On another level, I feel pressure to complete this thesis while my mother’s health is stable (even writing this makes me nervous). My mother and I joke: “Just live long enough to let me finish my thesis.” This research project has felt like a race against time, against the illness. The legitimacy of this feeling was reinforced by the deaths of Melissa’s mother and Rachel’s father in the months shortly after our interviews.

On Creating a Story

In my first interview, I realized the power of having someone ‘bear witness’ to my story. I began the interviews by describing the circumstances of my mother’s diagnosis and the following events. Telling my story from the beginning helped me to decode my emotions and my memories of the chaotic time around my mother’s diagnosis. Recounting this story on four different occasions revealed that my story changed over the course of the interviews. My version of the story became more rehearsed. The first telling was the choppiest. Eventually, some elements of the story became shorter while others expanded. The details changed, depending on my co-investigator, the comfort level between us, and the precise topics of discussion. Living through challenges, we formulate and tell our stories repeatedly, changing them to fit our fluctuating identities (Ellis, 1998).
In reading the transcripts, I became aware of the necessity of creating the story of my mother's illness, of my need to link the pieces together and create a meaningful account. In reality, this experience has been disconnected and overshadowed by uncertainty. During the interviews, I became conscious of how difficult it is to make a linear account of these events. I repeatedly made comments like “I thought I remembered this clearly...” or “I just don’t remember the timeline anymore.” I now realize the inaccuracy of memories: My recollections of events do not fit together or create a linear story. Ellis (1995, p. 315) offers: “We do not live life linearly.” Similarly, Frank (1991, p. 42) explains “writing creates an illusion of order, but in life the experiences overlap.” Telling stories about our experiences helps us to understand our lives. Stories provide order and coherence to the disorder of our existence.

As I write this, six months after I began interviewing, I realize: Writing is static. By recording and transcribing interviews, they become permanent, yet the interviews are only a snapshot, taken at the time of the interview. Research truly is a product of the time and place in which it is constructed. I have gained this insight by actively including myself in the interviews. If I were to conduct an interview today, the content of my disclosure would be different. I believe the themes would be consistent, but the details would be distinct. Reflecting on the months in which I conducted the interviews, I am aware that what I shared reflects my specific personal challenges at the time of the interviews. This in turn was reflected in the topics I discussed during the interviews, and in the themes that I created.

*On Benefits*

To seize the opportunities offered by illness, we must live illness actively: we must think about it and talk about it, and some, like me, must write about it.
Through thinking, talking and writing we can begin as individuals and as a society, to accept illness fully. Only then can we learn that it is nothing special. Being ill is just another way of living, but by the time we have lived through illness we are living differently. (Frank, 1991, p. 3)

These words from Frank’s personal account of cancer struck me deeply. Frank voiced my own desire to live my mother’s illness actively. I must reiterate: it was a long process before I could do this research. However, from the time of her diagnosis I felt, on some level, that it was important to be involved in her illness and all that it entailed.

During my interview with Amanda I explain:

I know other people I’ve talked to [have said], ‘I’ve never been with my mom to chemo,’ or ‘I’m sort of OK with not knowing.’ But I always felt... ‘I want to know every part of this experience.’ I go with her to chemo because she likes having me there... I’ll just be there and I’ll make her laugh... but, maybe similarly, I want to know what’s happening and I want to be part of that.

Doing this research has allowed me to “seize the opportunities offered by illness” (Frank, 1991, p. 3). I have benefited from this process on academic, professional, and personal levels.

Academically, this project allowed me to experience the rewards and challenges of conducting research. By planning and implementing a research project myself, I am a better consumer of other research literature. In the course of this research, I have developed an appreciation for theory, and a recognition of its value in providing structure to life circumstances. As a result of my positive experiences with this research, I am considering potential involvement in future research and further graduate studies.

On a professional level, I am certain that my experience of my mother’s illness will make me a better social worker. While I had decided to pursue a career in social work before my mother was diagnosed with cancer, as a result of her illness, I am now
committed to pursuing a social work career in a healthcare setting. I feel that the insights I have gained from my experiences will allow me to better support other families facing illness and loss. Regardless of the situations faced by my clients, I can empathize with the feelings of acute stress that may accompany their circumstances. Also, I am aware of the type of support that is helpful in times of crisis, and I have a deeper understanding of (anticipated) grief and loss. The self-awareness demanded by my research approach will benefit my practice. Being aware of my own sensitivities and strengths will be essential when working in an emotionally challenging profession like social work.

While not directly related to this research, one outgrowth of this project was a support group at the British Columbia Cancer Agency for young adults facing parental cancer. Through collaboration with another MSW candidate who was completing her practicum placement at the Cancer Agency, and under the supervision of a professional social worker, we initiated a group for young adults. This group has been well received, and was central in supporting two group members through the deaths of their parents. At this time, the group has been meeting for approximately seven months and has five core members, all young women in their early to mid-twenties. More women have expressed interest in the group, which the Cancer Agency continues to promote. This research helped create the opportunity to start this group, and reinforced the need for specialized services for this population.

On a personal level, this research has been a therapeutic process. During my interview with Melissa I reflected:

It’s just sort of interesting thinking of this now, how long this has been going on for and...I guess how far we’ve come. I’ve come... Like I guess just how much has changed in how we think about it from the beginning.
For a long time, I was very angry about my mother’s illness. I am not so angry anymore. It astounds me that living with such uncertainty can become normal. I had to learn consciously to focus on the present. The year of my mother’s diagnosis, I had a Zen wall calendar. One month had the inscription: “You are here. This is now.” I wrote this on a piece of paper, and kept it beside my bed. Today I have managed to balance being in the present, with “glancing toward the future” (Grbich et al., 2001).

As a result of this research, I have become much more comfortable disclosing my mother’s illness. I have formed new friendships because of my research. When I introduce my thesis topic, I open the conversation for people to share their similar experiences. I am shocked by the number of people I have spoken to who have a family member with cancer, and amazed by the similarities in our experiences.

Through my interviews, I have learned how other young women are coping with their parents’ cancers. I cope by trying to find meaning in this, by trying to learn from this experience. This research is a way for me to make an account of my experience, and through my dialogue with other young women, to make sense out of the past three years. This research is a way for me to tell my story, even if I am unsure how it will end.
Future Directions

This exploratory study raised many issues that warrant further inquiry. As this study had a relatively small sample size, expanding or replicating this study with more diverse samples may reveal novel findings or reinforce the findings from my study. Additionally, a larger sample could provide more insight into the difference between having an ill mother and an ill father. My study did not consider the staging of a parent’s cancer. I anticipate the experience would be distinct depending on the parent’s expected prognosis. Other areas that should be further investigated include the common desire to accelerate life events and the challenge of disclosing a parent’s illness. As well, the lived experiences of young adult women who have lost a parent to cancer is an area worthy of investigation. Advances in cancer treatment will continue to impact the course of the disease. In light of this, more inquiry is needed to explore the impact of ongoing parental illness on young adult development. Despite suggestions in the literature that daughters are more distressed by parental cancer, more research is needed to understand how young adult sons are affected by a parent’s illness. The increased distress measured in daughters may reflect the measures used or gender variations in expressed emotion. Finally, research approaches that draw on the personal experiences of the researcher should continue to be developed and utilized. These studies provided unique insights into the lived experience of illness and the process of doing research, and will contribute to increasing the acceptance of alternative approaches to academic inquiry.
Implications for Practice

Young adult children of cancer patients are an under-served population. A number of suggestions can be drawn from my study for social work practice and other counselling professions. As indicated by my co-investigators, it may be a common instinct for young adult children to ‘run’ from their parents’ illnesses. In addition to well-advertised services in cancer treatment facilities, support services also need to be readily available in places frequented by young adults, such as college campuses. The off-time nature of serious parental illness during young adulthood means that these young people may have less access to social support. Targeted support groups for this population can be beneficial in counteracting this potential isolation.

Many issues arising from parental cancer may need to be addressed in individual counselling. Therefore, young adults need access to appropriate and accessible counselling services. Parental illness during young adulthood frequently presents a conflict with the developmental goals of this stage. Individual counselling can provide an opportunity for young adults to acknowledge and work through these conflicts, and to continue negotiating their development in the context of family illness. Developmental issues likely to be discussed include leaving or returning home, and intimate relationships. Counselling can also be beneficial for processing the difficult emotions that arise from a parent’s illness.

Living with uncertainty can be overwhelming. Social workers and other practitioners can assist young adults in managing their fears for the future, and in developing an appreciation for the present time. Helping young adults maintain or
reframe hope can also help them to endure the uncertainty of the future. As well, they can be supported in identifying positive outcomes and meaning in their experiences.

Daughters in this study commonly expressed concerns about developing cancer in the future. Meeting with a physician, oncologist or genetic counsellor to evaluate their actual risks for the disease may reduce daughters’ anxieties. Anticipatory grief may underlie many reactions to a parent’s illness. Daughters can be helped in understanding this phenomenon and in drawing from this knowledge to strengthen their relationships with their ill parents.

In respect to relationships and interactions, if young adults feel reluctant to disclose their parents’ cancers, a practitioner can provide suggestions for introducing this sensitive topic to others. In terms of intimate relationships, the potential impact of a parent’s illness on relationships should be addressed. Those working with this population should be alert to the risk of young adults forming harmful relationships out of their desire for connection.

A parent’s cancer diagnosis often forces young adults to examine their spiritual beliefs and confront mortality for the first time. Practitioners should be sensitive to the significance of spiritual and existential issues for young adults. As indicated in other studies, the support and interventions offered should reflect the stage of the parents’ illness.
Conclusion

A parent's cancer diagnosis during young adulthood is a life-altering experience. Overall, young adult daughters demonstrated resiliency and adaptability in response to their parents' illnesses, and managed to negotiate their own needs while continuing to support their families. Although parental cancer presents numerous challenges, the experience appears to become a learning opportunity that can be incorporated into development. However, young adult daughters may benefit from support in coping with their parents' illnesses, and in meeting the developmental goals of this transitional phase of the life course. Ultimately, these young adult women revealed that living nearer to death allowed them to develop a greater appreciation for life.
References


Appendix I: Topics for Discussion

1. What was happening in your life before your mother/father was diagnosed?
2. What was it like when your mother/father was diagnosed?
3. Could you tell me about your mother/father’s health currently?
4. How have you been involved in your parent’s treatment/healthcare?
5. What has changed since your parent’s diagnosis? In your life? In your family?
6. Has your mother/father’s diagnosis influenced your life plans?
7. What is your relationship like with your ill parent, other family members?
8. What is the hardest part of dealing with this?
9. What has helped you deal with this?
10. Have you learned or gained anything since the diagnosis?
11. What is unique about being your age and dealing with this?
12. What would you tell someone else your age whose parent has just been diagnosed with cancer?
13. Is there anything else you want to tell me?