ADOLESCENTS' RESPONSES TO HAVING A MOTHER WITH CANCER

by

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Introduction: Each year potentially 1:270 children in the US are affected by the diagnosis of cancer in their mother. The diagnosis of cancer in a woman may cause changes in her behavior, emotions, and physical and family functioning (Lewis, 1996). In turn, these changes may impact her adolescent's behavior, school performance, emotions, and physical functioning (Visser et al., 2004). **Purpose:** The purpose of this study was to elicit and understand the adolescents' experience of having a mother with early stage cancer, the meaning that adolescents construct about having a mother with early stage cancer, and the processes that adolescents use in coping with having a mother with early stage cancer. **Methods:** This qualitative study used a grounded theory method to guide the exploration of the experience of male and female adolescents, ages 12-17 years, whose mother had been diagnosed with early stage cancer a minimum of 6 months and a maximum of 2 years ago. Each early stage cancer had a 5-year relative survival rate of 80% or greater. Adolescents' responses were elicited by a semi-structured interview guide. **Findings:** Adolescents experienced a process after their mother was diagnosed with cancer. After they learned the diagnosis, the process became cyclical and at times simultaneous, as cancer changed the family, the adolescents' coped, and demonstrated a sense of purpose. **Conclusions:** Having a mother with cancer is a significant life changing event for adolescents.

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PREFACE

This dissertation is dedicated to my family

Dr. Gregory D. Grabiak and Mrs. Rita R. Grabiak

Leonard, Tracy, Samantha, Nicholas and Alexander Rosky

William, Lynn, Jackson, Delaney and Dylan Murphy

Thank You

Mothers and Adolescents
To the mothers and adolescents who participated in this study

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1.0 CHAPTER I

1.1 INTRODUCTION

In 2000, 41,000,000 adolescents ages 10-19 years lived in the US (http://www.census.gov). In 2007, an estimated 76,000 women between the ages of 20-44 years were diagnosed with cancer in the US (American Cancer Society, 2007). Although the parity status of these women was unknown, assuming one to two adolescents per household, potentially 152,000:41,000,000 adolescents or 1:270 adolescents in the US are affected by the diagnosis of cancer in their mother, annually.

The diagnosis of cancer in a woman may cause changes in her behavior, emotions, and physical and family functioning (Lewis, 1996). In turn, these changes may impact her adolescent's behavior, school performance, emotions, and physical functioning (Visser et al., 2004). For example, adolescents who have a mother with cancer encounter stressors; studies have found that these children are at risk for behavior problems in the school or in the home. Poor concentration, poor academic performance, and increased conflict with peers and siblings is common among these adolescents (Birenbaum et al., 1999; Christ et al., 1994; Compas et al., 1994; Fasciano et al., 2007; Helseth & Ulfsaet, 2003). Problems with schoolwork and attendance include truancy, having to arrive to school late, and having to leave early to pick up younger siblings from school (Nelson et al., 1994).

Female adolescents of women with cancer feel increased vulnerability to cancer related to genetic risk (Grandstaff, 1976; Kristjanson et al., 2004; Spira & Kenemore, 2000; Wellisch et al., 1991) and can identify symptoms of breast cancer (Wellisch et al., 1991). Adolescent females' fears are associated with physical / sexual development (Spira & Kenemore, 2000); adolescent females report significantly less frequent sexual intercourse and lower sexual satisfaction (Wellisch et al., 1991). Female adolescents also indicate that they suffer from a variety of symptoms including headaches, abdominal pain, dizziness, sleeping problems and loss of appetite (Rosenfeld et al., 1983; Spira & Kenemore, 2000). Adolescents who have a mother with cancer develop new coping strategies, such as a search for meaning in the illness and seeking social support (Christ et al., 1994), yet struggle with the impact of the mother's illness on the family (Fasciano et al., 2007).

The literature documents that having a mother with cancer affects adolescents' behavior, school performance, emotions, and physical functioning; however, the male and female adolescents' experience of having a mother with early stage cancer is under studied. This dissertation describes the process by which adolescents begin to address and cope with issues that emerge within the family and the meaning of the diagnosis in their lives (Figure 1, p.67).

1.2 PURPOSE OF THE RESEARCH STUDY

The purpose of this research study was to elicit and understand: 1) the adolescent's experience of having a mother with cancer; 2) the meaning that adolescents construct about having a mother with cancer; and 3) the processes that adolescents use in coping with having a mother with cancer. Male and female adolescents, ages 12-17 years, whose mother had been diagnosed with early stage cancer a minimum of 6 months and a maximum of 2 years prior to study participation, were eligible for the study. Each early stage cancer had a 5-year relative survival rate of 80% or greater.

1.3 SIGNIFICANCE

This research study is significant in several respects. First, to date, the dominant research tradition has been to examine the woman with breast cancer, her spouse, and school age children. The three studies that have been conducted on the adolescent of a woman with cancer have been limited to adolescents whose mothers have breast cancer (Kristjanson et al., 2004; Lewis & Hammond, 1996; Spira & Kenemore, 2000). Second, most studies in the area have used standardized measures to record the psychosocial and behavioral functioning of the adolescent whose mother has cancer. These standardized measures may not fully capture the adolescents' experience. Third, of the three studies that include only adolescents, Lewis and Hammond's (1996) and Kristjanson et al.'s (2004) studies included both *male and female* adolescents. Male adolescents of women with cancer have been under studied. This qualitative research study used a semi-structured interview to elicit the adolescent's experience of having a mother with cancer from the adolescent's point of view and in his/her own words. The knowledge gained from this dissertation research may inform and guide the development of future studies.

1.4 PERSPECTIVE OF THE INVESTIGATOR

Beth R. Grabiak, PhD(c), MSN, CRNP, is an otorhinolaryngology head and neck cancer nurse; family nurse practitioner; graduate student researcher; and doctoral candidate at The University of Pittsburgh School of Nursing. As a nurse / family nurse practitioner, she has worked clinically in a rural otorhinolaryngology office and in an urban emergency department. Anecdotally, she has found that women with cancer are concerned about their adolescents and how they are coping with the diagnosis of cancer in their mother.

While working at The University of Pittsburgh School of Nursing as a graduate student researcher, her preliminary research study and doctoral dissertation grew out of two projects: one assessing depression in infertile women and the other providing an intervention targeting anger as a factor that contributes to high-risk behavior for youth living in rural areas. These early experiences taught her valuable skills that were applied to the dissertation study. She has experience in recruiting, consenting and enrolling subjects; Institutional Review Board submissions; coordinating and conducting adolescent interviews; qualitative and quantitative analysis; presentation of research results at local and national scientific meetings and in peer-reviewed journal publications. She was principal investigator on a secondary data analysis which served as a preliminary research study for this dissertation. The parent study for this secondary data analysis, the “Enhancing Connections Program” (EC), was a 6-state randomized clinical trial that evaluated the efficacy of a 5-session educational counseling program for child-rearing mothers with recently diagnosed breast cancer and their school-age and young adolescent children. The randomized clinical trial was funded by the National Institutes of Health and led by University of Washington researchers (PI: Frances M. Lewis, Ph.D.; University of Washington). Results showed that when adjusting for other variables like children’s age and gender, depression in mothers with breast cancer significantly predicted children having overall concerns about the illness. Furthermore, the mother's depression significantly predicted increased family-related worries in children.

1.5 DEFINITION OF TERMS

1.5.1 Adolescence

Adolescence is a period of life in which the biological and psychosocial transition from childhood to adulthood occurs. Tasks such as achieving independence from parents, adopting peer influenced social codes and lifestyles, assigning increased importance to body image, acceptance of one's body image, and establishing sexual, ego, vocational and moral identities characterize maturation of the normal adolescent (Neinstein, 1996). Early adolescence includes years 10 to 14; middle adolescence includes years 15 to 17; and late adolescence includes years 18 to 20 (Lerner, 2002).

Adolescence is defined as "including those ages between 10 and 19, and *youth* as those between 15 and 24; *young people* is a term that covers both age groups, i.e. those between the ages of 10 and 24. True adolescence, however, being the period of physical, psychological and social maturing from childhood to adulthood, may fall within either range" (World Health Organization, 2001, p.1). This research study included early and middle adolescents as defined by the age range of 12-17 years.

1.5.2 Women with Cancer

Women were mothers of adolescents, and diagnosed with early stage cancer a minimum of 6 months and a maximum of 2 years prior to research study participation. Each early stage cancer has a 5-year relative survival rate of 80% or greater.

1.5.3 Cancer

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. After diagnosis, most cancers are staged to provide information about the anatomic extent of disease (Greene, et al., 2006). The staging system includes primary tumor site, tumor size, number of tumors, depth of invasion and extension to regional or distant tissues, involvement of regional lymph nodes and distant metastases. There are two staging classifications developed by the Surveillance, Epidemiology and End Results Program of the National Cancer Institute: extent of disease and summary staging (Table 1). Classifications of the summary staging system include:

- in situ – the presence of malignant cells within the cell group from which they arose,
- localized – a malignancy limited to the organ of origin; no spread beyond the organ of origin,
- regionalized - tumor extension beyond limits of organ of origin,
- distant – tumor which has spread to areas of the body distant or remote from the primary tumor, and
- unknown – sufficient evidence is not available to assign a stage (http://training.seer.cancer.gov).

The American Joint Committee on Cancer (AJCC) staging scheme is based on the tumor (T), node (N), and metastasis (M) components. Subscripts are ascribed to the T, N, and M. The following is a general description of the meaning of the T, N, M subscripts:

- T is the extent of the primary tumor,
- T1 - a small lesion confined to the organ of origin,
- T2 - a larger tumor size or deeper extension into adjacent structures, tissues, capsules, or ligaments,
- T3 - a larger tumor size or extension beyond the organ of origin but confined to the region,
- T4 - a massive lesion or one that directly invades another organ or viscera, major nerves, arteries or bone,
- N is the absence or presence and extent of regional lymph node metastasis, and
- M represents the presence or absence of distant metastases.

The staging of cancer is illustrated in Appendix A. There are four stages of cancer. This research study includes women with early stage cancer (0, I and II cancer). The staging of the cancer (stage 0 – stage II) differs according to the type of cancer. For example, stage I breast cancer includes stage I; stage I cervical cancer includes stage I, IA, IB; and stage I endometrial cancer includes stage I, IA, IB and IC. Following diagnosis, patients and families are introduced to the treatment phase of the clinical course. The initial treatment may involve surgery, chemotherapy, radiation therapy, biological (hormonal) therapy, or some combination of each. In some cases, no primary treatment is available. Treatment options depend largely on the type and severity of the cancer, and the initial treatment may vary from a surgical intervention to a course involving combination treatments that may extend for months.

Table 1. Summary Staging System

(T) Primary Tumor	(N) Regional Lymph Nodes	(M) Distant Metastasis
TX: primary tumor cannot be assessed	NX: regional lymph nodes cannot be assessed	MX: distant metastasis cannot be assessed
TO: no evidence of primary tumor	NO: no regional lymph node metastasis	MO: no distant metastasis
Tis: carcinoma in situ		
T1, T2, T3, T4: increasing size and local extent of the primary tumor	N1,N2,N3:increasing involvement of regional lymph nodes	M1: distant metastasis

(http://training.seer.cancer.gov)

2.0 CHAPTER II

2.1 REVIEW OF THE LITERATURE

This chapter presents the current literature on adolescents who have a mother with cancer. In 2007, the author published a critical analysis of descriptive studies, intervention studies, and data-based book chapters, published between 1966 and 2006, that examined the impact of parental cancer on the adolescent (Grabiak, Bender & Puskar, 2007). The following analysis of the literature, which is a modified version of the original analysis, presents the results of 21 descriptive studies, three intervention studies, and three data-based book chapters that examined the impact of having a mother with cancer on the adolescent.

A search for published studies and literature reviews on the impact of parental cancer on the adolescent was conducted using PubMed, a service of the National Library of Medicine and included the databases MEDLINE, 1966 to 2006; CINAHL, 1982 to 2006; PsycINFO, 1967 to 2006; the Cochrane Database of Systematic Reviews, and http://highwire.stanford.edu. The keyword combinations used in the search were adolescent and parent and cancer; cancer and family and literature review; and cancer and adolescent and literature review. A search for data-based book chapters was conducted in *Pittcat,* the online library catalog of The University of Pittsburgh. The keyword combinations and subject headings included cancer patients and family relationships; cancer and social aspects; cancer patients and adolescent children; cancer patients and children; and cancer patients and family.

This comprehensive search and review of *children and parental cancer* revealed 82 studies and 14 data-based book chapters. A research study or data-based book chapter was excluded if it was not in English; discussed only the impact of parental cancer on pre-school, school-age, young adult or adult children; focused on children of individuals who had died of cancer; dealt with pre-death and post-death adaptation of children; or included a *father* with cancer.

Twenty-one descriptive studies (Compas et al., 1994; Forrest et al., 2006; Grant & Compas, 1995; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Hoke, 2001; Huizinga et al., 2005; Issel et al., 1990; Kristjanson et al., 2004; Lewis & Darby, 2003; Lewis & Hammond, 1996; Nelson & While, 2002; Spira & Kenemore, 2000; Sigal et al., 2003; Visser et al., 2005; Watson et al., 2006; Welch et al., 1996; Wellisch et al., 1991; Wellisch et al., 1992; Wellisch et al., 1996; Zahlis & Lewis, 1998), three intervention studies (Davey et al., 2005; Fasciano et al., 2007; Lewis et al., 2005), and three data-based book chapters (Grandstaff, 1976; Lewis, 1996 and Lewis et al., 2000) specifically addressed *women* with cancer and their families with *adolescents.*

In 2008, an updated search for published studies and literature reviews on the adolescent who has a mother with cancer was conducted on PubMed, a service of the National Library of Medicine and included the databases MEDLINE, 2007-2008; CINAHL, 2007-2008; PsycINFO, 2007-2008; the Cochrane Database of Systematic Reviews, 2007-2008; and http://highwire.stanford.edu, 2008. The keyword combinations used in the search were adolescent and mother and cancer; cancer and family and literature review; and cancer and adolescent and literature review. This search revealed three descriptive studies (Brown et al., 2007; Edwards et al., 2008; Stiffler et al., 2008) that addressed women with cancer and their families with adolescents.

A review of these collective studies yielded four categories that begin to uncover the adolescent's experience of having a mother with cancer: 1) adolescents' *emotions and behaviors* introduces internalizing and externalizing behaviors exhibited by the adolescent; 2) adolescents' *perceptions and knowledge* describes how the adolescents learned about having a mother with cancer; 3) adolescents' *roles* discusses the adolescents' role in the family after the diagnosis of cancer in their mother; and 4) adolescents' *ways of coping* (Table 2).

Table 2. Classification of Adolescents' Experiences of Having a Mother with Cancer

Author(s)	Emotions & Behaviors	Perceptions & Knowledge	Roles	Ways of Coping
Grandstaff, 1976	X			
Issel et al., 1990			X	X
Wellisch et al., 1991	X			X
Wellisch et al., 1992			X	
Lewis, 1996	X			
Hilton & Elfert, 1996	X	X	X	
Wellisch et al., 1996		X		
Lewis & Hammond, 1996				X
Zahlis & Lewis, 1998		X		
Spira & Kenemore, 2000	X		X	X
Lewis et al., 2000	X			
Hoke, 2001	X			
Hilton & Gustavson, 2002	X	X	X	
Lewis & Darby, 2003	X			
Sigal et al., 2003	X			
Kristjanson et al., 2004	X	X		X
Watson et al., 2006	X			
Forrest et al., 2006		X		
Brown et al., 2007	X			
Edwards et al., 2008	X			
Stiffler et al., 2008			X	

2.1.1 Category I. Adolescents' Emotions and Behaviors

Research on adolescents who have a mother with cancer encompasses the adolescents' emotions and behaviors. Internalizing behaviors are behaviors that are "directed inward to the individual that affect his or her mental, cognitive, or emotional functioning, such as depression or anxiety" (Lerner, 2002, p. 299). Fear is the anticipation of "the possibility that something dreaded or unwanted may occur. Fear may be regarded as a predisposition to perceive a set of conditions as a threat and to react with anxiety when exposed to these conditions" (Beck & Rush, 1985, p.354). Anxiety is a state of uneasiness and distress about future uncertainties, apprehension, and worry (Beck & Rush, 1985).

A salient point in the literature is that adolescents feared that their mother would die (Grandstaff, 1976; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Lewis et al., 2000) and the piece of information that adolescents sought, regardless of their age, was whether or not their mother was going to survive (Kristjanson et al., 2004). When children were told that their mother was not going to die, they generally felt relieved (Hilton & Gustavson, 2002). Female adolescents of women with cancer felt increased vulnerability to cancer related to genetic risk (Grandstaff, 1976; Kristjanson et al., 2004; Spira & Kenemore, 2000; Wellisch et al., 1991) and could identify symptoms of breast cancer (Wellisch et al., 1991). Adolescent female's fears were additionally associated with physical / sexual development (Spira & Kenemore, 2000) and adolescent females reported significantly less frequent sexual intercourse and lower sexual satisfaction (Wellisch et al., 1991). Fear of recurrence and loss of their mother may be expressed through somatic symptoms (Spira & Kenemore, 2000). Lewis and Darby (2003) noted that when both parents' relationships with the adolescent were poor, adolescents (n = 8) showed significantly lower self-esteem on the Rosenberg Self-Esteem Scale ($F_{2, 84} = 8.55$, p <.001) and increased anxiety on the State-Trait Anxiety Inventory Form Y1 ($F_{2, 84} = 10.45$, p =.001).

Compas and colleagues (1994) assessed depression/anxiety and stress response symptoms in adult cancer patients (n = 117), spouses (n = 76), and their children (n = 110). There was a significant main effect for sex of adolescent ($F_{1, 45} = 5.24$, p=.027), and a significant interaction of sex of patient and sex of adolescent, ($F_{1, 45} = 8.61$, p=.005). Adolescent females reported more symptoms on the Impact of Events Scale (IES) (M=15.68) than adolescent males (M=11.91). Furthermore, adolescent females whose mothers had cancer reported more stress-related symptoms on the Impact of Events Scale than females whose fathers were ill or males whose fathers or mothers were ill. Grant and Compas (1995) analyzed scores on the Anxious - Depressed Scale of the Youth Self Report (YSR; Achenbach, 1991) as a function of gender of the adolescent and gender of the parent with cancer. An ANOVA indicated a significant main effect for gender of adolescent ($F_{1, 51} = 12.64$, p= <.001), and a significant interaction of gender of adolescent and gender of ill parent, ($F_{1, 51} = 5.42$, p<.02). Adolescent females whose mothers' had cancer (M=63.9, SD=10.7) reported significantly more anxious/depressed symptoms than did females whose fathers were ill (M=55.5, SD=6.3) or males whose mothers (M=50.2, SD=0.6) or fathers (M=53.0, SD=4.8) had cancer.

Brown et al. (2007) conducted a study of children (n=80), ages 8-19 years, and their mothers with breast cancer (n=80). Half of the women (n = 40) had breast cancer or a history of breast cancer and the other half (n = 40) were a healthy community control sample. The study measured maternal stressors and resources, maternal and child adjustment, posttraumatic stress, and maternal uncertainty and coping as reported by both the women and their children. Results showed few differences between the two groups. One notable finding was a trend that females of women with breast cancer had a higher frequency of depressive symptoms (M=49.8; SD=15.20) than males (M=39.8; SD=13.4) as measured by The Children's Depression Inventory (CDI) (Kovacs, 1981). When the model controlled for the child's gender, children of women who perceived social support from family and friends had fewer depressive symptoms.

According to Watson et al. (2006) maternal depression combined with poorly defined family roles increased the likelihood of internalizing problems, especially in females. Welch and colleagues (1996) noted that adolescents' self-reported symptoms of depression / anxiety did not vary according to type of parental cancer. Thus, adolescent females whose mothers had breast cancer were no more likely to experience higher levels of depression / anxiety symptoms than adolescent females whose mothers had other types of cancer.

Lewis and Darby (2003) demonstrated that adolescents tended to show increased behavioral problems when both parents had depressed mood; maternal depressed mood was the main source of influence. However, Hoke (2001) reported that children of mothers with breast cancer ($n=34$) reported fewer anxiety symptoms than the Revised Children's Manifest Anxiety Scale (RCMAS) normative sample ($M = 44.0$, $SD = 11.3$, $z = -3.51$, $p < 0.01$), as did children of mothers with benign breast biopsies ($n = 33$) ($M = 46.2$, $SD = 10.8$, $z = -2.18$, $p < 0.05$). In addition, mothers in the breast cancer group reported fewer behavioral problems in their children ($n=21$), compared with the Child Behavioral Checklist (CBCL) normative sample ($M = 44.2$, $SD=10.0$, $z = -2.67$, $p<0.01$). Watson et al. (2006) reported that an adolescent's ($n=107$) externalizing problems were predicted when the adolescent reported worse communication ($p = 0.001$), family affective responsiveness ($p = 0.007$), family affective involvement (p = 0.002), family behavioral control (p = 0.004), and family general functioning (p=0.002) on the McMaster Family Assessment Device (FAD). An increase in the adolescent's externalizing problems was also associated with lower family cohesion on the Family Environment Scale (FES) (p = 0.001).

Edwards and colleagues (2008) identified factors associated with psychological functioning in adolescents (n=56), ages 11-17 years, of women with early stage breast cancer. Overall, high rates of stress were found in 33% of the males and 45% of the females on the Child Impact of Events Scale (C-IES) (Yule, 1997). Psychological problems were reported in 28% of the males and 32% of the females on the Youth Self Report Form (YSR) of the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001). Poor family functioning was associated with the adolescents' internalizing (p=0.009) and externalizing (p<0.001) problems on the Youth Self Report Form (YSR). Poor family cohesion was associated with higher externalizing and total Youth Self Report (YSR) psychological problems in the adolescent. Maternal depression scores were significantly associated with internalizing problems reported by the adolescent (p=0.014).

2.1.2 Category II. Adolescents' Perceptions and Knowledge

Kristjanson et al. (2004) elicited detailed descriptions of adolescents' information and support needs in response to their mother's breast cancer. Adolescents stated that when they were given information, the timing of the information in relation to their mother's cancer was important. They required understandable, detailed information soon after diagnosis and reported the importance of receiving information as the illness progressed such as the potential side effects of treatment, alternative therapies, the seriousness of the illness, and the medical "facts" about the disease. According to Forrest et al. (2006), in addition to written information, adolescents would have also valued the health care providers recommending a website on parental cancer. Adolescents wanted to be informed about treatments by attending appointments, reading books and looking things up in the dictionary or on the internet (Hilton & Gustavson, 2002). In a study by Issel, Ersek, Lewis and Germino (1990), 15% of adolescents ages 13-20 years said that the family did nothing to help them. Adolescents (n=31) mentioned that people from the community (churches and neighbors) were helpful to their family but did not offer them personal support (Kristjanson et al., 2004).

2.1.3 Category III. Adolescents' Roles

A role is "a socially prescribed set of behaviors to which a person can show commitment" (Lerner, 2002, p. 136). According to Erikson (1968), identity can be thought of as a "stable mental picture of the relation between the self and the social world in various contexts" (Cole & Lightfoot, 2005, p.33). A task during adolescence is to achieve *identity versus role confusion* (Erikson, 1968). During this stage of psychosocial development, adolescents establish a sense of personal identity, or they become confused about who they are and what they want to do in life (Cole & Lightfoot, 2005).

The results of Wellisch and colleagues' (1992) research study showed that adolescents (n=60) were prone to "change roles" with their mother during their mother's illness. Hilton and Gustavson (2002) and Issel et al. (1990) revealed that adolescents were influenced by changes in family patterns and were involved in helping at home. The majority of adolescents remembered having to take on extra domestic chores and responsibilities for sibling care during diagnosis and treatment (Hilton & Elfert, 1996). Role shifting and confusion resulted when adolescents, who wanted distance from the family, were required to stay at home and attend to demands related to their mother's illness (Hilton & Elfert, 1996). Rolland (1994) stated that illness in the mother forces the family into a centripetal (centered on the family) rather than centrifugal (centered away from the family) position. At a time when adolescents are moving away from the family, the need to focus on their mother may be difficult. Stiffler et al. (2008) used audio-taped interviews to examine the parenting of adolescents (n=8) by women diagnosed with, and being treated for breast cancer. Adolescents were ages 10-15 years at the time of diagnosis and 13-24 years at the time of the interview. Six categories were uncovered which aided the researchers in concluding that women with breast cancer need assistance in maintaining a relationship with, and communicating with their daughter.

2.1.4 Category IV. Adolescents' Ways of Coping

Adolescents cope in different ways. According to Moos (1993, p.1) "contemporary theorists emphasize the multidimensional aspects of appraisal and coping processes. Researchers have used two conceptual approaches to classify coping responses. One approach emphasizes the orientation or *focus* of coping (problem-focused or emotion-focused), whereas the other emphasizes the *method* of coping (cognitive or behavioral)." (See Compas, 1987; Compas, Malcarne & Fondacaro, 1988; Folkman & Lazarus, 1985; Lazarus & Folkman, 1984). Eight types of coping responses emphasize the focus and method of coping. Approach coping includes logical analysis, positive reappraisal, seeking guidance and support, and problem solving. Avoidance coping includes cognitive avoidance, acceptance or resignation, seeking alternative rewards and emotional discharge (Moos, 1993).

Adolescents used problem-focused coping as they asked questions, read about the illness, and assumed responsibility for household chores or sibling care (Nelson et al., 1994).

Adolescents reported using emotion-focused coping by refusing to think or talk about the illness (Issel et al., 1990) and dual-focused coping (both problem-focused and emotion-focused in intent) (Compas et al., 1996). According to Compas et al. (1996), emotion-focused coping is related to greater avoidance and to higher symptoms of anxiety / depression in the adolescent. Adolescents stressed the importance of family, friends and the school system in providing a sense of normality about their life which helped them cope (Issel et al., 1990; Kristjanson et al., 2004). Humor was also used as a way of coping (Spira & Kenemore, 2000), and friends were described as being supportive when they tried to be close, asked about their parent, and offered hugs and jokes (Kristjanson et al., 2004).

Adolescents discussed the importance of having time to be a normal teenager. Teens valued information about the normal feelings of the adolescent whose mother had cancer, for example, wanting to spend time with friends and away from the day to day management of their mother's illness. Some wished that their mother would die because they wanted their life to return to normal, and felt guilty for the thought (Spira & Kenemore, 2000). They appreciated health care professionals informing them that feelings such as anger and guilt were normal (Kristjanson et al., 2004).

2.2 INTERVENTION STUDIES

There were three intervention studies that focused on the adolescent of the woman with cancer. The *Enhancing Connections* Program (Lewis et al., 2005) is an intervention developed for school-aged children and young adolescents (ages 8-12 years) to reduce cancer-related distress and morbidity. The results of the pilot research study (n=13) revealed significant improvements in mother's depressed mood on the Center for Epidemiological Studies Depression Scale (CES-D) (M = 9.58, SD = 8.14, p = 0.03), and improvements in maternal anxiety on the State-Trait Anxiety Inventory form Y1 (M = 28.36, SD = 8.88, p = 0.02). Mother's report on the Child Behavioral Checklist (CBCL) showed a significant decrease in their child's behavioral problems (M = 17.85, SD = 14.50, p = 0.006). Davey, Gulish, Askew, Godette and Childs (2005) conducted focus groups with adolescents (n = 10) whose mothers had breast cancer to elicit their opinion about how future intervention programs should be developed. Adolescents suggested that intervention programs include adolescent groups of males and females within four months of the cancer diagnosis, teach coping skills sensitive to males and females of different ethnic and racial backgrounds, and be followed by family therapy groups that promote shared family understanding and open communication between parents and adolescents.

Fasciano and colleagues (2007) published information on their intervention, *When a Parent Has Cancer: Strengthening the School's Response.* The study described the development and pilot testing of a program that educated school professionals about cancer's impact on preschool, elementary, junior high and high school children. School professionals (n=244) completed self-report questionnaires before and after the program that assessed their knowledge and anxiety about assisting families. Results indicated that after the program, school professionals rated themselves as significantly more knowledgeable and confident about assisting families with parental cancer. Fasciano's investigation, however, included only a small sample of adolescents (n=38).

A number of methodological and conceptual issues are associated with studies exploring the effect of having a mother with cancer on the adolescent. First, the majority of the studies are limited to adolescents of women with breast cancer (Grandstaff, 1976; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Hoke, 2001; Issel et al.,1990; Kristjanson et al., 2004; Lewis & Hammond, 1996; Lewis, 1996; Lewis et al., 2000; Lewis & Darby, 2003; Sigal et al., 2003; Spira & Kenemore, 2000; Wellisch et al., 1991; Wellisch et al., 1992; Wellisch et al., 1996); therefore, the implications of different parental cancers on the adolescent are not well known. Second, the majority of studies are cross sectional with investigators examining the adolescent at time points ranging from two months to five years after their parent's diagnosis of cancer. Longitudinal studies will contribute to the literature by examining the impact of parental cancer on the adolescent over time and throughout the cancer illness trajectory. Third, with the exception of three studies which included only adolescents (Kristjanson et al., 2004; Lewis & Hammond, 1996; Spira & Kenemore, 2000), the studies often included school-age children, preadolescents, adolescents and young adults. Researchers need to define the children included in their research study, and a narrower conceptualization of the children to be included in each research study must be considered. For example, researchers may choose to include only pre-school children, school-age children, or adolescents in their research study. The three studies that included *only the adolescent*, defined as a person between the ages of 10-20 years (Lerner, 2002) are illustrated in Table 3. Fourth, of the three studies that included *only* adolescents (Lewis & Hammond, 1996; Spira & Kenemore, 2000; Kristjanson et al., 2004), two elicited responses of both *male and female* adolescents.

Table 3. Studies of the Impact of a Mother's Cancer on the Adolescent

Study	Sample Characteristics	Measures	Results
<u>Lewis & Hammond, 1996</u> *Purpose:* to test the theoretical model of the impact of the mother's breast cancer on adolescent-rearing households from the mother's, father's and adolescent's viewpoint *Design:* quantitative	Adolescents (n = 70) • 44% male • 56 female • adolescent mean age 16.3yrs Parents • mothers with cancer (n = 70) • mothers mean age = 42.9 yrs • Breast cancer 97.6 % (Stage 0, I, II, IIIA) • husbands/partners (n = 70) • fathers mean age = 46.9 yrs	F-COPES (McCubbin *et al.*, 1991) FACES II (Olson *et al.*, 1979) CES-D (Radloff, 1977) DOII (Haberman *et al.*, 1990) Spanier DAS (Spanier, 1989) Norbeck Social Support Scale (Norbeck *et al.*, 1981) Rosenberg Self Esteem Scale (Rosenberg, 1973) Relationships Scale (Greenberg *et al.* 1983)	As fathers reported more frequent coping behavior by their families, the quality of the relationship between the adolescent and the parents tended to be more positive ($p < 0.10$) Neither the gender of the adolescent, parental depressed mood, nor the level of marital adjustment significantly predicted the quality of the parent-adolescent relationship More positive parent child relationships significantly predicted more positive adolescent self-esteem ($p < 0.001$)

Table 3. continued

Lewis & Hammond, 1996			Fathers' positive perceptions of the family members' coping behavior were significantly associated with the adolescent's higher self esteem ($p < 0.01$) Marriages characterized as better adjusted by the fathers tended to significantly predict lower, not higher, self esteem in the adolescents ($p < 0.10$)

Table 3. continued

<u>Spira & Kenemore, 2000</u> *Purpose:* to illustrate concerns that adolescent daughters of mothers with breast cancer have about themselves and their mother's illness *Design:* qualitative	Adolescents: • female age range 12-19 yrs Parent: • mother with breast cancer	Clinical vignettes derived from adolescent interviews	Categories: • Fear of the illness • Fear of recurrence and loss of mother • Fear associated with physical/sexual development • Communication about the illness – the more communication about the disease process, the easier it was for the adolescent • Changes in roles – increased anxiety that change in roles would alter the mother/daughter relationship • Coping – adolescents used humor • Some adolescents demonstrated strength, resilience and hope

Table 3.continued

Kristjanson et. al., 2004 *Purpose:* to elicit detailed descriptions of adolescent's information and support needs in response to their mother's breast cancer *Design:* qualitative	Adolescents (n = 31) • 22 females, 9 males mother with cancer • age <12-18 yrs at diagnosis • age 12-20 yrs at interview Parent (n = 31) • Breast cancer Stage I or II cancer 29% Stage III or IV cancer 7% First recurrence 13% Remission 39% Advanced or terminal 13%	Semistructured adolescent interviews and focus groups McMaster FAD (Epstein *et al.*, 1983)	Adolescents reported a number of information and support needs, although needs assessment was minimal The one piece of information that adolescents consistently sought, regardless of their age, was whether or not their mother was going to survive Adolescents perceived their needs as individualized, based on their family situation and own personal needs Adolescents considered support from school to be important because it allowed them to continue with their lives and feel hopeful

Table 3 continued

Kristjanson et. al., 2004			Specific individualized interventions are needed to address adolescent's needs

NOTE: CES-D = Center for Epidemiological Studies – Depression scale, DAS = Dyadic Adjustment Scale, DOII = Demands of Illness Inventory, FACES II = Family Adaptability and Cohesion Evaluation Scales II, FAD = Family Assessment Device, F-COPES = Family Crisis Oriented Personal Evaluation Scales

Grabiak, B., Bender, C. & Puskar, K. (2007). The impact of maternal cancer on the adolescent: An analysis of the literature. *Psycho-Oncology, 16*, 127-137.

Editors of *Psycho-Oncology*: Frances M. Lewis, PhD, RN; Paula K. Rauch, MD; Jimmie C. Holland, MD.

2.3 THEORETICAL FRAMEWORKS IN THE LITERATURE

A theory is "a set of interrelated concepts, definitions, and propositions that present a systematic view of essential elements in a field of inquiry by specifying relations among variables" (King, 1997, p.23). Lazarus and Folkman's Stress and Coping Theory (1984), Piaget's Theory of Cognitive Development (1970), and Kuzel's Family Systems Theory (1978) were the theories used in the twenty-one descriptive studies, three intervention studies, and three data-based book chapters written about the adolescent and their mother with cancer.

Lazarus and Folkman's Stress and Coping Theory (1984)

Coping is defined as "ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus, 1993, p. 237). According to Lazarus (1993) what a person (the adolescent) does to cope will depend on the *situational context.* Coping will change over time because threats change over time. For example, 6 months after the diagnosis of cancer in their mother, a threat to the adolescent may be having to talk to friends at school about the diagnosis. One year after diagnosis, a threat may be the growing likelihood of their mother's death. Therefore, when studying how the adolescent copes with having a mother with cancer, it is necessary to determine the threats of primary concern and examine them separately rather than focusing on the overall illness. Coping may be the attempt to deal with a problem and does not need to be successfully completed (Lazarus, 1993). When measuring coping, it is important to describe what the person (the adolescent) is thinking and doing in the effort to cope with having a mother with cancer (Lazarus, 1993).

Piaget's Theory of Cognitive Development (1970)

Knowledge of the adolescent's normal growth and development is important in understanding how they perceive and respond to the events associated with having a mother with cancer. The meaning of having a mother with cancer may be related to the adolescent stage of cognitive development, titled the formal operational stage (Piaget, 1970). Adolescents are cognitively more advanced than school age children in four ways: considering possibilities, thinking abstractly, thinking about thinking (metacognition), thinking about multiple dimensions simultaneously (Keating, 1990). Adolescents have greater cognitive abilities than school age children due to increases in skills such as attention, processing speed, memory, organization and metacognition (Keating, 1990).

Adolescents are able to use well developed abstract thinking about illness and death. They understand internal processes such as old age, deterioration, and chronic illness and realize that every human being will die (Adams-Greenly, 1986). Adolescents view death as a natural process that is universal, inevitable and irreversible (Hilton & Elfert, 1996). They are concerned about the abstract aspects of their relationship with their ill parent, such as loss of humor (Christ, Siegel, & Sperber, 1994). Adolescents are able to think philosophically and search for an understanding and meaning in illness and death (Lewandowski, 1996).

Bowen's Family Systems Theory (1976)

Family systems theory emphasizes that the whole is greater than the sum of its parts (von Bertalanffy, 1968) and that illness in one family member sends reverberations throughout the entire family system (Bowen, 1976). Each family member works to maintain a state of equilibrium in which s/he is optimally functioning. The family, as a set of interdependent units, is continually operating to maintain a dynamic level of functioning (Buckley, 1967; Broderick &

Smith, 1979; Hill, 1972). The adolescent’s equilibrium may be disrupted when having a mother with cancer is perceived as a threat.

This disruption of the adolescent’s equilibrium may be experienced as a stressor. A range of strategies may be used by the family and the adolescent to re-establish the adolescent’s equilibrium. Family adjustments made to help the adolescent re-establish equilibrium become important aspects of the adolescent’s adjustment. In this sense, the adolescent copes with the mother’s illness, and the family helps the adolescent cope (Issel et al., 1990). Broderick and Smith (1979) point out that life, especially family life, is nonlinear, and full of interactions. The systems perspective is particularly appropriate when examining the impact of a chronic, potentially life-threatening illness on families. The adolescents’ descriptions of coping with the mother’s illness and how the family is helping him/her cope with it may provide a direct measure of one family member’s response to a disruption in the family system caused by the mother’s cancer (Issel et al., 1990).

2.4 THEORETICAL PERSPECTIVE

The theoretical basis for grounded theory is symbolic interactionism, a philosophical perspective of Blumer (1969) built on the work of Mead (1934). According to Blumer (1969) the basic doctrine is that people give meaning to things based upon their interpretation of the interactions that they have with one another. Blumer (1969) proposes that meanings and interactions change within different contexts. Symbolic interactionism is useful in guiding a research study of the impact of having a mother with cancer on the adolescent. This theoretical perspective invites the investigator to explore the meaning that adolescents have given to having a mother with cancer.

For example, what does it mean to the adolescent that his/her mother has cancer and how does this meaning influence their actions? Meanings are generated from the interactions that occur between the woman and her adolescent and the woman, her adolescent and others. Symbolic interactionism, a metatheory, is based on the following three premises:

1. “Human beings act toward things on the basis of the meanings that things have for them” (Blumer, 1969, p.2). To understand how adolescents cope with having a mother with cancer, it is necessary to understand what it means to them. For example, if the adolescent views their mother’s cancer as many hospitalizations that require surgery or treatment, they may seek support from their friends. According to Blumer (1969) meanings “dictate” actions and behaviors.

2. “The meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows” (Blumer, 1969, p.2). The following example illustrates the second premise. If the adolescent of a woman with cancer interacts with other adolescents whose mothers are healthy, this may influence how the adolescent interprets their mother’s cancer, which will influence how the adolescent interacts with their own mother. The meaning that the adolescent gives to having a mother with cancer may be affected by interactions.

3. “These meanings are handled in and modified through an interpretative process used by the person in dealing with the things that he encounters” (Blumer, 1969, p.2). This premise demonstrates that symbolic interactionism is process-oriented. The adolescents’ meaning of having a mother with cancer, and how they cope with it, may change as interactions occur and perceptions of having a mother with cancer may change over time. For example, an adolescent may experience fear regarding their own health, if one of their siblings is fearful. After interacting with a peer who believes that s/he may control threats to health, the same adolescent

may begin to construct a different meaning of cancer, and cope with it differently. According to Blumer's (1969) third premise, the action that the adolescent takes will change as their interpretation of having a mother with cancer changes.

2.5 SUMMARY OF THE LITERATURE

An extensive review of the literature on adolescents who have a mother with cancer revealed that adolescent females whose mothers are depressed and have cancer are significantly more anxious / depressed than females whose fathers are ill or males whose mothers or fathers are ill. Adolescent females whose mothers have breast cancer are no more likely to experience higher levels of anxiety / depression than females whose mothers have other types of cancer. However, the three studies published on the impact of having a mother with cancer on *only* the adolescent are limited to adolescents of women with *breast* cancer. Lewis and Hammond (1996) tested a theoretical model of the impact of a mother's breast cancer on adolescent-rearing households. Spira and Kenemore (2000) presented clinical vignettes derived from interviews with adolescent daughters living with mothers who have breast cancer while Kristjanson et al. (2004) elicited detailed descriptions of adolescents' information and support needs in response to their mothers' breast cancer.

The literature documents that women with cancer do not always know what their child is experiencing in relation to the cancer (Zahlis & Lewis, 1998). Adolescents report that within and outside of the family, their information and support needs are poorly met (Kristjanson et al., 2004). Adolescents remember having to take on extra domestic chores and responsibilities for sibling care during diagnosis and treatment (Hilton & Elfert, 1996). Adolescents cope with having a mother with cancer by using both emotion-focused and problem- focused coping. They use problem-focused coping as they ask questions, read about the illness, and assume responsibility for household chores (Nelson et al., 1994). Adolescents use emotion-focused coping by refusing to think or talk about the illness (Issel et al., 1990). Only three researchers (Lewis et al., 2005; Davey et al., 2005; and Fasciano et al., 2007) have conducted intervention studies on adolescents who have a mother with cancer. This dissertation study seeks to address a gap in the literature by eliciting both male and female adolescents' responses about their experience with their mother's early stage cancer.

3.0 CHAPTER III

3.1 METHODOLOGY

This qualitative study used grounded theory methodology (Glaser & Strauss, 1967) to guide the exploration of the experience of the male and female adolescent whose mother had been diagnosed with early stage cancer a minimum of 6 months and a maximum of 2 years prior to research study participation. Each early stage cancer has a 5-year relative survival rate of 80% or greater than 80%. This chapter explains the reason for using grounded theory methods, as well as procedures for data collection and analysis.

Grounded theory is a naturalistic, inductive / deductive method (Glaser & Strauss, 1967) for generating substantive theory that describes and explains basic social processes. Grounded theory methods allowed the investigator to learn about adolescents who have a mother with cancer from the adolescents who were experiencing it. The investigator learned the process of how adolescents cope with having a mother with cancer. The variables were not determined "a priori" or prior to and independent of experience. The variables as well as the social process generated were "grounded" in the data that were collected and analyzed. The majority of studies on the adolescent who have a mother with cancer have been quantitative. This qualitative study will contribute to the existing literature.

3.2 SETTING

The setting for data collection was one cancer center in southwestern Pennsylvania (Appendix C). The interviews occurred in a semi-private conference room in the cancer center. In Summer, 2006, the PI located a cancer center that provided treatment, diagnostic, and cancer care services to men and women with different types of cancer. The PI examined the facility carefully to: 1) determine suitability, or whether the site met requirements; 2) measure feasibility or size and population against resources of time, mobility, and skills and; 3) gather information about the cancer center and the clinical care team in preparation for negotiating entry (Schatzman & Strauss, 1973). The PI garnered information about the cancer center from a variety of sources, such as institutional documents and brochures. During Spring, 2006, the PI met with the office manager, hematology/oncology physicians and physician's assistants at the cancer center to explain the purpose of the research study, discuss the feasibility of recruiting participants, and obtain a written letter of support. In addition, the PI met with a psychiatrist and a crisis worker at the behavioral health outpatient department of the hospital's division of mental health to discuss the research study, the potential risks to participants, and obtain a written letter of support. The PI began to establish credibility and enter relationships suitable for research purposes. The clinical care team at the cancer center was promised confidentiality and respect (Schatzman & Strauss, 1973). Following approval from The University of Pittsburgh Cancer Institute Protocol Review Committee and The University of Pittsburgh Institutional Review Board, the PI entered the field.

The process of establishing rapport was an essential component of the interview (DiCicco-Bloom & Crabtree, 2006). Good rapport involves trust and respect for the adolescent as well as the information shared. Good rapport establishes a safe environment for the adolescent to share experiences. “It is through the connection of many truths that interview research contributes to our knowledge of the meaning of the human experience” (DiCocco-Bloom & Crabtree, 2006, p. 316). Stages of rapport include apprehension, exploration, co-operation, and participation (Spradley, 1979). The apprehension phase is characterized by uncertainty from the strangeness of the context. The goal in this phase is to start a conversation with the adolescent. The first questions were broad and open-ended, reflected the nature of the research, and were non-threatening. The adolescent was given time to hear what was being asked and given time to respond. The questions that followed encouraged the adolescent to think about and share feelings (DiCocco-Bloom & Crabtree, 2006). Throughout the interview, the goal was to have the adolescent share as much information as possible (Johnson, 2002). The adolescent became engaged in in-depth description in the exploration phase. This phase is characterized by learning, listening, testing, and a sense of bonding and sharing. During the co-operative phase, the PI and the adolescent became comfortable with one another and the PI took the time to clarify points and ask more sensitive questions. The participation stage reflected the greatest degree of rapport as the adolescent taught the PI about their experience (DiCocco-Bloom & Crabtree, 2006).

The PI displayed empathy during the interview process. Empathy is the “capacity to understand what another person is experiencing from within the other person’s frame of reference” (Bellet & Maloney, 1991, p.1831). The PI paid attention to the adolescent and communicated effectively with them. Empathy enhanced the adolescent’s trust in the PI and forged an emotional bond. The use of empathy enabled the PI to elicit more fully the meaning of the cancer to the adolescent (Bellet & Maloney, 1991; Spiro et al., 1993).

3.3 SAMPLE

Women and their adolescents were recruited through a cancer center in southwestern PA. Additional participants were successfully recruited through other venues such as the local newspaper and a flyer (Appendix D). Sampling began with a purposive sampling strategy. Participants were sampled in order to create variation in the characteristics likely to be important, such as adolescents' age and gender (Sandelowski, 1995). The PI made sampling decisions using predetermined criteria. For example, because the goal was to represent the experiences of both male and female adolescents, the initial sampling strategy was to include 50 percent male adolescents and 50 percent female adolescents. As the data were collected and analyzed and patterns were seen in the data, sampling proceeded to theoretical sampling (Sandelowski, 1995) guided by the process that was unfolding. Theoretical sampling allows comparisons to be made among research participants, which aids in uncovering commonalities and variations in the participants. For example, if data collection revealed that female adolescents were afraid of being diagnosed with cancer at a young age, female adolescents would be theoretically sampled to validate this finding or males would be sampled to validate this finding among the females. While sample size is determined by theoretical saturation, it was anticipated that 12-30 adolescents would be interviewed.

Qualitative or field researchers focus on small samples, even single cases (n=1), selected purposefully (Patton, 1990; Kuzel, 1999) and sample with the aim of testing new interpretations. The goal of the investigation is to create a deeper understanding of the phenomenon of interest (Kuzel, 1999). In qualitative research, sampling strategies aim for information-richness (Patton, 1990). Quantitative researchers focus on larger samples selected randomly and sampling is guided by the need to generalize or predict. The sampling strategies focus on representativeness (Patton, 1990; Kuzel, 1999).

Theory development also guides sampling. All forms of inquiry begin with a priori understanding or theory about the subject of interest - no investigator is a blank slate (Kuzel, 1986). In quantitative research, the investigator begins with a priori theory which is tested using large enough numbers to demonstrate statistical significance (Guba & Lincoln, 1989). The inquiry usually starts with a theory that is either supported or not supported. Qualitative inquiry, on the other hand, starts with a priori theory or understanding that is expanded and modified in the context of the study (Lincoln & Guba, 1985).

In qualitative studies, validity and representativeness of findings are proportionate to sample size and diversity, respectively. Saturation is the main principle guiding sample size in qualitative studies, a process by which a researcher collects and analyzes data until s/he is not learning anything new (Strauss & Corbin, 1998). Many researchers suggest that the saturation point may be reached with 12 to 20 participants (Kuzel, 1992). The PI and dissertation co-chair analyzed the semi-structured interviews until they “identified no new categories or themes, thus providing assurances regarding adequacy of sample size” (Miller et al., 1994, p.180). Open-ended participant enrollment occurred until saturation.

According to Rolland (1984) and Walsh (2003), the psychosocial themes of chronic disease can be divided into three phases: crisis, chronic, and terminal. The *crisis* phase “includes any symptomatic period before diagnosis and the initial readjustment period after diagnosis and the initial treatment planning” (Walsh, 2003, p.469). Moos (1984) describes that during this phase the ill member and the family need to adapt to the health care setting and treatments; cope with symptoms; establish and maintain workable relationships with the health care team and cope with the immediate crisis. “Because families are so vulnerable at this point, clinicians need to be extremely sensitive in their interactions with family members” (Walsh, 2003, p.469). The *chronic* phase “is the time span between the initial diagnosis/readjustment and the third phase when issues of death and terminal illness predominate. Often the patient and the family have come to grips psychologically and organizationally with permanent changes and have devised an ongoing coping strategy” (Walsh, 2003, p.470). Because families are so vulnerable during the crisis phase of the illness, the adolescents in this study were interviewed during the chronic phase of their mother’s illness and asked to reflect on the crisis phase.

Inclusion criteria were male and female adolescents between the ages of 12-17 years: 1) who were able to read and write English; 2) whose biological or adoptive mother had been diagnosed with early stage cancer, which has a 5-year relative survival rate of 80% or greater, a minimum of 6 months and a maximum of 2 years prior to interview; and 3) who had been informed that their mother had been diagnosed with cancer. The exclusion criterion was adolescents who were undergoing treatment for an emotional problem.

3.4 PROCEDURES

The clinical care team approached potentially eligible women and asked if they were interested in learning about the research study. As part of this introduction, the physician confirmed with the woman that her adolescent knew of her diagnosis of cancer. If eligible women were interested in learning more about the research study, the woman was asked to sign a HIPAA Authorization Form for Sharing Health Information. The Principal Investigator determined the relative survival rate of the woman’s early stage cancer via The National Cancer Institute’s

Surveillance Epidemiology and End Results (SEER) database; The American Joint Committee on Cancer (AJCC) database; or The American Cancer Society's Cancer Facts & Figures 2008. These databases provide publicly available information. One of the following then occurred:

1) The PI entered the room, verbally re-confirmed the eligibility of the woman and her adolescent and explained the research study to the woman.

2) The clinical care team provided the interested woman with the PI's contact information so that she could learn more about the research study.

3) After confirming that the HIPAA Authorization Form for Sharing Health Information had been signed, the clinical care team provided the PI with the woman's diagnosis and contact information. The PI scheduled a day and time for the interview that was convenient for the woman and her adolescent. Those invited to participate in the research study were given both verbal and written descriptions of the study's aims and methods, a thorough description of the interview procedures, the potential risks and benefits of study participation, and their rights as a research participant.

Data collection was carried out by the PI and occurred systematically. On the day of the scheduled interview, the PI arrived at the cancer center, met the mother and her adolescent, and escorted them to a semi-private conference room. The PI answered any questions that the mother and her adolescent had and engaged in general conversation to put them at ease. The mother was asked to read and sign the consent form, which included an assent form for her adolescent. The adolescent then read and signed the assent form (Appendix E). The mother was asked to complete the investigator-developed demographic data and diagnosis and treatment questionnaires. The demographic data questionnaire contained a list of questions about the adolescent (e.g., age, gender, race). The diagnosis and treatment questionnaire was a list of questions about the mother (e.g., age, type and stage of cancer) (Appendix F and G). The principal investigator reviewed the mother’s medical record to confirm her age, type and stage of cancer, and time since diagnosis of cancer. The mother’s self-report of her adolescent's age was also obtained, after the consent was signed. The mother was then escorted to the waiting room. The mother was not present during the interview because, according to Reuband (1992), replies to questions in personal interviews are influenced by the presence of third persons. The PI provided the adolescent with a snack and beverage before the interview began.

The PI and the adolescent were seated face to face. The audiotape recorder was turned on and placed in the center of the table. The adolescent was asked open ended questions to elicit responses about their experience of having a mother with cancer, the meanings that they constructed about having a mother with cancer, and how they were coping with having a mother with cancer. A semi-structured interview guide (Appendix H) was used to initiate data collection. “Semi-structured” means that the interview guide has a list of questions that are asked of the participant in the same order. The question “how about your feelings, have they been affected” was difficult for the first two participants to answer. It was replaced with “tell me what you are thinking/feeling now?” and replaced a second time with “when you think about your mom’s cancer now, what kinds of things go through your mind.” The question, “other kids have told me about feeling afraid / worrying. Can you tell me what this has been like for you?” was added.

After each question, the participant was asked to elaborate as the PI “probed” the participant’s response and refocused the interview. The interviews took between 5-15 minutes. The transcripts were between 3 and 15 pages in length. Each participant was compensated $10.00 per interview with the PI. The adolescent was then escorted to the waiting room. The PI returned to the semi-private conference room and audio- recorded field notes regarding the characteristics of the adolescent such as their demeanor, facial expressions and emotions displayed during the interview. The impressions, responses, and initial thoughts of the PI were also recorded. All 12 adolescents were comfortable during the interview process. The following four participants provide brief examples of the interview process. The names are fictitious.

Rose, 15 years old, was talented and gifted. She was enthusiastic about the opportunity to convey her experience because she wanted to assist other children who had a mother with cancer. During the interview she was articulate and at the end, she sang a few lines from the high school musical in which she was the lead performer.

Samantha, 17 years old, walked confidently into the conference room. Before the interview began, she told me that dissertation study was “cool and wonderful” and that she was not afraid because her mother told her that I was a “good woman.” She spoke eloquently about her experience.

Steven, 12 years old, arrived in a sweat shirt as he had just finished basketball practice. He appeared fragile, and answered the interview questions in a soft voice with his head lowered. His responses, although brief, were insightful.

William, 16 years old, arrived with his sister, who was also to be interviewed. He hesitated and thought about the questions before he responded. During the interview, his face became flushed as he described his mother’s absence at one of his track meets.

Each participant was interviewed once; all participants agreed to be contacted again either in the clinical area or by phone to clarify responses or confirm analysis.

3.4.1 Medical Record Review

Data were collected from the mother's medical record. Medical records were reviewed to confirm the mother's age, type and stage of cancer, and time since diagnosis of cancer.

3.4.2 Demographic Data Questionnaire

An investigator-developed demographic data questionnaire was used to collect data on the adolescent's age, gender, race, siblings, and emotional problems.

3.4.3 Diagnosis and Treatment Questionnaire

An investigator-developed diagnosis and treatment questionnaire was used to collect data on the mother's age, time since diagnosis, type and stage of cancer, and race.

3.4.4 Semi-structured Interview

No standard measures or surveys were used. The primary data collection technique was an individual, investigator-developed, semi-structured interview. As the research study progressed, minor changes in the semi-structured interview questions were made to clarify wording or focus the discussion.

3.4.5 Field Notes

Observations of the adolescent during the interview, such as verbal and nonverbal interactions, were documented in the form of field notes. The initial impressions, responses and thoughts of the PI were also recorded. Notes were dictated following each participant interview and underwent constant comparative analysis along with the other data.

3.4.6 Memos

Analytic memos were recorded throughout the research study, from the start of the analysis to the development of the theory. The memos documented decisions about theoretical sampling, and coding (Strauss & Corbin, 1998). Memos were written throughout data collection, from the medical record review, interviews, field notes and analysis. Memos were written whenever thoughts related to analysis occurred.

3.5 DATA MANAGEMENT

Information such as the adolescent's gender and age, and the stage of the mother's cancer were entered into a spread sheet. The PI transcribed all audio taped interviews, dictated field notes, and memos. All data pertaining to this research study were kept in a locked filing cabinet at The University of Pittsburgh School of Nursing. The data will be stored in the locked filing cabinet at The University of Pittsburgh School of Nursing for five years.

3.5.1 Credibility and Trustworthiness

Five principles of qualitative methodological rigor include: 1) credibility 2) trustworthiness 3) applicability or fittingness 4) consistency and 5) usefulness. Credibility was established when the process that resulted from analysis was understood and based on data from the study (Glaser & Strauss, 1967). To guarantee credibility, the PI had prolonged or sufficient engagement in the field (Lincoln & Guba, 1985) and maintained a journal to document her biases and ideas. Peer debriefing occurred when the PI shared data with members of the dissertation committee. Dissertation committee members and the co-coder were asked to code transcripts or listen to analysis and provide feedback. Credibility was also established through the prevention of premature closure on the data. Data collection continued until theoretical saturation was reached or until no new information was adding to the explanation (Strauss & Corbin, 1998). A research study is considered trustworthy because the research findings are found to be believable (Lincoln & Guba, 1985). The fittingness of the analysis to the data and applicability to other contexts were enhanced by the PI providing examples of data, and through line by line analysis of the transcripts.

Different perspectives of the PI, co-coder, and dissertation committee members were present in the analysis. A thick description of the data was achieved when analysis reflected the different perspectives of the research participants, leading to an interpretation that included the variabilities and commonalities of the participants (Lincoln & Guba, 1985). Consistency was established when the dissertation co-chair verified that the code labels and the categories created by the PI made sense in relation to the data from which the PI worked, and the data were appropriately arranged into the category system (Guba & Lincoln, 1981). Usefulness occurred when the theoretical framework or trajectory resulting from the analysis was applicable to practice (Glaser & Strauss, 1967).

3.6 DATA ANALYSIS

Qualitative Data Analysis: The dissertation co-chair (Judith Erlen, PhD, RN, FAAN) randomly selected and verified transcribed interviews by listening to the audiotapes while reviewing the transcripts word by word. During this process, all personal identifiers were removed and a subject / interview code was assigned to protect confidentiality. The resultant “clean” transcripts were used in the analysis. Each team member (PI, co-coder, and two dissertation committee co-chairs) received clean transcripts for independent analysis, in preparation for team analysis. Areas where coding differed were reconsidered and an attempt was made to include the perspectives of the team members to form a dense analysis. The PI and one of the dissertation co-chairs (Janet Stewart, PhD, RN) made final decisions regarding the assignment of codes. All interviews and memos were entered into ATLAS.ti 5.2 (Scientific Software, 2008), a computer program that provides tools for the analysis of textual, graphical, audio, and video data. The program enables the researcher to manage, extract, compare, explore, and reassemble data in systematic ways by allowing the user to connect codes, memos and passages http://www.atlasti.com/features.html.

Constant comparative analysis is a method in which the investigator codes categories from incidents in the data (Glaser, 1992). Consistent with grounded theory methods, data collection and analysis were concurrent. This iterative process, with ongoing data collection and analysis, allows for more focused data collection as relevant themes emerge and stimulate additional areas of inquiry. With ongoing data collection, provisional hypotheses were verified, modified or discarded. Data were analyzed by using the constant comparative analytic technique. The categories were coded and compared with incidents in the same or different groups of data (Glaser, 1992).

The specific steps in data analysis consisted of open coding, selective coding, and theoretical integration. Open coding (substantive coding) is a method in which any and all code labels are generated from the data (the transcripts of the interviews) in a very inductive manner without restricting the focus. This phase of data analysis was the brainstorming phase. Word by word or line by line, the data were examined for all meaningful words which were then were assigned a code label. The passages were compared based on their properties using constant comparative analysis (Glaser, 1992).

Selective coding occurred systematically as data analysis became more focused and selective. The PI was looking for verification, saturation, and relevance of codes (Strauss, 1987). As coding continued, the codes were seen in several data sources (verification), no new information was adding to the explanation (saturation) and codes were found to be related to other codes (relevance) (Strauss, 1987). The codes that were most salient were named categories. It is important not to "foreclose" on the data prematurely or choose an unsupported category. As the data were collected and analyzed, the PI found support for, and saturated the categories (Strauss, 1987). Theoretical sampling is sampling that is directed by the theory that is unfolding. In this study, with each new participant the PI sought to confirm the salience of previous findings and probe for additional explanations of responses. Comparisons were made among adolescents in order to gain a better understanding of their experience of having a mother with cancer (Strauss, 1987).

Theoretical integration is the process that results in the depiction of the process under study. The interpretive processes used by the adolescent when coping with having a mother with cancer were illustrated by a figure of the categories and the relationships between them. Theoretical integration was accomplished by retrieving, sorting, and resorting the memos or descriptions of the categories. The memos served as tools for the synthesis and integration of the categories.

Quantitative Data Analysis**:** Descriptive statistics were used to characterize each of the mother and adolescent samples. In particular, for continuous descriptors (e.g., age) measures of central tendency (means, medians) and dispersion (range) were computed. For categorical descriptors (e.g., race, gender) frequencies, counts, and percentages were calculated.

Exploratory Analysis: Analytic matrices were constructed to further explore potential hidden patterns in the data that were affected by adolescent development and gender.

3.7 PROTECTION OF HUMAN SUBJECTS

3.7.1 IRB Approval

The research study protocol underwent review by The University of Pittsburgh Cancer Institute Protocol Review Committee and The University of Pittsburgh Institutional Review Board (Appendix I). Data collection began following approval of the research study protocol.

3.7.2 Potential Risks and Methods Used to Minimize Risks

Risks for research study participants were minimal. The research study entailed minimal time and effort (approximately 1 hour), and was designed so as to not interfere with usual patient care. Mothers who enrolled their adolescents in this project did not receive different care than those who did not enroll. Participation was voluntary and participants could refuse to take part or stop at any time. Research study participants were assured that participation was completely voluntary and that they had the right, at any time, to withdraw from the research study. The primary risk associated with participating in this research study was the psychological discomfort some people might feel with either the audio recording or disclosing sensitive information about themselves during the semi-structured interview. The procedures for addressing recognizable psychological discomfort included:

a) If at any time over the course of the interview the participant became frustrated or developed symptoms of severe depression or anxiety and was in need of psychological counseling or psychiatric referral, the interview was discontinued and usual care for depression or anxiety instituted, which included a psychiatric referral to the behavioral health outpatient department at the local hospital. Behavioral health crisis walk-in services were provided by a crisis worker on call (an MD on-call was available for consultation). These services were provided to research study participants from 8:30am - 4pm, Monday – Friday. After 4 pm and on weekends all research study participants were to report to the emergency department.

b) In the case of a psychiatric emergency, the interview was discontinued and an ambulance was called to transport the research study participant to emergency department. A crisis worker evaluated the participant in the emergency department. S/he then called the on-call psychiatrist and discussed the findings. Recommendations were then relayed to the emergency department physician. If there was a difference in opinion regarding the psychiatric patient, the emergency department physician talked directly with the psychiatrist on-call and, if necessary, the psychiatrist visited the emergency department. These services were available 24 hours a day 7 days a week.

c) Children ages 5-18 years old who were in need of admission and were still in high school, were admitted to the child and adolescent inpatient unit of the hospital. At no time during any of the interviews were the adolescents distressed, therefore, none of the above measures were taken.

3.7.3 Potential Benefits

a) Benefits to subjects: Benefits to the research study participants were minimal. Indirectly, through being reflective during the interview, participants may have benefited by learning more about their own attitudes and experiences with cancer.

b) Benefits to science/society: The long-term goal, to create an intervention that will teach adolescents effective coping strategies, was enhanced as a result of the knowledge generated by this research study.

3.7.4 Anonymity and Confidentiality

Any information about the participant from this research was kept as confidential as possible. Data were identified by a code number known only to the investigators. Identifying information was kept separately from the data. When the results of the research study are published or reprinted, there will be no identification of any participant. All of the information is locked in a filing cabinet at The University of Pittsburgh School of Nursing for a minimum of five years. All of the information is to be destroyed at the end of a five-year period. No participant is to be identified by name in any publication of the research results unless the participant signed a separate consent form giving the PI permission (release). This research study involved the recording of current and/or future identifiable medical information from the physician's medical records. The information that was recorded was limited to information concerning the woman's age, race, type and stage of cancer, time since diagnosis of cancer, family composition, and age and gender of the adolescent. Any breach in confidentiality of the data was reported to The University of Pittsburgh Cancer Institute Protocol Review Committee and The University of Pittsburgh IRB as an adverse event. There were no adverse events to report.

3.7.5 Data Safety and Monitoring Plan

A data safety and monitoring plan was implemented by the PI to ensure that there were no changes in the risk / benefit ratio during the course of the research study and that confidentiality of research data was maintained. The PI and a dissertation co-chair met monthly to discuss the research study (e.g., research study goals and modifications of those goals; subject recruitment and retention; progress in data coding and analysis; documentation, identification of adverse events or research subject complaints; violations of confidentiality) and addressed any issues or concerns at that time. Minutes were kept of these meetings and were maintained in the research study regulatory binder. Any instances of adverse events were reported immediately to The University of Pittsburgh Protocol Review Committee and The University of Pittsburgh IRB using the standard forms and/or procedures that had been established by the IRB. No adverse events were reported. The yearly IRB renewal for this research study included a summary report of the Data Safety and Monitoring Plan findings from the prior year.

3.7.6 Costs and Payments

Participants did not incur any costs for participating in the project. Participants were each given $10.00 upon completion of the research study.

3.7.7 Summary

This chapter presented grounded theory methodology and constant comparative analysis. It has also presented participant recruitment, data collection procedures, data management and human subjects issues.

4.0 CHAPTER IV

4.1 FINDINGS

This chapter presents the findings of the study illustrating the process, *Cancer is a Life Changing Experience for the Adolescent* (Figure 1, p.67). Learning the diagnosis was followed by a cyclical, and at times, simultaneous process - cancer changed the family, adolescents' coped, and demonstrated a sense of purpose. The sample characteristics are followed by the presentation of the findings that led to the identification of the process.

Sample Characteristics

The sample consisted of 12 adolescents whose mothers were being treated at one cancer center in southwestern Pennsylvania. As part of the inclusion criteria, the adolescents had not been previously diagnosed with an emotional problem and were not undergoing any treatment for an emotional problem. The adolescents were not participating in any professional individual counseling for issues related to the mother's cancer nor were they participating in a cancer support group.

The participants were recruited and enrolled between October, 2007 and May, 2008. Women and adolescents (n = 271) were screened for eligibility (e.g., woman's type and stage of cancer, time since diagnosis, adolescent's age). Fourteen women were HIPAA consented.

Four of the women that were HIPAA consented refused participation because their spouse did not support the study, their adolescent did not wish to come to a cancer center, or their adolescent was not interested. Twelve adolescents and 10 mothers participated in the study. Adolescent participants were Caucasian (n=11, 91.6%) and African American (n=1, 8.4%). There were 7 females (58.3%) and 5 males (41.7%). They ranged in age from 12-17 years (M=14.6 years, SD=2.0). The age range for males was 13-17 years (M=15.6 years, SD=1.52). The age range for females was 12-17 years (M=14.1 years, SD=1.77). The sample included two sibling pairs, a 12 year old sister /16 year old brother, and a 14 year old sister/16 year old brother. Each adolescent in the two sibling pairs was interviewed individually (Table 4).

The 10 mothers were Caucasian (n=9, 90%) and African American (n=1, 10%) and ranged in age from 38 to 52 years (M= 45.5 years, SD=5.3). They were diagnosed with early stage cancer a minimum of 7 months and a maximum of 24 months (M=15 months, SD=6.4) prior to their adolescent's interview. Most were diagnosed with stage I breast cancer (n=7, 70%). All of the women (n=10, 100%) were the biological mothers of the participating adolescents. The majority (n=9, 90%) were married and one (n=1, 10%) was separated (Table 5).

Table 4. Demographic Characteristics of the Adolescents (n=12)

CHARACTERISTICS	**n (%)**
Sex	
Male	5(41.7)
Female	7(58.3)
Ages of Males and Females	
12-14 years	4(33)
15-17 years	8(67)
Ages of Males	
12-14 years	1(20)
15-17 years	4(80)
Ages of Females	
12-14 years	4(57)
15-17 years	3(43)
Race	
Caucasian	11(91.6)
African American	1(8.4)
Number of siblings	
1-2	8(67)
3-4	4(33)

Table 5. Demographic and Clinical Characteristics of the Mothers (n=10)

Characteristics	**n (%)**
Age in years (M=45. 5; SD=5. 3)	
35-39	3(30)
40-44	1(10)
45-49	3(30)
50-54	3(30)
Race	
Caucasian	9(90)
African American	1(10)
Time Since Diagnosis of Cancer in months (M=15; SD=6.4)	
6-11	4(40)
12-17	1(10)
18-24	5(50)
Type & Stage of Cancer	
Breast, Stage I	7(70)
Breast, Stage II	1(10)
Hodgkin’s Lymphoma, Stage II	1(10)
Endometrial, Stage I	1(10)
Marital Status	
Married	9(90)
Separated	1(10)

During the interviews, the 12 participants readily spoke about their experiences and provided narratives to illustrate their perceptions of having a mother with cancer. Interestingly, the adolescents were most interested in having their story published in a book (dissertation). The responses of the 12 adolescents were highly personalized and contextualized, based on their current life situation, previous experience of having loved ones with cancer, and friends who had a parent with cancer. Most participants talked about having a mother with cancer in terms of their own feelings, how they were coping with it, and the impact that this event had on their life. Participants' descriptions of their experiences fell into four categories: 1) the experience of learning the diagnosis; 2) how cancer changed their families; 3) coping with their mother's cancer; 4) and a sense of purpose.

The combined perspectives of the 12 participants provided clear evidence that adolescents experienced a process after their mother was diagnosed with cancer. This process is depicted in Figure 1. Learning the diagnosis triggered various reactions, such as changes in the family, adolescent coping, and developing a sense of purpose, which interacted in a dynamic relationship. These elements interacted with each other and continued over time such that there was no particular beginning or ending point.

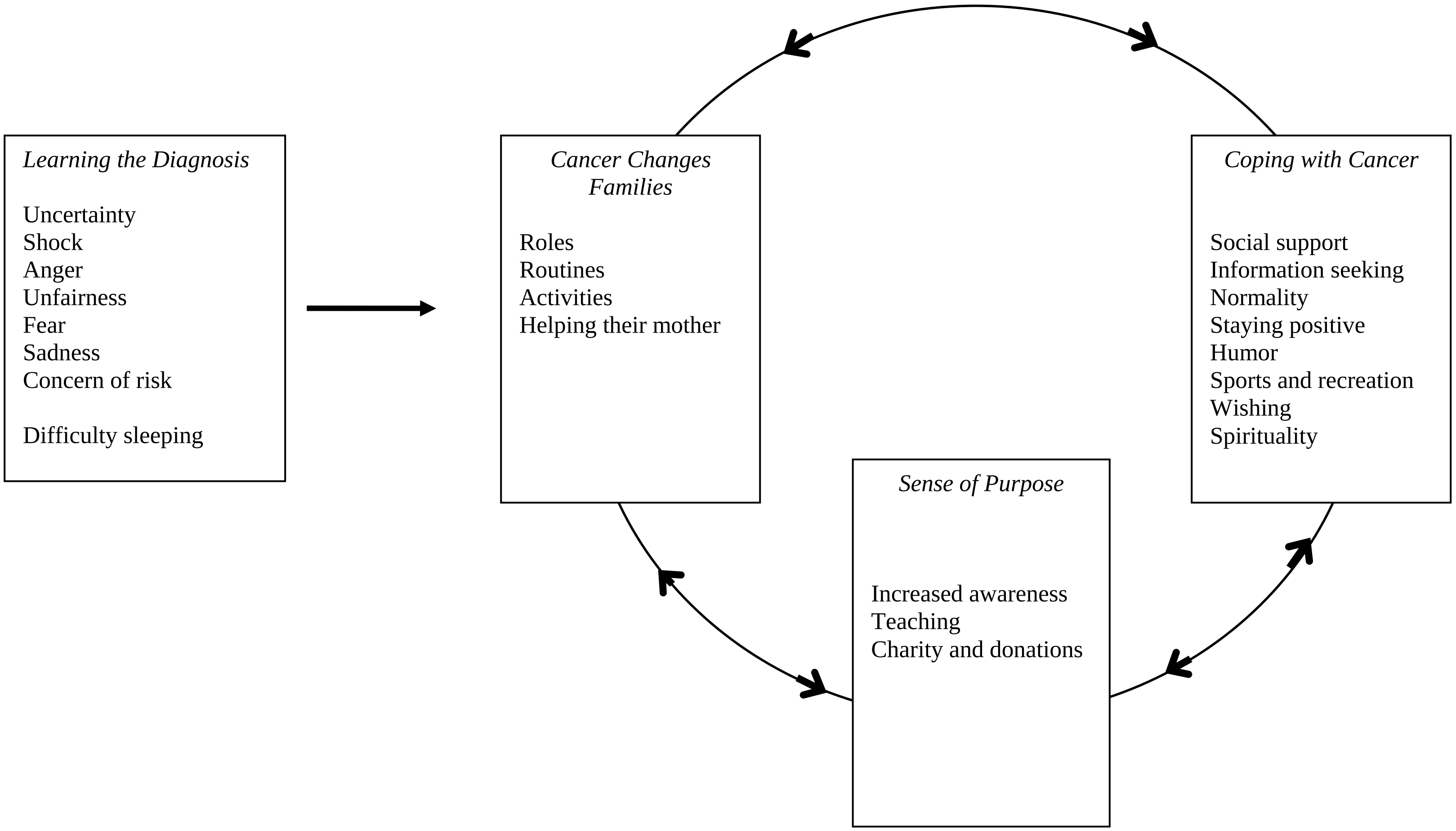


Figure 1. Cancer is a Life Changing Experience for the Adolescent

Learning the Diagnosis

The first step in the adolescent's experience of their mother's cancer was the moment when their mother, and in a few cases their father, informed the adolescent that their mother had been diagnosed with cancer. How, when, and where the adolescents learned of the diagnosis was an important part of their story. They were told in a variety of settings such as the waiting room of the oncologist's office, at the county fair, in the car on the way home from a park, and in their house.

> My mom and dad came home after one of her appointments and just sat us down on the couch and told us. ~ *12 year old male*
>
> Well I remember that I came home from school one day and everybody was standing in the kitchen and she kept like reassuring me that she was alright but then she finally told me that she had breast cancer. ~ *12 year old female*
>
> I was with my friend and I came home and I couldn't find my mom and she was laying on her bed and I went back to see what was wrong and she told me she had cancer and I was upset that I was not there when she got the phone call and she laid in bed most of day and really didn't talk to anyone. ~ *17 year old female*

Emotional responses.

During the interview, the majority of the adolescents remembered and readily shared their emotional responses upon learning that their mother had cancer. Since the interviews were conducted at least 6 months after diagnosis, they were recalling the emotions that they felt at the time of diagnosis. Their emotional responses included shock, anger, sadness, and concern of risk.

Uncertainty.

Uncertainty is "the inability to determine the meaning of illness-related events" (Mishel, 1988, p.225). The adolescents expressed uncertainty about what was going to happen, what the consequences of a diagnosis of cancer were, and what the diagnosis meant. A 12 year old female stated that she was unable to determine or predict where this event would lead to in her or her mother's life. She repeatedly questioned what was going to happen and how her life would change as a result of the cancer diagnosis.

> I was actually at the appointment with her, sitting out in the waiting room….and, um they said, my mom said I might have cancer and it was just like, what is going to happen? That was all that was going through my mind, what if I get it? What is going to happen? How is my life going to change? How is my mom's life going to change and what is basically going to happen?
> *~ 12 year old female*

Shock, anger, and unfairness.

One of the male participants learned that his mother was diagnosed with cancer when he came home from a cross country track meet. He was shocked.

> When I first learned about my mom's cancer, I was very shocked, um, I had no idea at all and because I would come home from school, and it was cross-country season then and I would come home from school and everything would be fine, everyone would be there and like my mom would have her like her doctor's appointments before, before earlier in the day and I was, it was shocking when I first found out. *~ 16 year old male*

A 17 year old female was out, spending time with her friend. When she came home, she found her mother lying on her bed, not speaking to anyone. She became upset because she was not home when her mother received the news. In addition to initially feeling upset, shocked, and unsure of how to cope, she spoke about later feeling angry at God and at the world. She felt that the diagnosis of cancer in her mother was unfair.

> I was unsure of how to deal with it at that point. I was in shock and as time went on and we were making appointments with doctors and meeting all these new people, I was angry. I was angry that it had to happen to her, I was angry that it had to happen now, she has other health problems. It didn't seem fair. I was angry at God, I was angry at the world. I was just really upset that it happened. It just didn't seem fair that it was my mom. *~ 17 year old female*

Fear and concern of risk.

Fear is the anticipation of "the possibility that something dreaded or unwanted may occur" (Beck & Rush, 1985, p. 354). Fear of loss was reported by one adolescent male.

> I was afraid cause I was just thinking about what I would do without my mom?
> *~ 17 year old male*

When he first learned of his mother's diagnosis, this male expressed fear of his mother's death.

> Um on the car ride home is when she told us that she first had cancer….well, like I was really scared at first, you know and, like, just afraid of like, of my mom, like, dying or something, like, crazy like that. *~ 16 year old male*

One clear pattern identified in the data was that females were concerned about their own risk of being diagnosed with cancer, specifically those whose mothers were diagnosed with breast cancer.

A 12 year old female expressed concern of risk.

> Like, I knew that there is one question in my head that I still have not gotten answered. It is um, since my mom got it at a younger age, am I going to get it at a younger age? *~ 12 year old female*

Her mother's diagnosis heightened a 15 year old female's concern about her own risk for cancer, already on her mind because of awareness of cervical cancer and the newly-recommended HPV vaccine. The thought of developing cancer scared her.

> Well, yeah it kind of, it worries me because, I don't know it just worries me because I have a sister and she is already at high risk for cervical cancer and I don't know if I am at risk or anything and I haven't had my HPV shot so I just, I don't want to get cancer, it just scares me. *~ 15 year old female*

This 17 year old female revealed a family history of cancer and expressed fear that cancer is hereditary.

> I don’t want it to sound selfish, but I am afraid for me, too, because my aunt died of breast cancer and got it really, really young and we just found out that my mom could carry a cell and it could be passed on because, um, they think that because she got cancer really young and so did my aunt and if she carries it then I either have it or I carry it also. *~ 17 year old female*

These adolescent females were aware of their inherited predisposition to cancer. They expressed concern about developing cancer at a young age, and verbalized awareness of genetic susceptibility. Having a mother with cancer, and being at increased risk for cancer, could contribute to the formation of these adolescents’ identity or “set of thoughts, feelings, values, attitudes and behaviors that define a person’s self” (Lerner, 2002, p.135).

Somatic response.

In response to the life event, a mothers’ cancer diagnosis, two of the males reported difficulty sleeping. Both of them described this as a direct consequence of learning the diagnosis.

> The first night, I probably didn’t sleep pretty good and probably neither of my brothers did, too. Then, after the first week of that, we all started getting better.
> *~12 year old male*

> I just thought about it and I couldn’t really, I didn’t fall asleep on the regular time that I usually do. And it was just, I just thought about it a lot.
> *~ 17 year old male*

Cancer Changes Families

Relationships between parents, siblings, and other family members transition as the family moves through the six stages of the family life cycle. The families in this study were in family life cycle stage 4 named *families with adolescents* (Veach et al. 2002, Walsh, 2003). During this stage boundaries among members change, and roles are constantly being redefined (Walsh, 2003). Acute onset illnesses generally require high levels of adaptability, problem solving, and role reallocation (Walsh, 2003). The adolescents’ routines, roles, activities, and responsibilities changed as the demands of the illness changed.

Changes in routines.

Family routines were disrupted when the mother's cancer treatment affected her physical functioning. The mother's not feeling well changed her family's routine or commonly practiced activities.

> That year my mom normally works, and she works as a school teacher. That year, she was home all of the time and my dad was not home in the morning and my mom was. We had good breakfasts unlike cereal and then, um, it was just like my whole routine for my family changed. My mom sometimes, like, she wouldn't eat dinner with us, she would come out like, at maybe um, like 6 o'clock at night, come out for like 1/2 hour and then go back to sleep because she did not feel good and she would go to bed at like 7 and stuff and it was really, really different but it was ***a life changing experience*****.....**and having that small piece of cancer in my mom just really kind of changed many people's lives, like mine, my mom's, greatly and everyone else in my family. ~ *12 year old female*
>
> We just waited for our dad to come home to study with us. ~ *12 year old male*

Changes in roles and responsibilities.

Fatigue is a common side effect of cancer treatment, such as chemotherapy. As a result of their mothers' fatigue, adolescents assumed new responsibilities, such as preparing meals or supporting younger siblings. The adolescents' facial expressions, and voice inflection (e.g., voice low and soft) during the interviews, when describing these new responsibilities, suggested that they did not welcome the changes.

> Ok, when she started going through chemo, um, she couldn't really help with anything, she would just sleep on the couch - on the chair- the whole time so (inaudible) we had to do more stuff for ourselves…. she couldn't play with us or cook us food, we had to do all of that stuff ourselves. ~ *12 year old male*
>
> It has changed because my mom has been a lot more tired but we all help out a lot more and everything gets done. ~ *15 year old female*
>
> You know just simple things, like, you know, helping prepare dinner, helping to take out the trash. ~ *16 year old male*

> At home I had to be very strong about it because my sister was very worried and my mom…she was 7 at the time and she turned 8, now she is almost 9…and well, she was really scared. She kept asking me, like, what is going to happen, what is mom going through and everything? ~ *12 year old female*

Impact on activities.

One mother was unable to attend her adolescent's school activity, a cross country track meet because she was recovering from surgery. During the interview, this male's face became flushed and he lowered his head after revealing that his mother missed his track meet.

> Um, just back to like the cross country meets and stuff, um, the one time that I can recall is, um, it was like a really big meet and um, it was the WPIAL meet for cross country which is like, if you can do good there, you go to states and she had surgery the next day and she couldn't make it and um, I, I um, I can't think of the words but, it hurt that she wasn't there…..I wished that she could have seen me, yeah. ~ *16 year old male*

The adolescents described that the mother's cancer treatment made her feel fatigued and affected her physical functioning. The fatigue made her less able to perform her roles as a mother, such as cooking, helping with schoolwork and childcare. The adolescents came to understand that their morning and evening routines would be affected by her fatigue and unavailability. Therefore, they assumed new roles and responsibilities. They came to recognize that she might be absent from sports and other activities.

Helping their mother.

The adolescents began to develop a sense of purpose in their lives as they helped their mother. In response to the question of what advice they would give to another adolescent whose mother had been diagnosed with cancer, several children spoke about being present and helping their mother.

> I would just tell her to help her, make sure she is feeling good. If she is not feeling good, to help her in any way she needs help and just be there for her when she needs help. ~ *14 year old female*

> um, um, well like she, when like when she was going through everything like, I helped her out a lot, like I was there for her, and like, I made sure I like, I listened to her and did everything that I could possibly do to help her and make her feel more comfortable about the situation. I showed her I loved her more and just was there for her. ~ *17 year old male*

When asked what advice she would give to another child whose mother has cancer, this 15 year old female responded:

> Probably, just don't ever give up hope in that everything will be ok and try to make it easier for them and um, like, they are just as scared as you are, maybe even more. ~ *15 year old female*

Coping with Cancer

Adolescent participants were articulate and insightful in describing the means they used to cope with the uncertainty, anger, isolation, and sadness that accompanied learning the diagnosis of cancer, and how they coped with the changes in their family. A compelling finding was that the adolescents used social support to cope with their mother's diagnosis and treatment. Peer groups have an important role in adolescents' emotional health (Lerner, 2002). When adolescents have friends that provide them with strength, sustenance, and positive feelings, they feel supported. The following examples illustrate the importance of support from friends.

Social support.

> I told, like, my best friends, like the ones that are closest to me and they, like, understood and they helped me through….well they would like, make sure and reassure me that everything is going to be alright. They would just say, like, oh it is ok. ~*12 year old female*

> I just really didn't think about it that much. I just kept going on with my normal life. Hanging out with my friends, um, going to a movie sometimes…~ *12 year old male*

> It was definitely scary but, it wasn't as hard as it would have been if I would have been at home because I was surrounded by my friends. ~ *15 year old female*

A 14 year old female revealed that talking about the diagnosis with her friends and family helped her cope. She accepted the social support, embraced the opportunity to let her feelings be known to those that cared about her, and encouraged other children not to withdraw.

> Um, don’t make yourself go into a clam shell and not talk to anybody. You should probably talk to your friends about it and family members or whoever you can talk to. ~ *14 year old female*

One adolescent disclosed that talking to friends was an effective coping strategy; however, if worrying became excessive, seeking professional help was an option.

> They should worry about their parents but they should talk to someone, and like, if it is severe then they should seek like professional help, but, you should just, like talking to people, it just helps me deal with things ten times better…..well, I didn’t like go to see a psychiatrist or anything but I talked to my friends because like, my friends are who I trust, and I talk to my sister.
> ~*15 year old female*

Friends responded to one woman’s diagnosis of cancer by organizing a dinner and making donations to her family.

> Yeah, when my mom had her cancer, like, my friends, like threw this like, surprise spaghetti dinner thing for my mom and they, like donated all kind of money and stuff to help us out. Yeah it was like this big dinner, yeah. ~ *16 year old male*

Not every adolescent had the ideal support network or social skills necessary to effectively cope with the diagnosis. This female expressed withdrawal because she was afraid of being treated as an outcast.

> At first, I felt withdrawn from people and I was afraid that people would treat me different or I would feel like an outcast a little bit but as it went on, I mean, cancer is a very common thing. A lot of people have breast cancer. It’s I really don’t talk about it too much with my friends because I am kind of a private person and sometimes it is hard to talk about it. ~ *17 year old female*

One adolescent’s friend feigned a cancer diagnosis to gain attention, which angered her. The consequence was that their friendship deteriorated and eventually ended.

> Um, like a lot of things have changed, like, um, I have a "MySpace" and my one friend put up this bulletin to try to get people to look at her pictures. It was like, I have cancer and it was just, and then you opened it and it was like, look at my new pictures and I flipped out on her. I was, like, that is not something that you should even say, like, um….she was joking and, I was like, it is not a funny thing, my mom has cancer. It is not funny at all. ~ *14 year old female*

Information seeking.

A way of coping for one adolescent was seeking information and uncovering facts about cancer on the internet and in books in the school library.

> At first I went on the internet because whenever we found out it was over summer break from school and I looked online and she got a book and I read all through the book. It was, like 2 inches it was just humungous and I read everything and then whenever I got back into school, my first and second day I went to the library and took out books about breast cancer and radiation, chemo and that tamoxifen drug. I felt like I needed to… ~ *17 year old female*

Normality.

Maintaining a sense of normality, or following a regular pattern, also helped the adolescents cope.

> It is a fact of life, you just have to accept it and keep moving forward….well, actually at our house, I know that this sounds weird but I feel like nothing has changed whatsoever. I feel like it is just another day. Nothing is different about my mom, which is really nice. ~ *15 year old female*

When asked what advice he would give to another child whose mother has cancer, a 12 year old male said:

> I just really didn't think about it that much. I just kept going on with my normal life….probably just to keep trying to go on with your normal life and then just keep assuring yourself and your family that it is going to be ok. ~ *12 year old male*

Staying positive.

A few adolescents attempted to stay positive, look on the bright side of things, and not dwell on the negative, as a way to cope with their mother's cancer.

> But, the point is if you quit everything that you are doing, it is kind of hard because all you do is think about it. You have to keep yourself busy. It is still

> important to think about it, but, if all that you do is think about it, it gets really hard. Basically, you just start thinking negatively, I think…like, you think, oh what if something else happens. Whereas, I try to think positively all of time.
> ~ *15 year old female*

> Well, I was definitely very worried and afraid that, that it wouldn't get better and there was always that one thought of, I guess, like not having a mom…at one point, but I just try not to, I just really tried to stay positive. ~ *16 year old male*

Throughout the cancer experience, the adolescents reported having to stay strong, steadfast, unwavering, and faithful to their family and mother. When asked what advice she would give to another child whose mother has cancer, this 17 year old said:

> I see what my mom goes through and it is so difficult for her and I know that she gets down and she feels like she has no one sometimes….build a strong close relationship because that is what her mother needs right now and that will help her pull through it. ~ *17 year old female*

Humor.

The use of humor was a way for a 15 year old female to cope with her mother's hair loss.

> She had a really hard time when she was losing her hair and it was really funny. One day I woke up and looked at her and I am like, mom you know, you look just the same, like I keep forgetting that you don't have hair. ~ *15 year old female*

Sports and recreation.

Sports and recreational activities, such as swimming and basketball, were frequently used by the adolescents to help them cope. Sometimes these activities provided distraction.

> Well, I remember well I dealt with it like, I tried to deal with it really good and I remember like going to sports would help me, like swimming, cause I would be like away, and it would get my mind off of it. ~ *12 year old female*

> Like, my own little world was like, basically listening to my music, playing my guitar, programming my game, building my computers. I got a long list of things I can do in my own little world. ~ *16 year old male*

> Um, basically, sports, yeah cause that's… that really did cause ah, I was like, deep into basketball at that time and we had a lot of games, early tournament games so I was into that and that is basically what kept my mind off of it.
> ~ *17 year old male*

> Oh, yeah, yeah because I, um, was in cross country at the time ~ *16 year old male*

Staying active.

One 15 year old female coped with the diagnosis by staying very active and involved in her social club and school activities.

> 4-H is basically agriculture, all of the sciences, like, home economics, and everything put together in one big group…..I am in 7 clubs and we meet a lot. I belong to a travel club….I do sewing, cooking, knitting crocheting and I show market animals. I have goats, sheep and lambs….I also am involved in musical theater and I play the trumpet, the French horn, the piano and the guitar, and I sing. We had auditions for our musical, last, maybe I think 2 weeks ago and I got the lead…. ~ *15 year old female*

Wishing.

Another way to cope with the diagnosis of cancer in his mother was expressed by a 16 year old male who wished that his mother's cancer was gone.

> Like, I just, like, wish that it was gone and everything and like wish that she was all better. ~ *16 year old male*

Spirituality.

Spirituality and faith gave the adolescents hope. A 12 year old female revealed that she asked her school teacher and classmates to pray for her mother every day.

> At the beginning of the day I go to a Catholic School and whenever we, um pray at the beginning of the day, like almost every day I would say for my mom, because she (the teacher) says what would you like to pray for today? And everybody, some people raise their hands and every day I raise my hand and say, my mom. ~ *12 year old female*

Another 16 year old male chose to leave the issue in God's hands.

> I thought basically, uh, it's not my issue, I am leaving it in God's hands because I was brought up in a religious background, so, I am not worried about it. I am

> just going to leave it in God's hands, let him take care of it. I will leave it in God's hands. ~ *16 year old male*

Sense of Purpose

A result of the adolescents' coping with their mothers' cancer and the changes it brought to them and their families was an expressed sense of purpose. The experience provided the adolescents with meaning in their lives and they formed personal goals and objectives related to their mother's cancer. They spoke of their intentions to teach others about cancer, donate to charity, and help their mother. The diagnosis changed their lives and began to shape their identity. "An identity allows (them) to explore (their) world in ways specific to (their) particular abilities, thoughts, feelings and interests"(Lerner, 2002, p. 137).

Increased awareness.

One female realized that she was not alone – other children at her school had a mother or father with cancer, and she was able to relate.

> Since we have found out, I have noticed breast cancer awareness, more so, um sometimes I find out other people at school have moms with cancer or even fathers with different kinds of cancer, you know, and I am a lot more sympathetic and I would not say that I am happy, but, I almost glad that someone else can relate to me. ~ *17 year old female*

Teaching.

Adolescents educated and informed their peers about cancer. One female verbalized that while cancer is scary, informing others made it a "good" experience for her.

> I think just talking about it with people, and getting them to like understand it. Like, teaching people about what happened. I think that really helped me. Like, talking to people about it, like, teaching them about it. ~ *12 year old female*

> Inform people about it because it happens and it is scary but, if you can help other people, I think that it's even a good experience. ~ *15 year old female*

In other situations, the experience of having a mother with cancer inspired the adolescent to use their talents to express their experience and inform others. They made posters and wrote reports for school.

> I think talking about it a little bit, because, I know that last year we had to do a poster on, like whatever, and I did mine on relay for life, which I am sure that you are familiar with…. and I did my poster on that and, um, I just wrote that report about it. ~ *12 year old female*

Charity and donations.

Another female wanted to start a cancer support group and donate money to charity.

> I want to help other people through this. I would love to start, like a group in xx, whenever my mom is finished, and just for her to tell people about what she is going through, especially young women. Any way that I could help, any kind of charity or donations. I feel like I want to start a revolution…I just want to help everyone who has cancer. ~ *17 year old female*

A 17 year old female took photos of horses and leaves and mounted them on barn wood. She sold the product, donated the money to a cancer society, and named the effort “The Crafts for Cancer.”

> My photography…photography helped me the most. We had to write a 5 page research paper that related to our senior project which my senior project actually is “The Crafts for Cancer” is what I called it. ~ *17 year old female*

4.1.1 Exploratory Analysis

The quantitative studies involving adolescents suggest that the experience of younger versus older adolescents are the same or different (Armsden, 1986; Armsden et al., 1990; Lewis & Darby, 2003). In order to further explore potential patterns in the data that were affected by adolescent development, interview data were divided into early (12-14 years) (n=4) and middle (15-17 years) (n=8) adolescence and analyzed using analytic matrices. Results for this analysis showed no detectable differences developmentally between males and females.

The literature also suggests that there may be gender differences in the adolescents' experiences of having a mother with cancer. According to Compas et al. (1994), adolescent females (58% female; mean age =14.6 years, SD=2.2) whose mothers had cancer were most significantly distressed. Additional analysis, using analytic matrices, revealed very beginning patterns in the behavior of males and females. Only females (n=3) were concerned about their own risk of being diagnosed with cancer and only males (n=2) experienced difficulty sleeping. Although the qualitative paradigm used in the current study did not require this exploration, analyses were carried out in order to potentially inform the need for future studies specifically testing the relationship of maturation and/or gender to the adolescents' adjustment to their mother's cancer.

5.0 CHAPTER V

5.1 SUMMARY

The goal of the current study was to elicit and understand the adolescent's experience of having a mother with early stage cancer, the meaning that they constructed about having a mother with early stage cancer, and the coping processes that they used. This qualitative study used grounded theory methodology to guide the exploration of the experience of Caucasian (n=11, 91.6%) and African American (n=1, 8.4%) adolescents ages 12-17 years (M=14.6 years, SD=2.0) whose mothers had cancer. There were 7 females (58.3%) and 5 males (41.7%). The 10 mothers were Caucasian (n=9, 90%) and African American (n=1, 10%) and ranged in age from 38 to 52 years (M = 45.5 years, SD=5.3). They were diagnosed with early stage cancer a minimum of 7 months and a maximum of 24 months (M=15 months, SD=6.4) prior to their adolescent's interview. Most were diagnosed with stage I breast cancer (n=7, 70%). Adolescents' responses were elicited by a semi-structured interview guide. Results revealed that *both* males and females expressed emotional responses to the diagnosis of their mother's cancer such as shock and anger. Adolescents stressed the importance of friends (social support) throughout the illness experience. *Cancer is a Life Changing Experience for the Adolescent* (Figure 1, p.67) emerged as the social process which suggests that when a mother has early stage cancer, issues emerge within that family as a result of the mother’s diagnosis and adolescents begin to address and cope with the meaning of that diagnosis in their lives.

5.2 DISCUSSION

Breast cancer is the most commonly diagnosed cancer in women (26%), followed by cancer of the lung and bronchus (14%), and cancer of the colon and rectum (10%) (American Cancer Society, 2008). Most studies of adolescents who have a mother with cancer are limited to women with breast cancer (Lewis & Hammond, 1996; Spira & Kenemore, 2000; Kristjanson et al., 2004). The findings of this study also showed that the mothers of the adolescents were most often diagnosed with breast cancer (n=7), followed by Hodgkin’s lymphoma (n=1) and endometrial cancer (n=1).

This qualitative study on adolescents’ coping with the life event, their mother’s cancer, documented the adolescents’ experience, in their own words. Both males and females were affected by the diagnosis, treatment, symptoms, and prognosis. Although the study participants’ mothers were diagnosed at an early stage, adolescents’ views of the cancer were dominated by uncertainty, emotional distress, concern about risks, and sadness. The diagnosis intruded into their family life and altered their existing routines, roles and activities. They coped by staying positive, seeking information and social support, attempting to stay “normal” and strong. The adolescents in this study empathized with their mothers’ situation. As mothers became fatigued as a result of treatment, adolescents assumed roles and responsibilities in the home, such as cooking. These findings corroborate those of Hilton and Elfert (1996) who reported that adolescents, particularly females, provided considerable household help.

Compas et al. (1994) revealed that adolescent females whose mothers had cancer manifested more stress-related symptoms than females whose fathers were ill or males whose fathers or mothers were ill. In this sample, *both* the male and the female adolescents verbalized emotional responses to the diagnosis of the mother's cancer, responded to changes in the family, and implemented coping strategies.

In this study, two male adolescents expressed difficulty sleeping upon learning their mother's diagnosis. Previously this stress related symptom had been reported only by females facing their mother's breast cancer (Rosenfeld et al. 1983). Additionally, only female adolescents in the current study expressed increased vulnerability related to their own genetic risk. This finding is similar to results reported by Grandstaff (1976), Kristjanson et al. (2004) and Spira and Kenemore (2000) who noted that females expressed fear of being diagnosed with cancer. Prior literature (Grandstaff, 1976; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Lewis et al. 2000) reported that male and female adolescents feared that their mother would die. Adolescents in this study also spoke of a fear of their mother's death, confirming the importance of recognizing the depth and intensity of the adolescent's fear.

Even though not all of their experiences were positive, adolescents stressed the importance of friends (social support) throughout the illness experience. This finding is similar to results reported by Issel, Ersek, Lewis (1990) who found that 57% of adolescents (ages 13-20 years) revealed that friends helped them throughout their mother's illness. Likewise this finding supports the work by Kristjanson et al. (2004) who found that adolescents (ages 12-10 years) discussed the importance of family and friends in providing a sense of normality, which helped them cope.

The adolescents in this study actively looked up information about cancer on the internet and in textbooks which is consistent with prior research. Kristjanson et al. (2004) reported that sources of information for adolescents whose mothers had cancer included school classes (biology class), books, library resources, brochures and the media. Likewise, Hilton and Gustavson (2002) stated that adolescents wanted to be informed about treatments by reading books and looking things up in the dictionary or on the internet.

Inconsistent with the findings of Nelson et al. (1994), who found that as a result of their mother's illness male adolescents gave up sports, the adolescents in this study continued to participate in sports and recreational activities. They swam, ran track, played basketball, took photos, made crafts, wrote research reports and made posters. They listened to music, sang, played the guitar, French horn, trumpet and piano. In addition they programmed computers, sewed, cooked, knitted, and showed market animals.

The use of humor was another way for the adolescent to cope with their mother's cancer. This finding is consistent with Spira and Kenemore (2000) who reported that females used humor as a means of coping.

A sense of purpose was expressed by the adolescents. As a result of their experience of having a mother with cancer, they revealed new goals which began to direct their actions. The adolescents spoke about an increased sense of awareness of cancer, focused on teaching others about the disease, made donations to cancer charities, and helped their mother throughout her illness. The earlier work by Spira and Kenemore (2000) found that a female adolescent organized a benefit through her youth group to raise money for cancer research.

5.3 CONCLUSIONS

From this study we are able to conclude that having a mother with cancer is a significant event in the life of an adolescent. After learning that their mother has cancer, adolescents experience a dynamic and interactive process through which they respond to changes in the family, cope with cancer, and demonstrate a sense of purpose that continues over time.

5.4 LIMITATIONS OF THE STUDY

There were limitations associated with the study. First, the quality of the findings in any qualitative study is heavily dependent on the individual skills of the interviewer. To address this potential limitation, the PI practiced conducting the semi-structured interviews prior to the start of the study. One dissertation co-chair (Judith Erlen, PhD, RN, FAAN) listened to the first three interviews and provided suggestions on how to improve the interview process. As the semi-structured interviews progressed, both co-chairs (Judith Erlen, PhD, RN, FAAN and Janet Stewart, PhD, RN) provided feedback on the questions and the interview process. Second, generalizability of the findings to other adolescent populations is limited because of the small sample size, nonprobability sampling technique, the use of a single cancer center, and a lack of diversity in the race and socioeconomic status of the participants. The study sample reflected the population of the geographic area, which is predominantly Caucasian (98.6%), with a median household income of $35,000.00 (U.S. Census Bureau, 2006). However, adolescents from diverse cultural and socioeconomic backgrounds might have different experiences when their mother is diagnosed with cancer. Third, the study was limited to adolescents of mothers with early stage cancer that had a 5 year relative survival rate of 80%. Thus this study did not yield information about the experience of adolescents who have a mother diagnosed with advanced cancer. Fourth, participation was sought from adolescents whose mother had been diagnosed with early stage cancer between 6 months and 2 years ago. The adolescents in this study were interviewed during the chronic phase of their mother's illness, reflecting on their feelings in the crisis phase. Additional information could be uncovered with interviews conducted closer to the time of diagnosis. Fifth, adolescents were interviewed at one time point. Interviewing adolescents over time would provide an opportunity to learn how the adolescents' responses to the mother's diagnosis of cancer change over time.

5.5 DIRECTIONS FOR FUTURE RESEARCH

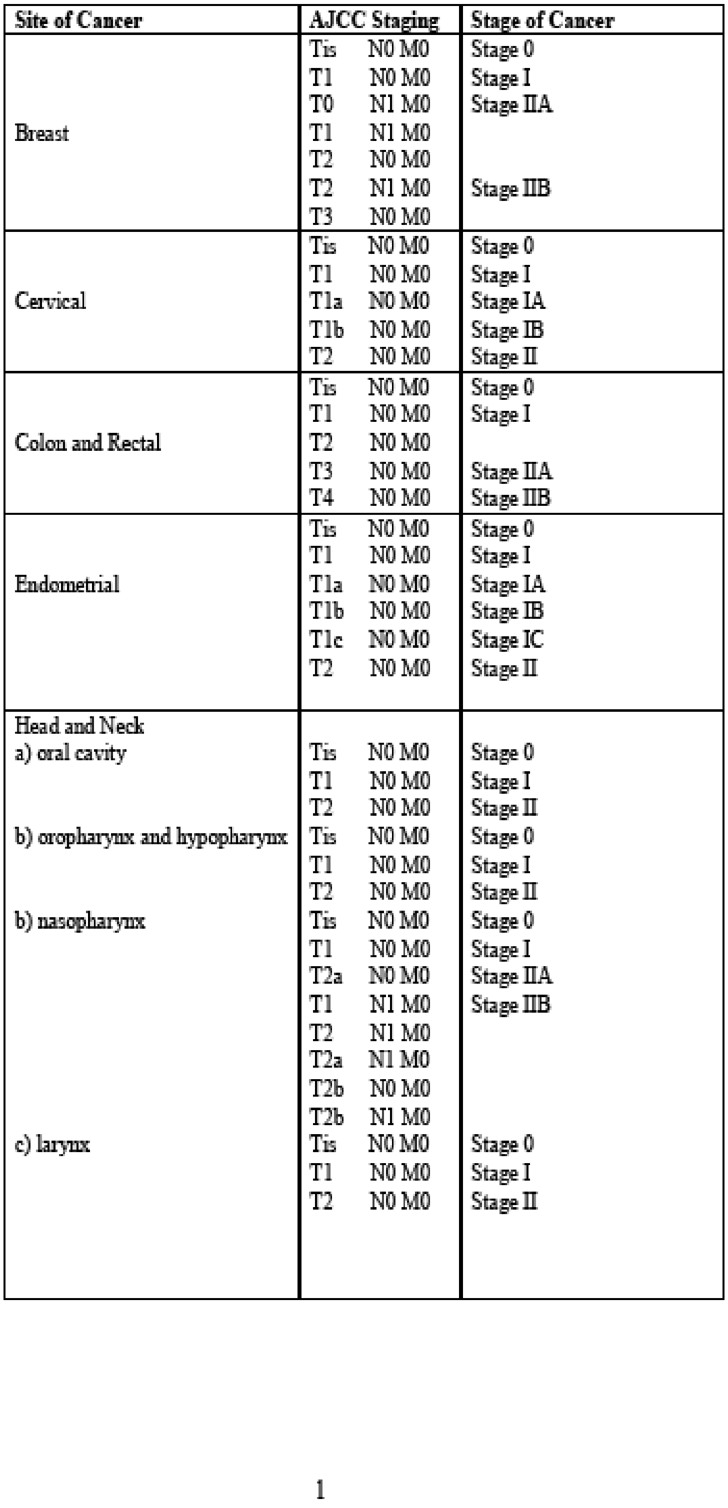
This qualitative study supports the findings from previous studies. Adolescents are influenced by the diagnosis of cancer in their mother. However, further research on this topic is warranted. Twenty one descriptive studies specifically addressed *women* with cancer and their families with *adolescents.* Of these twenty one studies, three included *only* the adolescent (Kristjanson et al., 2004; Lewis & Hammond, 1996; Spira & Kenemore, 2000). Two (Lewis & Hammond, 1996; Kristjanson et al., 2004) of these three studies included *both* male and female adolescents. The findings of this dissertation suggest that both male and female adolescents are influenced, highlighting the importance of examining the experience of adolescent males as well as females. A larger quantitative study is needed to examine the differences in the male and female adolescent's experience. Developmental differences in adolescents as related to the experience of a mother's diagnosis of cancer also need to be studied. Early, middle and late adolescents need to be sampled to determine if their age influences their experience. The sample consisted of predominantly Caucasian adolescents. This study may need to be replicated in more heterogeneous populations to examine the extent to which factors such as race, culture, and sociodemographics influence important aspects of the adolescents' experience.

Having a mother with cancer is a significant life event for the adolescent. Of interest are similarities in the adolescent experience across other chronic disorders. For example, the experience of the adolescents who have a mother with heart disease or diabetes should be investigated to examine if the findings of this study extend to adolescents whose mothers have different chronic disorders.

Future studies need to test the process *Cancer is a Life Changing Experience for the Adolescent* (Figure 1, p.67) including its antecedents, processes, and consequences. The codes that were derived, such as uncertainty, anger, and fear, suggest the variables to be used in a larger quantitative study. A longitudinal study would present the adolescents' experience of a mother's cancer over time and examine if there are changes in this experience. Finally, the growing body of descriptive studies needs to move toward intervention research.

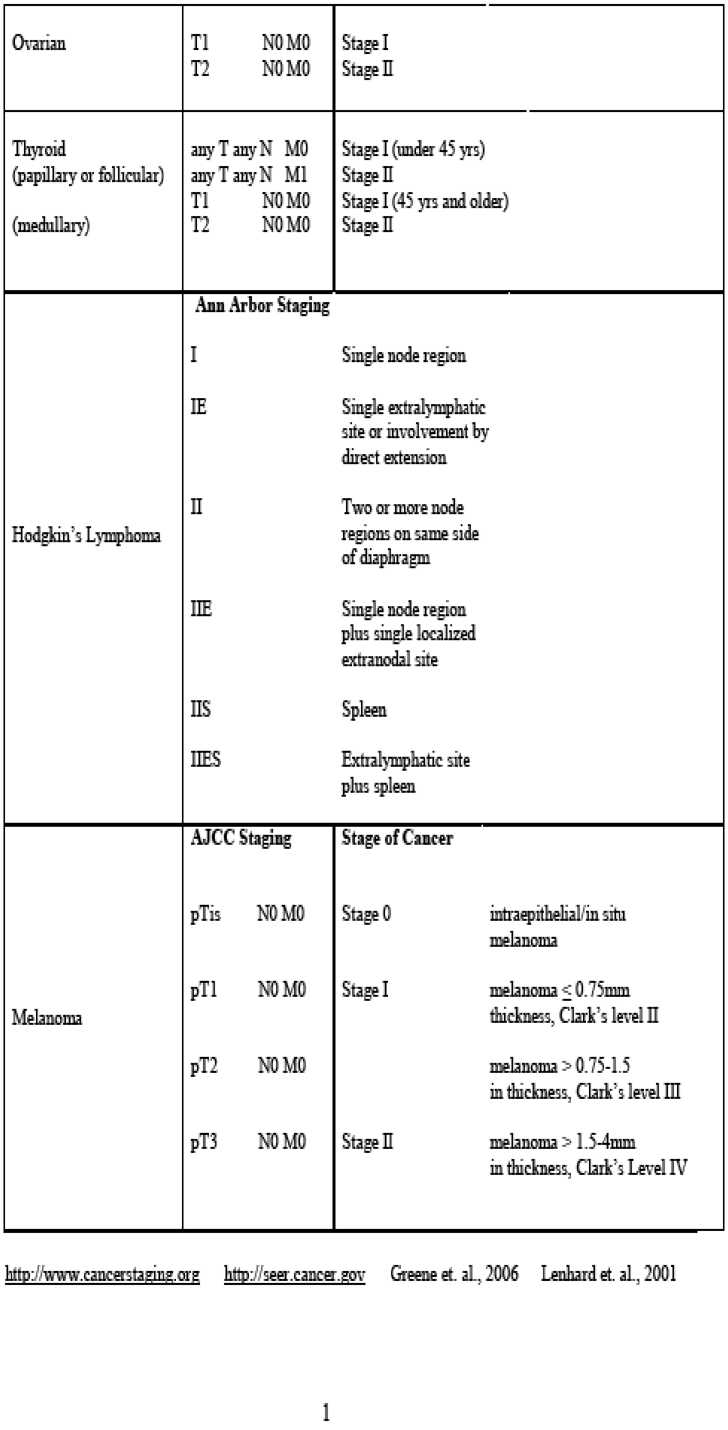
APPENDIX A

STAGING OF CANCER



Site of Cancer	AJCC Staging	Stage of Cancer
Breast	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T0 N1 M0	Stage IIA
	T1 N1 M0	
	T2 N0 M0	
	T2 N1 M0	Stage IIB
	T3 N0 M0	
Cervical	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T1a N0 M0	Stage IA
	T1b N0 M0	Stage IB
	T2 N0 M0	Stage II
Colon and Rectal	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T2 N0 M0	
	T3 N0 M0	Stage IIA
	T4 N0 M0	Stage IIB
Endometrial	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T1a N0 M0	Stage IA
	T1b N0 M0	Stage IB
	T1c N0 M0	Stage IC
	T2 N0 M0	Stage II
Head and Neck		
a) oral cavity	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T2 N0 M0	Stage II
b) oropharynx and hypopharynx	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T2 N0 M0	Stage II
b) nasopharynx	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T2a N0 M0	Stage IIA
	T1 N1 M0	Stage IIB
	T2 N1 M0	
	T2a N1 M0	
	T2b N0 M0	
	T2b N1 M0	
c) larynx	Tis N0 M0	Stage 0
	T1 N0 M0	Stage I
	T2 N0 M0	Stage II

1



Ovarian	T1 N0 M0 T2 N0 M0	Stage I Stage II	
Thyroid (papillary or follicular) (medullary)	any T any N M0 any T any N M1 T1 N0 M0 T2 N0 M0	Stage I (under 45 yrs) Stage II Stage I (45 yrs and older) Stage II	
Hodgkin's Lymphoma	**Ann Arbor Staging**		
	I	Single node region	
	IE	Single extralymphatic site or involvement by direct extension	
	II	Two or more node regions on same side of diaphragm	
	IIE	Single node region plus single localized extranodal site	
	IIS	Spleen	
	IIES	Extralymphatic site plus spleen	
Melanoma	**AJCC Staging**	**Stage of Cancer**	
	pTis N0 M0	Stage 0	intraepithelial/in situ melanoma
	pT1 N0 M0	Stage I	melanoma ≤ 0.75mm thickness, Clark's level II
	pT2 N0 M0		melanoma > 0.75-1.5 in thickness, Clark's level III
	pT3 N0 M0	Stage II	melanoma > 1.5-4mm in thickness, Clark's Level IV

http://www.cancerstaging.org http://seer.cancer.gov Greene et. al., 2006 Lenhard et. al., 2001

APPENDIX B

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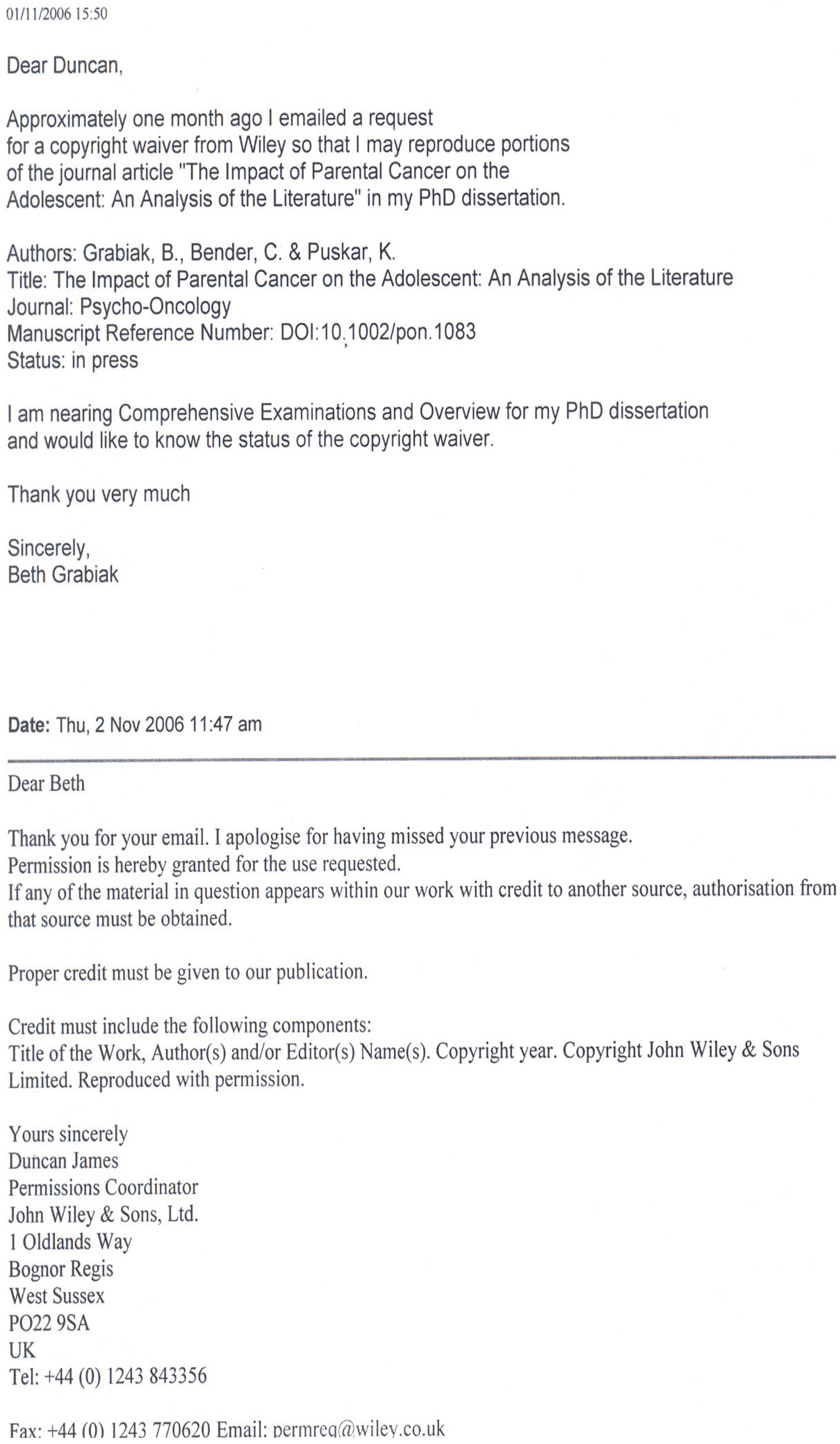

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The impact of parental cancer on the adolescent: An analysis of the literature

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Abstract

Research has revealed the impact of the diagnosis of cancer on an individual, their spouse, and their family. One dimension that has received little attention is the impact of the cancer diagnosis on the patient's adolescent. This article offers an analysis of descriptive studies, intervention studies, and' databased book chapters, published between 1966 and 2006, that examined the impact of parental cancer on the adolescent. The results of 45 studies and three databased book chapters are organized around four themes: adolescents' (1) emotions and behaviors (2) perceptions and knowledge of parental cancer (3) changes in roles and (4) ways of coping. These themes will assist the reader in understanding the application of the knowledge gained from the analysis of the literature to directions for future research.

Keywords: adolescent; cancer; oncology; coping; family; literature review; parent

Introduction

In 2006, an estimated 1,399,790 men and women in The United States of America will be diagnosed with cancer and an estimated 5% of these will be in their child-rearing years [1]. While most of the research has focused on the impact of cancer on the individual, the spouse, and the family, one area that has received little attention is the impact of parental cancer on the patient's adolescent.

According to [2], the physiological and physical changes of adolescence typically span the second decade of life, involving early adolescence (around years 10–14 or 15), middle adolescence (years 15–17), and late adolescence (years 18–20). Tasks such as achieving independence from parents, adopting peer codes and lifestyles, and assigning increased importance to body image characterize maturation of the normal adolescent [3].

The diagnosis of cancer in a parent with subsequent treatment, remission, recurrence, and possible terminal phase causes changes in parental behavioral, emotional and physical functioning as well as family functioning [4]. These changes impact the adolescent's behavioral, emotional and physical functioning as well as their school performance [5]. The purpose of this paper is to critically review and analyze descriptive studies, intervention studies, and databased book chapters that have investigated the impact of parental cancer on the adolescent. This analysis will provide the basis for directing future research that is needed in the area.

Methods

A search for published studies and literature reviews on the impact of parental cancer on the adolescent was conducted on PubMed, a service of the National Library of Medicine and included the databases MEDLINE, 1966–2006; CINAHL, 1982–2006; PsycINFO, 1967–2006; the Cochrane Database of Systematic Reviews and http://highwire.stanford.edu. The keyword combinations used in the search were adolescent and parent and cancer; cancer and family and literature review; and cancer and adolescent and literature review.

A search for databased book chapters was conducted in *Pittcat*, the online library catalog of The University of Pittsburgh. The keyword combinations and subject headings included cancer patients and family relationships; cancer and social aspects; cancer patients and adolescent children; cancer patients and children; and cancer patients and family.

This comprehensive search and review revealed 81 studies and 14 databased book chapters. A study or databased book chapter was excluded if it was not in English; discussed only the impact of parental cancer on pre-school, school-age, young adult or adult children; focused on children of individuals who had died of cancer; or dealt with pre-death and post-death adaptation of children. The 45 studies and three databased book chapters that remained are included in this analysis of the literature.

Results

Three databased book chapters [4,6,7] have been written about individuals with cancer and their families with adolescents. Three researchers have reviewed the literature on the information needs of individuals with cancer and their family members [8–10]. Pederson and Valanis [11] synthesized the research on the effects of breast cancer on the family while Lewis and Bloom [12] reviewed the clinical and research literature concerning women's emotional adjustment to the detection of breast cancer and its management. The literature on the impact of cancer on the family was synthesized by three researchers [13–15]. One paper reviewed the literature on the impact of parental cancer on school-age children, adolescents and the family [5]. This literature review will differ from past reviews because the focus is on the adolescent of the parent with cancer.

The studies were conducted in five different countries, including the Australia (3), Canada (4), Netherlands (4), UK (4) and US (33). The majority of the studies were cross sectional with the exception of [16–18]. Only women with breast cancer were included in over one-half of the studies in this review [4,6,7,16,17,19–33]. Men and women with various types of cancer were included in 16 studies [18,34–48].

Six investigators examined female adolescents [20–23,25,46]. Male and female adolescents were examined by 27 investigators [4,6,7,16–18,24,26–29,31–33,35–45,47,48]. The majority of studies included in this analysis of the literature focused on four themes: (1) adolescents' emotions and behaviors; (2) adolescents' perceptions and knowledge of parental cancer; (3) adolescents' changes in roles; and (4) adolescents' ways of coping. This analysis is organized around the four themes that were dictated by the literature.

Themes from the literature

Theme 1: adolescents' emotions and behaviors

Research on adolescents who have a parent with cancer encompasses the adolescents' emotions and behaviors. Internalizing behaviors are behaviors that are 'directed inward to the individual that affect his or her mental, cognitive, or emotional functioning, such as depression or anxiety.' ([2], p. 299). Fear is the anticipation of 'the possibility that something dreaded or unwanted may occur. Fear may be regarded as a predisposition to perceive a specific set of conditions as a threat and to react with anxiety when exposed to these conditions.' ([49], p. 354). Anxiety is a state of uneasiness and distress about future uncertainties, apprehension, and worry. 'It is clear that the object or situation is not feared, per se, but rather the possible consequences of exposure to such an object.' ([49], p. 354).

A salient point in the literature is that adolescents feared that their parent would die [6,7,16,26] and the piece of information that adolescents sought, regardless of their age, was knowing whether or not their parent was going to survive [29]. When children were told that their parent was not going to die generally, they felt relieved [26].

Female adolescents of individuals with cancer felt increased vulnerability to cancer related to genetic risk [6,20,23,29,45] and could identify symptoms of breast cancer [20]. Adolescent female's fears were associated with physical/sexual development [23] and [20] adolescent females reported significantly less frequent sexual intercourse and lower sexual satisfaction. Nelson *et al.* [36] reported that males felt anxious about their parent's illness but felt unable to discuss their fears with either parent. Evidence suggests that adolescents conceal their thoughts, fears, and feelings in an attempt to protect the parent and not cause tension in the relationship [45]. Fear of recurrence and loss of the parent may be expressed through somatic symptoms [23]. However, according to Davey *et al.* [45], adolescents tried to maintain positive thoughts or attitudes, talked about the cancer, and relied on faith to alleviate fear and sadness.

Heiney *et al.* [39] reported that adolescents showed significantly higher state and trait anxiety compared to an age-normed sample. Lewis and Darby [27] noted that when both parents' relationships with the adolescent were poor, adolescents showed significantly lower self-esteem and increased anxiety. Adolescent females whose mothers had cancer were significantly distressed [18,35,37,42,47,48]. According to Watson *et al.* [32] maternal depression combined with poorly defined family roles increased the likelihood of internalizing problems, especially in females. Increased family responsibilities and the use of ruminative coping were also examined as possible mechanisms leading to increased distress in females with ill mothers [37]. According to Welch *et al.* [18], adolescents' self-reported symptoms of anxiety/depression did not vary according to type of parental cancer. Thus, adolescents whose mothers had breast cancer were no more likely to experience higher levels of anxiety/depression than adolescents whose mothers had other types of cancer [18].

Externalizing behaviors are behaviors that are 'directed to other people or, more generally, to the social context, i.e. aggression, arson, or disruptive behavior in the school or home.' ([2], p. 299). According to Lewis and Darby [27] adolescents tended to show increased behavioral problems when both parents had depressed mood; maternal depressed mood was the main source of influence. Males reported that parental illness had affected

DOI: 10.1002/pon

their schoolwork and amount of leisure time for sports and activities with friends [36]. Family functioning was significantly related to emotional and behavioral problems; extremely high adaptation and extremely low family cohesion were related to the prevalence of emotional and behavioral problems in children [44]. Watson [32] reported that adolescent's externalizing problems were predicted when the adolescent reported worse family communication, family affective responsiveness, family affective involvement, family behavioral control, and family general functioning. An increase in the adolescent's externalizing problems was also associated with lower family cohesion.

Lewis' [4] correlational analyses between the mother's illness-related demands and the adolescent's functioning revealed that the greater the number of family-related illness demands the mother experienced, the greater the number of behavioral problems reported by the adolescent. Interestingly, [50] and [18] noted that parents do not perceive their children as being distressed, either in terms of internalizing (anxiety/depression) or externalizing (aggression) emotional or behavioral problems.

Theme 2: adolescents' perceptions and knowledge of parental cancer

To perceive is 'to take notice of; observe' and knowledge is 'the sum or range of what has been perceived, discovered or learned.' ([51], p. 920). Adolescents were in turmoil during the diagnosis and treatment of their parent's cancer however, once the immediate threat was over, they did not see the situation as a continued threat to themselves, their families or their parent [16]. Adolescents stated that when they were given information, the timing of the information in relation to their mother's cancer was important. They required understandable, detailed, information soon after diagnosis and reported the importance of receiving information as the illness progressed such as the potential side effects of treatment, alternative therapies, the seriousness of the illness, and the medical 'facts' about the disease [29]. They appreciated health care providers giving them information and providing them with local sources of support in a way that they understood [46]. In addition to written information, they would have also valued the health care providers recommending a website on parental cancer [33]. Adolescents wanted to be informed about treatments by attending appointments, reading books and looking things up in the dictionary or on the Internet [26,45]. They had a desire to know more about their parent's illness so that they could contribute to the family in a positive way and be supportive of other family members [46]. Huizinga *et al.* [44] reported that whether or not the child was well informed was a factor that was perceived as having an impact on the child's coping.

Unfortunately, mothers with breast cancer and other family members do not always know what the child is experiencing because of the breast cancer [52]. Adolescents reported that within and outside of the family, their information and support needs were poorly met [29,53]. In a study by Issel *et al.* [19], 15% of adolescents ages 13–20 years said that the family did nothing to help them. Adolescents mentioned that people from the community (churches and neighbors) were helpful to their family but did not offer them personal support [29].

Theme 3: adolescents' changes in roles

Roles are characteristic and expected social behaviors of individuals. The results of Wellisch *et al.* [21] study showed that adolescents were prone to change roles with the ill parent. The majority of children remembered having to take on extra domestic chores and responsibilities for sibling care during diagnosis and treatment [16,36,45]. According to Spira and Kenemore [23], females feared that changing roles would alter the existing mother/daughter relationship. They wanted to maintain the relationship with their mothers that they had before the illness. Adolescents were impacted by changes in family patterns and were involved in helping at home [19,26,38].

Theme 4: adolescents' ways of coping

Lazarus ([54], p. 237) defines coping as 'ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.' Problem-focused coping is 'the management or alteration of the person–environment relationship that is the source of stress' and emotion-focused coping is the 'regulation of stressful emotions' ([55], p. 223).

Adolescents used problem-focused coping as they asked questions, read about the illness, and assumed responsibility for household chores or sibling care [36]. They also reported using emotion-focused coping by refusing to think or talk about the illness [19,36] and dual-focused coping (both problem- and emotion-focused in intent) [38]. According to Compas *et al.* [38], emotion-focused coping is related to greater avoidance and to higher symptoms of anxiety/depression in the adolescent.

Adolescents stressed the importance of family, friends and the school system in providing a sense of normality about their life, which helped them cope [19,29,44,45]. Humor was used as a way of coping [23,45]; friends were described as being supportive when they tried to be close, asked about their parent, and offered hugs and jokes [29].

Adolescents discussed the importance of having time to be a normal teenager. Teens valued information about the normal feelings of the adolescent whose parent has cancer. For example, wanting to spend time with friends and away from the day-to-day management of their parent's illness. They emphasized the importance of continuing to meet their own needs such as moving away from home and working for the summer [46]. Some wished that their parent would die because they wanted their life to return to normal, and felt guilty for the thought [23]. They appreciated health care professionals informing them that feelings such as anger and guilt were normal [29] (Table 1).

Few intervention studies have focused on adolescents who have a parent with cancer [30,31,34]. The psychoeducational group intervention 'Kids Can Cope' [34] assisted school-age children and adolescents (ages 5–18 years) in learning about cancer and its treatments. The intervention provided them with the opportunity to share concerns in a safe environment and increase their coping strategies. Lewis *et al.* [31] stated 'research reveals that both mothers and children have elevated distress attributed to the cancer, struggle with how to talk about and deal with the impact of the cancer, and both fear that the mother will die.' The Enhancing Connections Program [31], was developed for school-age children and adolescents (ages 8–12 years) to reduce cancer-related distress and morbidity. Results revealed significant improvements in mother's depressed mood, anxiety and self-confidence to assist her child. There were also significant decreases in the child's behavioral problems, the child's cancer-related worries, and the child's anxiety/depressed mood. Davey *et al.* [30] conducted focus groups with adolescents whose mothers had breast cancer to elicit their opinion about how future intervention programs should be developed. Adolescents suggested that intervention programs: include adolescent groups of males and females within 4 months of the cancer

Table 1. Themes in the literature on the adolescent and parental cancer

Author (s)/Date	Emotions and behaviors	Perceptions and knowledge	Role changes	Ways of coping
Grandstaff, [6]	×			
Lewis *et al.*, [50]	×			
Issel *et al.*, [19]			×	×
Wellisch *et al.*, [20]	×			×
Wellisch *et al.*, [21]			×	
Taylor-Brown *et al.*, [34]				×
Nelson *et al.*, [36]	×		×	×
Compas *et al.*, [35]	×			
Grant and Compas, [37]	×			×
Lewis, [4]	×			
Hilton and Elfert, [16]	×	×	×	
Welch *et al.*, [18]	×			
Compas *et al.*, [38]			×	×
Lewis and Hammond, [17]				×
Wellisch *et al.*, [22]		×		
Heiney *et al.*, [39]	×			
Zahlis and Lewis, [52]		×		
Birenbaum *et al.*, [40]	×			
Spira and Kenemore, [23]	×		×	×
Lewis *et al.*, [7]	×			
Chalmers *et al.*, [53]		×		
Hoke, [24]	×			
Nelson and While, [42]	×			
Hilton and Gustavson, [26]	×	×	×	
Davey *et al.*, [45]	×	×	×	×
Huizinga *et al.*, [44]	×	×		×
Lewis and Darby, [27]	×			
Harris and Zakowski, [43]		×		
Sigal *et al.*, [28]	×			
Sears and Sheppard, [46]		×		×
Kristjanson *et al.*, [29]	×	×		×
Huizinga *et al.*, [47]	×			
Visser *et al.*, [48]	×			
Lewis *et al.*, [31]	×			
Davey *et al.*, [30]		×		
Watson *et al.*, [32]	×			
Forrest *et al.*, [33]		×		

Table 2. Studies of the impact of parental cancer on the adolescent

Study	Sample characteristics	Measures	Results
Nelson *et al*., 1994 *Purpose*: to investigate adolescents problems and anxieties related to parental cancer to consider adolescents perceptions and understanding of parental cancer *Design*: retrospective, mixed methods, cross sectional	Adolescents ($n = 24$) • 2 females, 11 males mother with cancer • 6 females, 5 males father with cancer • female age 11–18 years • male age 11–21 years Parent ($n = 16$) • Hodgkin's disease IIB-IVB • Non-Hodgkin's lymphoma • Breast cancer	Semistructured adolescent interviews RCMAS [56]	Sons, but not daughters, were significantly anxious Factors associated with sons high anxiety scores were: • less time for sports $p<0.02$ • less time for peers $p<0.01$ • poor schoolwork $p<0.01$ • unable to discuss with parents $p<0.01$ • continued anxiety over illness $p<0.01$ Adolescents used emotion focused coping: denial, refusing to think about or talk about the illness. Problem focused coping included seeking information (asking questions) or increasing knowledge (reading)
Grant and Compas, 1995 *Purpose*: identify mechanisms leading to distress in adolescents who have a parent with cancer *Design*: mixed methods, cross sectional	Adolescents ($n = 55$) • 12 males, 21 females mother with cancer • 10 males, 12 females father with cancer • male and female age 11–18 year Parent ($n = 55$) • Breast cancer • Ovarian cancer • Leukemia • Hodgkin's disease Stage I cancer 36% Stage II cancer 24% Stage III cancer 21% Stage IV cancer 19%	YSR [57] APES [58]	For the YSR anxious-depressed scale, an ANOVA indicated a significant main effect for gender of adolescent ($F(1,51) = 12.64$, $p<0.001$) and significant interaction of gender of adolescent and gender of ill parent ($F(1,51) = 5.42$, $p<0.02$) Girls whose mothers had cancer reported more family responsibility stress than did girls whose fathers had cancer or boys whose mothers or fathers were ill. There was a main effect of gender of adolescent for ruminative coping, with girls reporting more rumination ($F(1,46) = 4.85$, $p<0.03$) however the interaction of gender of ill parent and gender of adolescent was not significant for rumination. There were no main effects or interactions for the use of distraction coping
Lewis and Hammond, 1996 *Purpose*: to test the theoretical model of the impact of the mother's breast cancer on adolescent-rearing households from the mother's, father's and adolescent's viewpoint *Design*: quantitative	Adolescents ($n = 70$) • 44% male • 56% female • adolescent mean age 16.3 years Parents • mothers with cancer ($n = 70$) • mothers mean age = 42.9 years • Breast cancer 97.6% (Stage 0, I, II, IIIA) • husbands/partners ($n = 70$) • fathers mean age = 46.9 years	F-COPES [59] FACES II [60] CES-D [61] DOII [62] Spanier DAS [63] Norbeck Social Support Scale [64] Rosenberg Self-Esteem Scale [65] Relationships Scale [66]	As fathers reported more frequent coping behavior by their families, the quality of the relationship between the adolescent and the parents tended to be more positive ($p<0.10$) Neither the gender of the adolescent, parental depressed mood, nor the level of marital adjustment significantly predicted the quality of the parent–adolescent relationship More positive parent child relationships significantly predicted more positive adolescent self-esteem ($p<0.001$) Fathers' positive perceptions of the family members' coping behavior were significantly associated with the adolescent's higher self esteem ($p<0.01$) Marriages characterized as better adjusted by the fathers tended to significantly predict lower, not higher, self esteem in the adolescents ($p<0.10$)

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Table 2. *(continued)*

Study	Sample characteristics	Measures	Results
Spira and Kenemore, 2000 *Purpose:* to illustrate concerns that adolescent daughters of mothers with breast cancer have about themselves and their mother's illness *Design:* qualitative	Adolescents: ● female age range 12–19 years Parent: ● mother with breast cancer	Clinical vignettes derived from adolescent interviews	Themes ● Fear of the illness ● Fear of recurrence and loss of mother ● Fear associated with physical/sexual development ● Communication about the Illness—the more communication about the disease process, the easier it was for the adolescent ● Changes in roles—increased anxiety that change in roles would alter the mother/daughter relationship ● Coping—adolescents used humor Some adolescents demonstrated strength, resilience and hope
Harris and Zakowski, 2003 *Purpose:* to compare symptoms of distress in the adolescent whose parent has cancer with symptoms of distress in the adolescent whose parent is healthy to examine possible predictors of distress in the adolescent *Design:* cross sectional	Adolescents ($n = 50$) ● 18 females with ill parent ● 9 males with ill parent ● 11 females with healthy parent ● 12 males with healthy parent ● males and females age 12–19 years Parent ($n = 41$) ● 22 ill parent ● 19 healthy parent ● Breast ($n = 12$) ● Gynecological ($n = 4$) ● Prostate ($n = 1$) ● Lung ($n = 1$) ● Breast and Ovarian ($n = 1$) ● Gastric ($n = 1$) ● Bladder ($n = 2$)	CDI [67] RCMAS [56] IES [68] PCL-C [69] The Family Environment Scale [70] PR Scale—one item measure adapted from a questionnaire [71]	No significant differences in depression or anxiety between adolescents with an ill parent and adolescents with a healthy parent RCMAS $t(47) = -0.55$; $p = 0.58$ Ill parent ($M = 7.0$; $SD = 4.1$) Healthy ($M = 7.8$; $SD = 5.2$) Parent CDI $t(47) = -0.44$; $p = 0.66$ Ill parent ($M = 34.0$; $SD = 3.6$) Healthy Parent ($M = 34.5$; $SD = 3.6$) Adolescents in the ill parent group had lower levels of PTSD-like symptoms on both IES and PCL-C than adolescents in the healthy parent group IES $t(48) = -2.57$; $p = 0.01$ Ill parent ($M = 12.5$; $SD = 13.8$) Healthy Parent ($M = 23.8$; $SD = 17.3$) PCL-C $t(45) = -2.30$; $p = 0.03$ Ill parent ($M = 22.0$; $SD = 5.0$) Healthy Parent ($M = 27.0$; $SD = 9.6$) Adolescents in the ill parent group perceived themselves to be at a higher risk for developing cancer PR $t(48) = 4.35$; $p = 0.04$ Ill parent ($M = 2.9$; $SD = 0.99$) Healthy Parent ($M = 2.3$; $SD = 1.0$) Adolescents experienced less distress in families in which the members were highly cohesive, experienced less conflict, and were able to be expressive.

Table 2. *(continued)*

Study	Sample characteristics	Measures	Results
Davey *et al.*, 2003 *Purpose:* to develop an understanding of how adolescents are affected by non-terminal parental cancer to gain insight into how family members adjust to, and cope with non-terminal parental cancer *Design:* qualitative	Adolescents: ($n = 10$) ● 2 females, 1 male father with cancer ● 2 females, 6 males mother with cancer Parents: ● Breast cancer ● Hodgkin's disease ● Mercocell Carcinoma	Adolescent and parent interviews	Themes ● Worry and fear—adolescents experienced feelings of sadness ● Protection adolescents tried to protect their parents by hiding their feelings ● Adjustment adolescents reported role changes during diagnosis and treatment ● Coping adolescents coped by using faith, humor, talking things out, distraction, and cognitive skills ● Support parents, siblings and other relatives provided support school counselors, coaches and teachers offered adolescents support
Sears and Sheppard, 2004 *Purpose:* to explore the experience of the adolescent whose parent is diagnosed with cancer *Design:* qualitative	Adolescents ($n = 3$) ● female age 17–21 years Parent ($n = 3$) ● Cervical cancer ● Colon cancer ● Lung cancer	Semistructured adolescent interviews	Themes ● Family is the primary focus family members became closer than they were prior to their parent's illness, and families functioned as a unit individual family members focused more on their family's needs than their own needs ● Ways that parents can facilitate coping adolescents desired to know about their parent's illness so that they could contribute to the family in a positive way adolescents discussed the importance of time and space and being a *normal* teen ● Ways that others can facilitate coping adolescents described the importance of informal sources of support, including family and friends adolescents stressed the importance of informal sources of support, including extended family members and friends adolescents stressed the importance for professionals to provide information in a way that they understand

Table 2. (*continued*)

Study	Sample characteristics	Measures	Results
Kristjanson *et al.*, 2004	Adolescents ($n = 31$)	Semistructured adolescent interviews and focus groups	Adolescents reported a number of information and support needs, although needs assessment was minimal
Purpose: to elicit detailed descriptions of adolescent's information and support needs in response to their mother's breast cancer	● 22 females, 9 males mother with cancer ● age <12–18 years at diagnosis ● age 12–20 years at interview	McMaster FAD [72]	The one piece of information that adolescents consistently sought, regardless of their age, was whether or not their mother was going to survive
Design: qualitative	Parent ($n = 31$) ● Breast cancer		Adolescents perceived their needs as individualized, based on their family situation and own personal needs
	Stage I or II cancer 29% Stage III or IV cancer 7% First recurrence 13% Remission 39%		Adolescents considered support from school to be important because it allowed them to continue with their lives and feel hopeful
	Advanced or terminal 13%		Specific individualized interventions are needed to address adolescent's needs

Note: APES = Adolescent Perceived Events Scale, CDI = Children's Depression Inventory, CES-D = Center for Epidemiological Studies—Depression scale, DAS = Dyadic Adjustment Scale, DOII = Demands of Illness Inventory, FACES II = Family Adaptability and Cohesion Evaluation Scales II, FAD = Family Assessment Device, F-COPES = Family Crisis Oriented Personal Evaluation Scales, IES = Impact of Events Scale, PCL-C = the PTSD Checklist-Civilian Version, PR = Perceived Risk Scale, RCMA = Revised Children's Manifest Anxiety Scale, YSR = Youth Self Report.

diagnosis; teach coping skills sensitive to males and females of different ethnic and racial backgrounds; and be followed by family therapy groups that promote shared family understanding and open communication between parents and adolescents.

Several of the studies on children who have a parent with cancer examined school-age children and adolescents [39,40,42,44,48] or adolescents and young adults [47]. The eight studies that included *only* the adolescent, defined as a person between the ages of 10–20 years [2], are illustrated in Table 2.

Discussion

Methodological issues

A number of methodological issues are associated with studies exploring the effect of parental cancer on the adolescent. First, many studies included small numbers of adolescents with sample sizes ranging from 3 to 55 [16,18,19,26,29,35–37,39,42–46]. The results of these studies need to be interpreted with caution because they may not represent the wider population of adolescents who have a parent with cancer. Second, many samples combined school-age children, adolescents, and young adults and the age ranges for each developmental stage were not consistent across studies. These differences in age ranges may contribute to the interpretation of conflicting empirical results.

Third, approximately one-half of the studies were limited to adolescents of women with breast cancer therefore, the implications of different parental cancers on the adolescent are not well known. Finally, the majority of studies are cross sectional with investigators examining the adolescent at time points ranging from 2 months to 5 years after their parent's diagnosis of cancer. Little is known about changes in the adolescent's behavioral, emotional, and physical functioning as their parent's illness progresses.

Conceptual issues

Studies often lacked conceptual foundations and focused on undefined concepts such as *fear* [6,23,45] and *distress* [35,43]. Conceptual clarity was lacking with regards to the meaning of *children*. With the exception of eight studies which included only adolescents [17,23,29,36,37,43,45,46], the studies often included school-age children, preadolescents, adolescents and young adults. Researchers need to define the *children* included in their study, and a more narrow conceptualization of the *children* to be included in each study must be considered. For example, researchers may choose to include only pre-school children, school-age children, or adolescents in their study.

Recommendations for future research

Adolescence is characterized by three distinct periods: early (around years 10–14 or 15), middle (years 15–17), and late (years 18–20) [2]. Each period has a characteristic set of biological, psychological, and social issues. For example, during early adolescence secondary sex characteristics appear, bids for increased independence from the family are common, cliques form with peers [73] and cognition is usually concrete [74]. During middle adolescence growth peaks, body shape changes, a struggle for increased autonomy from the family is evident; dating begins [73] and cognition begins to be abstract [74]. During late adolescence, growth is slower, independence from the family and signs of intimacy with a significant other appear, [73] and cognitive development is complete [74]. Because biological, psychological and social issues differ across each developmental stage, research studies tailored to early, middle and late adolescents who have a parent with cancer are needed.

Several lines of inquiry appear promising for future studies. Quantitative, qualitative or mixed methods studies, with large sample sizes, focused on male and female adolescents who have a parent with any type of cancer are needed. With the exception of Davey *et al.* [45] and Harris and Zakowski [43] the studies included in this analysis of the literature are limited to well educated, Caucasian, middle class families. Cultural, socioeconomic, racial and ethnic diversity in the sample of adolescents is also needed in future studies. Longitudinal studies will contribute to the literature by examining the impact of parental cancer on the adolescent over time and throughout the cancer illness trajectory. These studies may inform and guide researchers to the times during parental illness that adolescents are most in need of supportive interventions.

Conclusion

In conclusion, the results of this analysis of the literature have shown that adolescents who have a parent with cancer are distressed and this distress must be recognized *and* addressed by the parent diagnosed with cancer, family members, health care professionals and school personnel. Only eight descriptive studies [17,23,29,36,37,43,45,46] have focused on adolescents who have a parent with cancer. Three intervention studies have included adolescents [33,34,45]. Therefore, more descriptive studies on adolescents are needed. Results of these studies can be used for the development and implementation of effective interventions. In this way, researchers and scientists may contribute to a future free of neglect for adolescents who have a parent with cancer.

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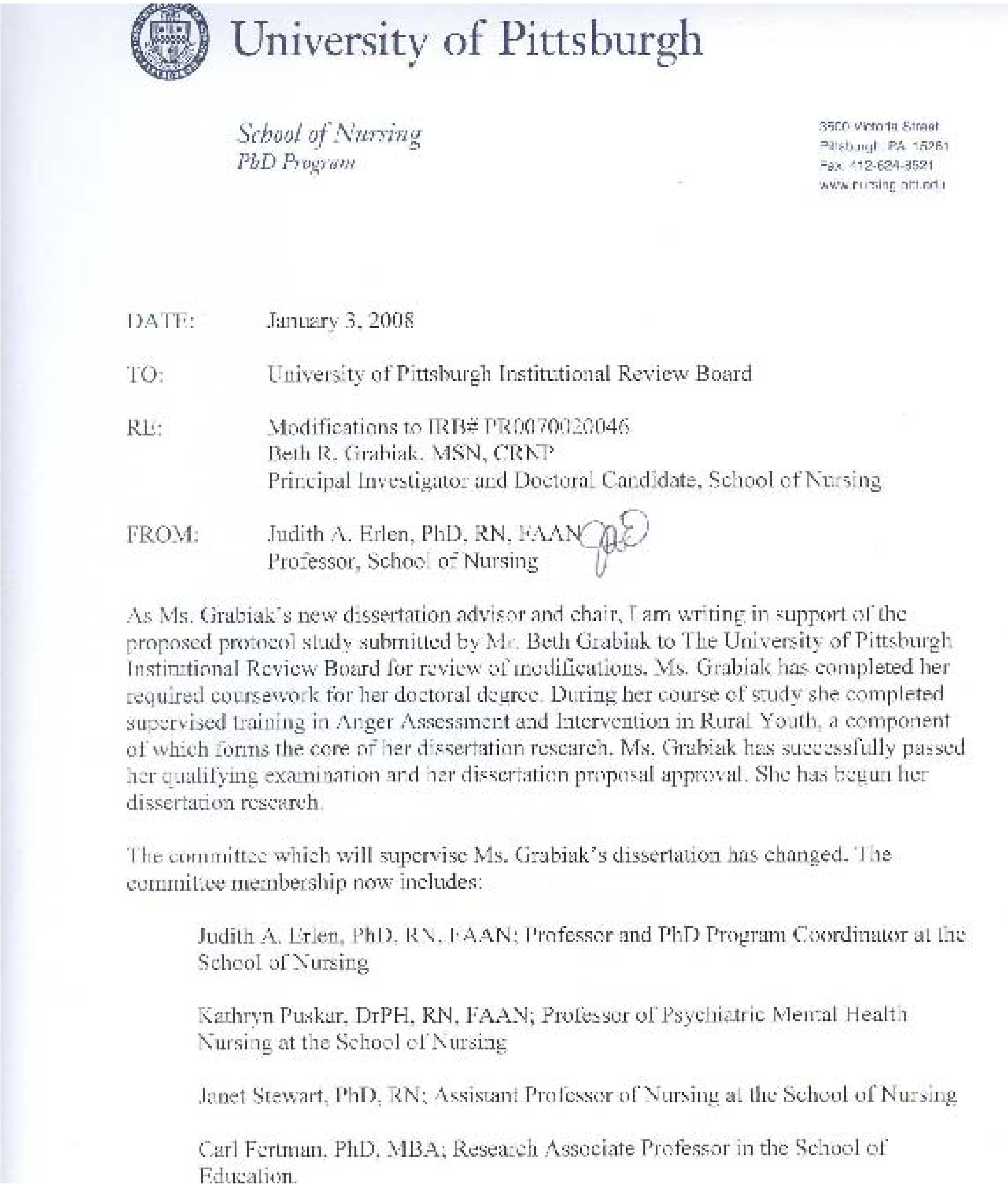
APPENDIX C

LETTERS OF SUPPORT



University of Pittsburgh

School of Nursing
PhD Program

3500 Victoria Street
Pittsburgh, PA 15261
Fax 412-624-8521
www.nursing.pitt.edu

DATE: January 3, 2008

TO: University of Pittsburgh Institutional Review Board

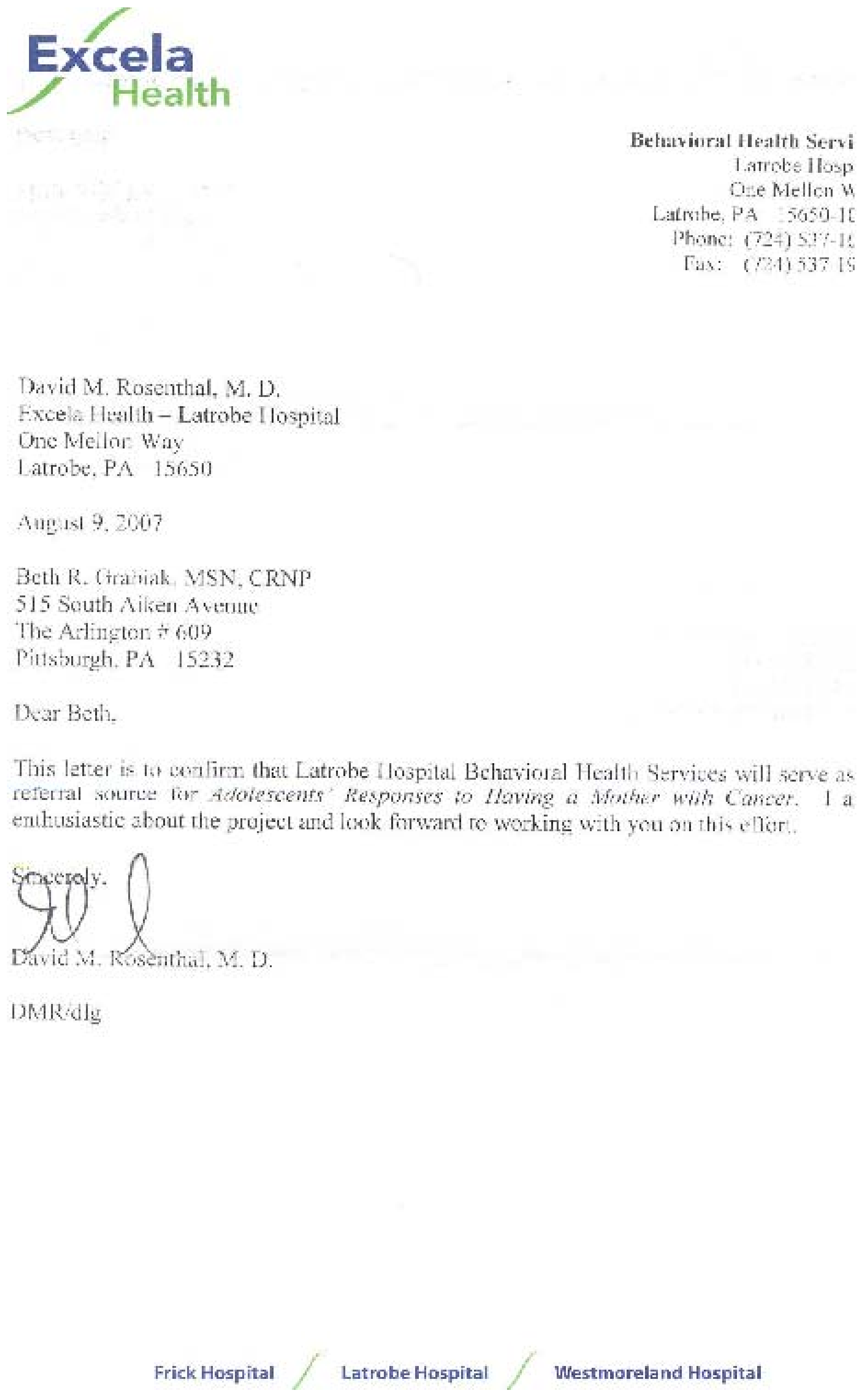
RE: Modifications to IRB# PR0070020046
Beth R. Grabiak, MSN, CRNP
Principal Investigator and Doctoral Candidate, School of Nursing

FROM: Judith A. Erlen, PhD, RN, FAAN
Professor, School of Nursing

As Ms. Grabiak's new dissertation advisor and chair, I am writing in support of the proposed protocol study submitted by Ms. Beth Grabiak to The University of Pittsburgh Institutional Review Board for review of modifications. Ms. Grabiak has completed her required coursework for her doctoral degree. During her course of study she completed supervised training in Anger Assessment and Intervention in Rural Youth, a component of which forms the core of her dissertation research. Ms. Grabiak has successfully passed her qualifying examination and her dissertation proposal approval. She has begun her dissertation research.

The committee which will supervise Ms. Grabiak's dissertation has changed. The committee membership now includes:

> Judith A. Erlen, PhD, RN, FAAN; Professor and PhD Program Coordinator at the School of Nursing
>
> Kathryn Puskar, DrPH, RN, FAAN; Professor of Psychiatric Mental Health Nursing at the School of Nursing
>
> Janet Stewart, PhD, RN; Assistant Professor of Nursing at the School of Nursing
>
> Carl Fertman, PhD, MBA; Research Associate Professor in the School of Education.



Excela
Health

Behavioral Health Servi
Latrobe Hosp
One Mellon W
Latrobe, PA 15650-1
Phone: (724) 537-1
Fax: (724) 537-1

David M. Rosenthal, M. D.
Excela Health – Latrobe Hospital
One Mellon Way
Latrobe, PA 15650

August 9, 2007

Beth R. Grabiak, MSN, CRNP
515 South Aiken Avenue
The Arlington # 609
Pittsburgh, PA 15232

Dear Beth,

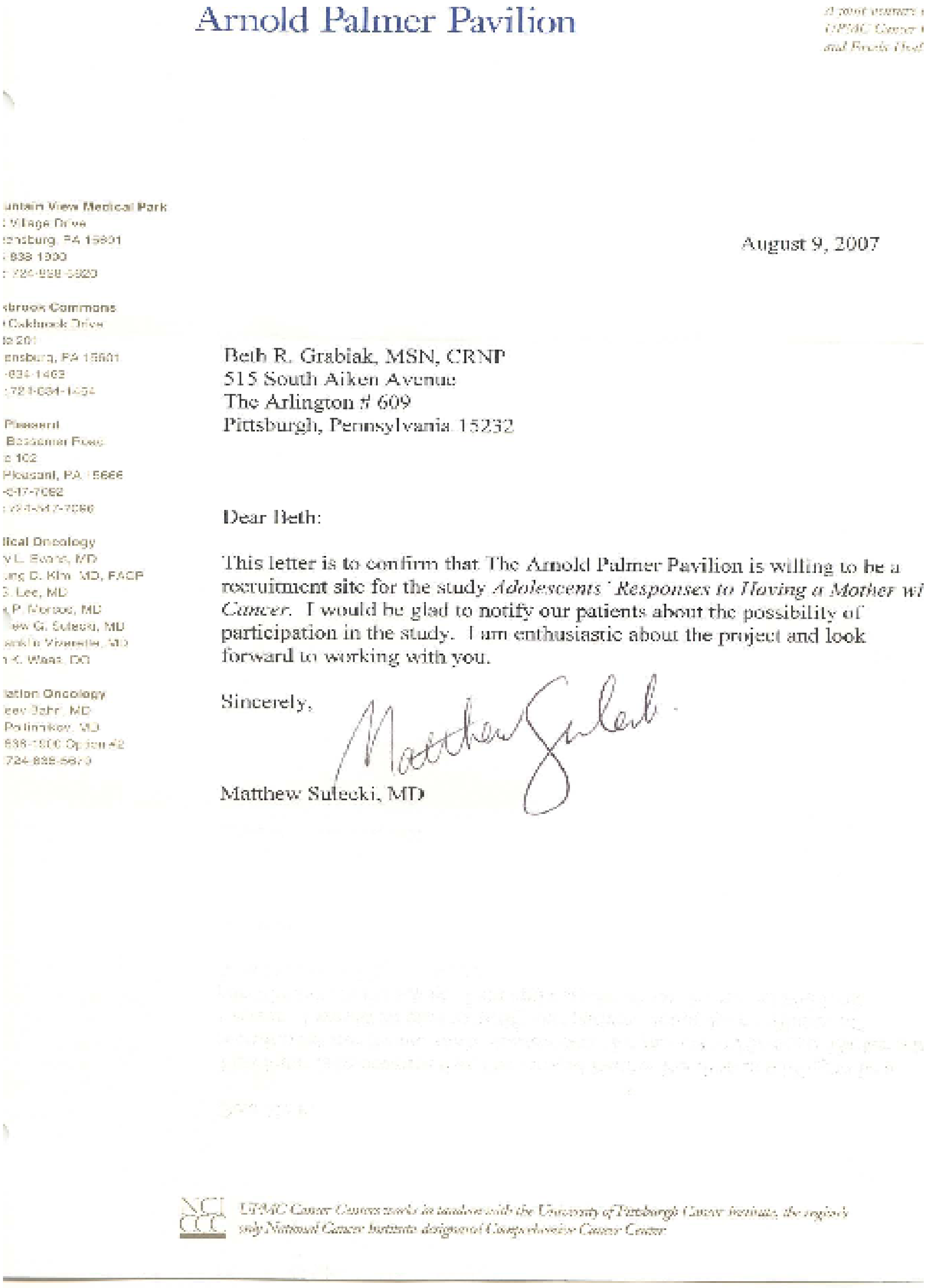
This letter is to confirm that Latrobe Hospital Behavioral Health Services will serve as referral source for *Adolescents' Responses to Having a Mother with Cancer.* I a enthusiastic about the project and look forward to working with you on this effort.

Sincerely,

David M. Rosenthal, M. D.

DMR/dlg

Frick Hospital / Latrobe Hospital / Westmoreland Hospital



Arnold Palmer Pavilion

A joint venture
UPMC Cancer
and Excela Heal

untain View Medical Park
: Village Drive
ensburg, PA 15601
: 838 1900
: 724-838-5820

sbrook Commons
Oakbrook Drive
te 201
ensburg, PA 15601
-834-1463
: 724-834-1454

Pleasant
Bessemer Road
e 102
Pleasant, PA 15666
-547-7062
: 724-547-7066

lical Oncology
v L. Evans, MD
ung D. Kim, MD, FACP
3. Lee, MD
P. Monzo, MD
ew G. Sulecki, MD
anklin Visnerelle, MD
n K. Waas, DO

iation Oncology
eev Bahri, MD
Patinnikov, MD
838-1900 Option 42
724-838-5870

August 9, 2007

Beth R. Grabiak, MSN, CRNP
515 South Aiken Avenue
The Arlington # 609
Pittsburgh, Pennsylvania 15232

Dear Beth:

This letter is to confirm that The Arnold Palmer Pavilion is willing to be a recruitment site for the study *Adolescents' Responses to Having a Mother wi Cancer*. I would be glad to notify our patients about the possibility of participation in the study. I am enthusiastic about the project and look forward to working with you.

Sincerely,

Matthew Sulecki

Matthew Sulecki, MD

NCI
CCC

UPMC Cancer Centers works in tandem with the University of Pittsburgh Cancer Institute, the region's only National Cancer Institute designated Comprehensive Cancer Center

APPENDIX D

RECRUITMENT FLYER

University of Pittsburgh

Adolescents' Responses to Having a Mother with Cancer

RESEARCH STUDY FOR

Males & females ages 12-17 years

Your child will be asked to answer questions about their
experience of having a mother with cancer

Your child will be compensated for their time

For more information, ask your oncologist, or call the investigator at
(412) 657-8139

APPENDIX E

HIPAA SHARING FORM AND CONSENT

AUTHORIZATION FOR THE SHARING OF HEALTH INFORMATION RELATED TO POSSIBLE PARTICIPATION IN A RESEARCH STUDY

Title of Research Study:	Adolescents' Responses to Having a Mother with Cancer
Research Study Investigator(s):	
Principal Investigator:	Beth Rene Grabiak, PhD(c), MSN, CRNP University of Pittsburgh School of Nursing telephone: (412) 621-9390
Co-Investigators:	Judith A. Erlen, PhD, RN, FAAN telephone: (412) 624-1905
	Janet L. Stewart, PhD, RN telephone: (412) 624-3854
	Kathryn R. Puskar, DrPH, RN, FAAN telephone: (412) 624-6933

What is the purpose of this authorization?

Your doctor or a member of your doctor's health care staff has discussed with you that you may be eligible to take part in the above-named research study. You have indicated an interest in learning more about this research study from the researchers who are involved in conducting the study. Thus, your authorization (permission) is being requested to:

- share the fact that you are interested in participating in this study with the involved researchers;
- share only your medical diagnosis which suggests you may be eligible to take part in this study with the involved researchers; and
- allow the involved researchers to contact you so as to permit additional discussions of this study with you and/or to provide you with information on how you may take part in this study.

What information about me will be shared with the researchers?

If you give your permission, the following information about you will be shared (for example, by telephone or FAX) with the researchers involved in the conduct of the above-named research study:

- your name, address, and telephone number
- only your medical diagnosis which suggests you may be eligible for this research study
- your interest in being contacted for the research
- a copy of this signed document

To whom will the above information be given?

We will share this information with one of the researchers listed above or a member of their research staff. This information will be used by the researchers to evaluate if you are eligible to participate in this research study and/or to contact you to further discuss this research study with you. These researchers recognize the importance of maintaining the confidentiality (privacy) of your health information, however it is not possible for us to guarantee its confidentiality after we have provided it to them.

For how long is authorization valid?

Once this information has been shared with the researchers, this authorization form will expire. We will not continue to share your future health information with these researchers, nor will we share your health information with any other researchers unless you sign a separate authorization form that permits us to do so.

Is my permission to provide this information to the researchers voluntary?

Your permission to provide this information to the researchers is completely voluntary. Whether or not you provide your permission will have no affect on your current or future medical care or your relationship with your doctor or health care provider. Whether or not you provide your permission will have no affect on your current or future relationship with the University of Pittsburgh or the University of Pittsburgh Medical Center.

May I withdraw, at a future date, my permission to provide this information to the researchers?

You may withdraw, at any time, your permission to provide this information to the researchers. However, once this information has been shared with the researchers, the information will be in their possession. Hence, should you decide to withdraw your permission after your information has been given to the researchers you should send a written and dated notice of this decision to the principal investigator of this research study at the address listed above. Upon receipt of this request, the researchers will destroy your information that was provided to them. If you wish to withdraw your permission to provide this information to the researchers before it is given to them, you should contact, by telephone, your doctor or a member of your doctor's health care staff. With receipt of this request, your information will not be shared with the researchers.

Your decision to withdraw your permission to provide this information to the researchers will have no effect on your current or future medical care or your relationship with your doctor or health care provider. Your decision to withdraw your permission will have no affect on your current or future relationship with The University of Pittsburgh or University of Pittsburgh Medical Center.

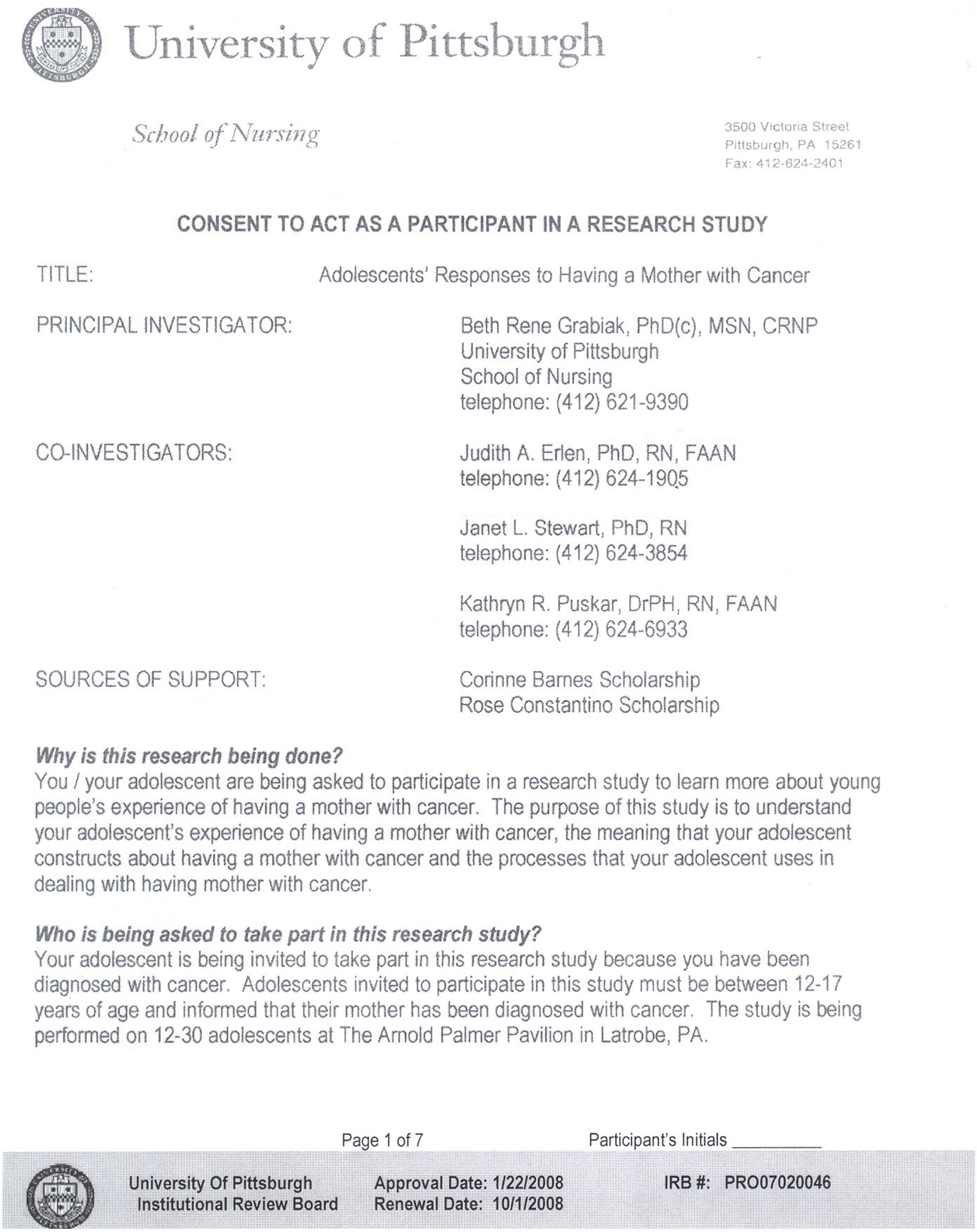
****

VOLUNTARY AUTHORIZATION

All of the above has been explained to me. By signing below I give my permission to share the information, specified above, with the researchers, identified above, for the purposes described.

____
Printed Name of Patient

______________________________________ ________________
Signature of Patient Date



University of Pittsburgh

School of Nursing

3500 Victoria Street
Pittsburgh, PA 15261
Fax: 412-624-2401

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: Adolescents' Responses to Having a Mother with Cancer

PRINCIPAL INVESTIGATOR:
Beth Rene Grabiak, PhD(c), MSN, CRNP
University of Pittsburgh
School of Nursing
telephone: (412) 621-9390

CO-INVESTIGATORS:
Judith A. Erlen, PhD, RN, FAAN
telephone: (412) 624-1905

Janet L. Stewart, PhD, RN
telephone: (412) 624-3854

Kathryn R. Puskar, DrPH, RN, FAAN
telephone: (412) 624-6933

SOURCES OF SUPPORT:
Corinne Barnes Scholarship
Rose Constantino Scholarship

Why is this research being done?

You / your adolescent are being asked to participate in a research study to learn more about young people's experience of having a mother with cancer. The purpose of this study is to understand your adolescent's experience of having a mother with cancer, the meaning that your adolescent constructs about having a mother with cancer and the processes that your adolescent uses in dealing with having mother with cancer.

Who is being asked to take part in this research study?

Your adolescent is being invited to take part in this research study because you have been diagnosed with cancer. Adolescents invited to participate in this study must be between 12-17 years of age and informed that their mother has been diagnosed with cancer. The study is being performed on 12-30 adolescents at The Arnold Palmer Pavilion in Latrobe, PA.

Page 1 of 7 Participant's Initials __________

University Of Pittsburgh
Institutional Review Board
Approval Date: 1/22/2008
Renewal Date: 10/1/2008
IRB #: PRO07020046

What procedures will be performed for research purposes?

If you / your adolescent express interest in study participation, the following will occur:

Screening Procedures:

Procedures to determine if you / your adolescent are eligible to take part in a research study are called "screening procedures." For this research study, the screening procedures include confirmation by the principal investigator of you / your adolescent's eligibility for the study. After you have signed the consent, you will be asked to complete an investigator developed demographic data questionnaire and a diagnosis and treatment questionnaire. The demographic data questionnaire is a list of questions about your adolescent (e.g., age, gender, race). The diagnosis and treatment questionnaire is a list of questions about you (e.g., age, type and stage of cancer). Your medical record will be reviewed to confirm your age, type and stage of cancer, and time since diagnosis of cancer. The principal investigator will confirm your adolescent's age with you, after the consent has been signed.

Experimental Procedures:

1. The procedures will take place in a semi private conference room at The Arnold Palmer Pavilion in Latrobe, PA and will take approximately 1 hour. Your adolescent will undergo the experimental procedures. The principal investigator will meet you / your adolescent. Your adolescent will be asked questions about their experience of having a mother with cancer. The questions will ask them about their home life, school life, and life with friends. They will also be asked about their feelings and how they are dealing with them. There is a list of interview questions which is available for you / your adolescent's review before signing the consent.

2. The interview will be tape recorded. The principal investigator will listen to the audiotapes, transcribe the interviews, and then the other investigators (specialists in cancer, psychology and child care) will view the transcribed interviews and provide an interpretation.

Monitoring / Follow-up Procedures:

For this study, we may "follow-up" in that you / your adolescent may be contacted at a later date to verify responses to interview questions or to answer further questions.

What are the possible risks, side effects, and discomforts of this research study?

The primary risk associated with participating in this study is the psychological discomfort some adolescents feel with either the audio recording or when they disclose sensitive information about themselves during the interview. If at any time over the course of the interview your adolescent becomes frustrated or develops symptoms of severe depression or anxiety and is in need of psychological counseling or psychiatric referral, the interview will be discontinued and usual care for depression or anxiety instituted which includes a referral to Latrobe Area Hospital Behavioral Health.

Otherwise, the risks for study participants are minimal. The study entails minimal time and effort (approximately 1 hour), and is designed so as to not interfere with usual patient care. Women who enroll their adolescent in this project will not receive different care than those who do not enroll. Participation is voluntary and participants may refuse to take part or stop at any time, even after signing the consent form.

What are possible benefits from taking part in this study?

There is no benefit from participation. Indirectly, through being reflective during the interview, participants may learn more about their attitudes and experiences of having a mother with cancer. We believe that our long-term goal, to create an intervention for adolescents with mothers diagnosed with cancer, will be improved as a result of the knowledge generated by this study and the research that will develop from it.

Will my insurance provider or I be charged for the costs of any procedures performed as part of this research study?

You will not be charged for any procedures performed for this research.

Will I be paid if I take part in this research study?

Your adolescent will be paid a total of $10 if s/he completes all parts of this study. In addition, any parking will be free of charge.

Who will know about my participation in this research study?

Any information about you / your adolescent obtained from this research will be kept as confidential (private) as possible. All records related to you / your adolescent's involvement in this research study will be stored in a locked filing cabinet at The University of Pittsburgh School of Nursing, indefinitely. You / your adolescent's identity on these records will be indicated by a case number rather than by you / your adolescent's name, and the information linking these case numbers with you / your adolescent's identity will be kept separate from the research records. You / your adolescent will not be identified by name in any publication of the research results unless you / your adolescent sign a separate consent form giving your permission (release).

Will this research study involve the use or disclosure of my identifiable medical information?

This research study will involve the recording of current identifiable medical information from your medical record held at the Arnold Palmer Pavilion. The information that will be recorded will be limited to information concerning mother's age, type and stage of cancer and time since diagnosis of cancer.

This research study will not result in identifiable information that will be placed into your medical records held at The Arnold Palmer Pavilion.

Who will have access to identifiable information related to my participation in this research study?

In addition to the investigators listed on the first page of this authorization (consent) form and their research staff, the following individuals will or may have access to identifiable information (which may include your identifiable medical information) related to your participation in this research study:

Authorized representatives of The University of Pittsburgh Research Conduct and Compliance Office may review your identifiable research information (which may include your identifiable medical information) for the purpose of monitoring the appropriate conduct of this research study.

In unusual cases, the investigators may be required to release identifiable information (which may include your identifiable medical information) related to your participation in this research study in response to an order from a court of law. If the investigators learn that you or someone with whom you are involved is in serious danger or potential harm, they will need to inform, as required by Pennsylvania law, the appropriate agencies.

For how long will the investigators be permitted to use and disclose identifiable information related to my participation in this research study?
The investigators may continue to use and disclose, for the purposes described above, identifiable information (e.g., the mother's age, type and stage of cancer, and time since diagnosis of cancer) related to your participation in this research study for a minimum of five years after final reporting or publication of a project.

May I have access to my medical information that results from my participation in this research study?
In accordance with the UPMC Notices of Privacy Practices document that you have been provided, you are permitted access to information (including information resulting from your participation in this research study) contained within your medical records filed with your health care provider.

Is my participation in this research study voluntary?
You / your adolescent's participation in this research study, to include the use and disclosure of your identifiable information for the purposes described above, is completely voluntary. (Note, however, that if you / your adolescent do not provide your consent for the use and disclosure of your identifiable information for the purposes described above, you / your adolescent will not be allowed to participate in the research study). Whether or not you / your adolescent provide your consent for participation in this research study will have no effect on your current or future relationship with The University of Pittsburgh. Whether or not you provide your consent for participation in this research study will have no effect on your current or future medical care at a UPMC hospital or affiliated health care provider or your current or future relationship with a health care insurance provider.

May I withdraw, at a future date, my consent for participation in this research study?
You / your adolescent may withdraw, at any time, your consent for participation in this research study, to include the use and disclosure of your identifiable information for the purposes described above. (Note, however, that if you / your adolescent withdraw your consent for the use and disclosure of you / your adolescent's identifiable medical record information for the purposes described above, you / your adolescent will also be withdrawn, in general, from further participation in this research study). Any identifiable research or medical information recorded for, or resulting from, your participation in this research study prior to the date that you formally withdrew your consent may continue to be used and disclosed by the investigators for the purposes described above.

To formally withdraw your consent for participation in this research study you should provide a written and dated notice of this decision to the principal investigator of this research study at the address listed on the first page of this form.

Your decision to withdraw your consent for participation in this research study will have no affect on your current or future relationship with The University of Pittsburgh. Your decision to withdraw your consent for participation in this research study will have no affect on your current or future medical care at a UPMC hospital or affiliated health care provider or your current or future relationship with a health care insurance provider.

If I agree to take part in this research study, can I be removed from the study without my consent?

It is possible that you / your adolescent may be removed from the research study by the researchers if, for example, your adolescent becomes distressed during the interview process. If you / your adolescent are withdrawn from participation in this research study, you will continue to undergo treatment as usual.

****

VOLUNTARY CONSENT

The above information has been explained to me and my adolescent's current questions have been answered. I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that such future questions will be answered by a qualified individual or by the investigator(s) listed on the first page of this consent document at the telephone number(s) given. I understand that I may always request that my questions, concerns or complaints be addressed by a listed investigator. I understand that I may contact the Human Subjects Protection Advocate of the IRB Office, University of Pittsburgh (1-866-212-2668) to discuss problems, concerns, and questions; obtain information; offer input; or discuss situations in the event that the research team is unavailable.

By signing this form, I agree to participate in this research study. A copy of this consent form will be given to me.

______________________	______________________	__________
Parent's (participant) signature	Printed name of parent (participant)	Date

Participant's Initials __________

I understand that as a minor (age less than 18 years), the adolescent named below is not permitted to participate in this research study without my consent. Therefore, by signing this form, I give my consent for his/her participation in this research study.

Parent's name and relationship to the adolescent (participant)

Parent's signature Date

This research study has been explained to me and I agree to participate.

Adolescent's (participant) name Date

Adolescent's (participant) signature

VERIFICATION OF EXPLANATION (for researcher to sign)

I certify that I have carefully explained the purpose and nature of this research study to the above named participant in appropriate language. S/he has had an opportunity to discuss it with me in detail. I have answered all his/her questions and s/he has provided affirmative agreement (i.e., assent) to participate in this study.

Investigator's Signature Date

CERTIFICATION of INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise. I further certify that no research component of this protocol was begun until after this consent form was signed.

______________________________	________________
Printed Name of Person Obtaining Consent	Role in Research Study
______________________________	____________
Signature of Person Obtaining Consent	Date

APPENDIX F

DEMOGRAPHIC DATA QUESTIONNAIRE

Demographic Data Questionnaire
(adapted with permission from Frances M. Lewis, PhD, RN)

Please answer the following questions about your adolescent who is participating in *Adolescents' Responses to Having a Mother with Cancer*

1) How old is your adolescent? _____

2) What is your adolescent's gender? _____male _____female

3) What is your adolescents' race?______________

4) Does your adolescent have brothers or sisters? _____ yes _____ no

Name	Age	Gender	Relationship

5) Has your adolescent been diagnosed with an emotional problem? _____yes_____no

Please explain____

____

6) Is your adolescent undergoing any treatment for an emotional problem? _____yes_____no
Please explain____

7) Is your child participating in any professional individual counseling for issues related to the cancer? (do not include cancer support groups) _____yes_____no

8) Is your child participating in a cancer support group? _____yes_____no

9) What is your relationship to your adolescent? (circle one)

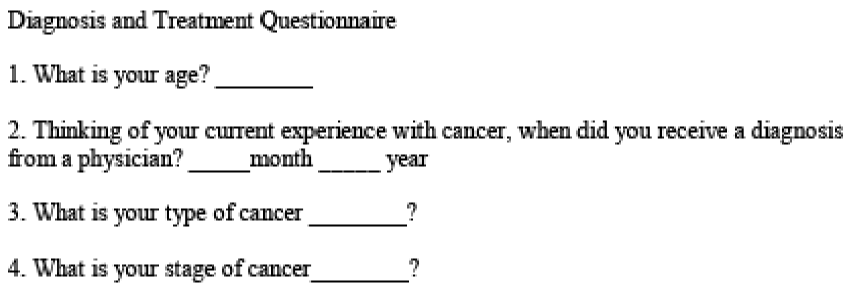
a) Biological mother b) Adoptive mother

10) What is your marital status? (circle one)

a) Married b) Single c) Divorced d) Widowed

APPENDIX G

DIAGNOSIS AND TREATMENT QUESTIONNAIRE



Diagnosis and Treatment Questionnaire

1. What is your age? ________

2. Thinking of your current experience with cancer, when did you receive a diagnosis from a physician? _____month _____ year

3. What is your type of cancer ________?

4. What is your stage of cancer________?

APPENDIX H

SEMI - STRUCTURED INTERVIEW GUIDE

Interview Guide (12/07, 2/08, 3/08)

Hi, my name is Beth. I am a nurse and I am part of a research team from The University of Pittsburgh School of Nursing. You are one of a small group of special kids that I am talking with whose mother has been diagnosed with cancer. I have invited you to share your experience and ideas so that you may advance science and help me help other kids who have a mom with cancer. I would like to ask you some questions which will take approximately 1 hour. Just to remind you, I will be audio-taping our talk. The reason that I am audio-taping and may be taking some notes is that I want to be able to review and report on what has been said at a later time. Members of the research team will listen to the tape and the tape will be stored in a locked cabinet at The University of Pittsburgh School of Nursing. I will erase any names on the tape in order to make sure that what you tell me is kept private. If you are carrying a cell phone, please turn down the volume now. There are no specific “right” or “wrong” answers to these questions. Do you have any questions before we get started?

1) Let’s start at the beginning. Tell me about when you first learned about your mom’s cancer.

- How did you find out about your mom’s cancer?
- What was the experience like?
- What did you think when you first found out?
- How did you deal with it?

2) Since you found out about the cancer, how has having a mom with cancer affected your life?

- How about your life at home, has it been affected?
- How about your life at school?
- How about life with friends?
- How about your feelings? Have they been affected? (replaced in 2/08)
- *Tell me what you are thinking / feeling now?* (replaced in 3/08)
- *When you think about your mom’s cancer now, what kinds of things go through your mind?*

3) Ok, you have told me about how your mom’s cancer has affected you. Now, I wonder if there has been anything that has helped you in dealing with these affects (probe with reference from the previous responses)

4) *Other kids have told me about feeling afraid / worrying. Can you tell me what this has been like for you?*

5) Now, the last part. I would like to get your advice for other kids who are going through what you have gone through. If you were going to give advice, privately, to another child whose mother has cancer, what would you tell them? What would you really want them to know?

6) Is there anything that we did not talk about today that you would like to discuss?

7) I appreciate the time that you have taken to talk with me today. It is really helpful to understand your experience so that we can better plan to be helpful to other families who are dealing with cancer. If you have any questions, comments or concerns, please feel free to contact me.

APPENDIX I

INSTITUTIONAL REVIEW BOARD APPROVAL

Brandon Kaukus, PRC Coordinator
Clinical Research Services
Hillman Cancer Center
Fourth Floor
5115 Centre Avenue
Pittsburgh, PA 15232-1305
Phone: 412-623-3376
Fax: 412-647-0949
Email: kaukusbm@upmc.edu

UPMC Cancer Centers
Hillman Cancer Center

University of Pittsburgh Cancer Institute

MEMORANDUM

TO: **Beth R. Grabiak, MSN, CRNP**

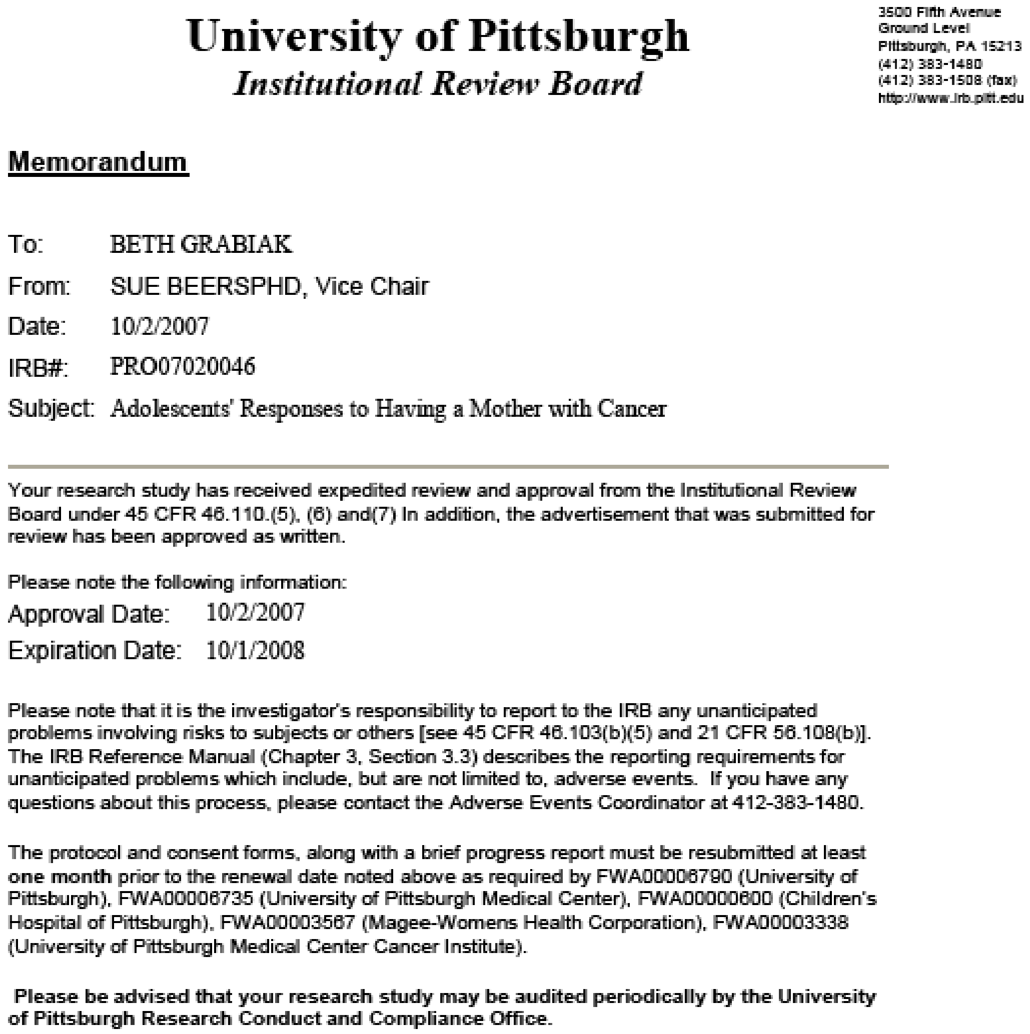
FROM: Brandon Kaukus
UPCI PRC Coordinator, Clinical Research Services

DATE: **August 9, 2007**

RE: **07-092: Adolescents' Responses to Having a Mother with Cancer**

Thank you for responding to the UPCI Protocol Review Committee (PRC) comments. The above referenced protocol has been reviewed and approved by committee and can be submitted to the IRB for review.   Please submit a copy of this memo along with your protocol when you submit it to the IRB. Any changes made to the study design in the future should be submitted to the committee for review prior to your submission to the IRB.

This is a trial that has not been coordinated by UPCI CRS; therefore, attached is a list of guidelines to assist you in the continuation process with UPCI. Should you have any questions, do not hesitate to contact me at 623-3376 or email to kaukusbm@upmc.edu.



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: BETH GRABIAK
From: SUE BEERSPHD, Vice Chair
Date: 10/2/2007
IRB#: PRO07020046
Subject: Adolescents' Responses to Having a Mother with Cancer

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Your research study has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110.(5), (6) and(7) In addition, the advertisement that was submitted for review has been approved as written.

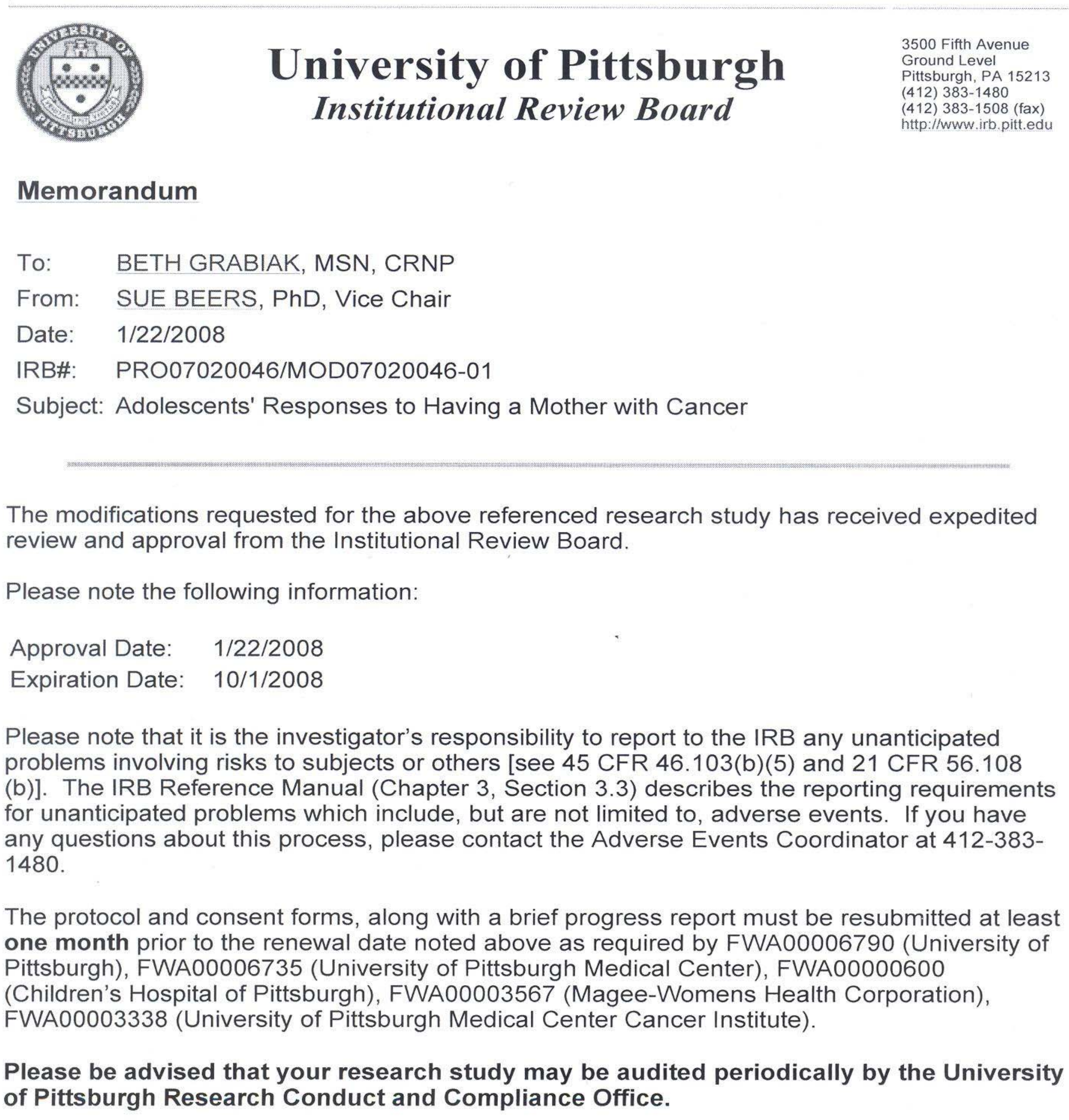
Please note the following information:

Approval Date: 10/2/2007
Expiration Date: 10/1/2008

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.



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Memorandum

To: BETH GRABIAK, MSN, CRNP
From: SUE BEERS, PhD, Vice Chair
Date: 1/22/2008
IRB#: PRO07020046/MOD07020046-01
Subject: Adolescents' Responses to Having a Mother with Cancer

The modifications requested for the above referenced research study has received expedited review and approval from the Institutional Review Board.

Please note the following information:

Approval Date: 1/22/2008
Expiration Date: 10/1/2008

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108 (b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

University of Pittsburgh

Institutional Review Board

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Pittsburgh, PA 15213
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Memorandum

To:	BETH GRABIAK, PhD(c), MDN, CRNP
From:	CHRISTOPHER RYAN, PhD, Vice Chair
Date:	8/8/2008
IRB#:	REN08050019 / PRO07020046
Subject:	Adolescents' Responses to Having a Mother with Cancer

Your renewal for the above referenced research study has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110 (5) (6) (7).
Please note the following information:

Approval Date:	8/6/2008
Expiration Date:	8/5/2009

Please note that it is the investigator’s responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b) (5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse=2 0events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children’s Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

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