DISSERTATION

ADULT CHILDREN OF MOTHERS WITH BREAST CANCER: A QUALITATIVE INVESTIGATION

Submitted by

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY JENNIFER A. FORSBERG ENTITLED ADULT CHILDREN OF MOTHERS WITH BREAST CANCER: A QUALITATIVE INVESTIGATION BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

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To date, there is a paucity of research that addresses biopsychosocial concerns from the perspective of the children of mothers with breast cancer. The scant research that is available speaks almost solely to the psychological issues relevant to daughters of mothers with breast cancer. Thus, the purposes of the present study are to expand the current literature on the experience of daughters with breast cancer and to provide a glimpse into what it is like to be the son of a mother with this illness.

Semi-structured interviews were conducted with eleven women and two men who have had a mother with breast cancer. The data were analyzed using a grounded theory approach. Results indicated that participants employed two primary coping styles in dealing with their mothers' illness: approach (i.e., information- gathering, seeking support, emotional expression) and avoidance (i.e., denial, distraction, physical or emotional removal from the situation). In general, participants who utilized approach strategies appeared to experience the least negative impact on the following areas: life views and plans, health views and behaviors, body image, relationships, and sexuality. However, it was determined that the level of biopsychosocial impact also depends upon a variety of contextual and mediating factors. A Transactional Model of Children's Experience with Maternal Breast Cancer is proposed to elucidate the nature of these relationships. The present findings point to a need for further development of psychological interventions for children (both male and female) of mothers with breast cancer.

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INTRODUCTION

"For this is the great error of our day, that in treatment of the human body, physicians separate the soul from the body." Plato (Joweth, 1898, p. 9)

In the early cultural and scientific heritage of the Western world, human thinking and feeling were all but banished from the domain of science. In the first half of the seventeenth century, Rene Descartes and his followers seized the fields of science and philosophy with a mechanical model of physics and biology. From this viewpoint, the human body was a machine that could be studied apart from its relationship with mind and social interactions.

According to Doherty and Campbell (1988), a modern descendant of Descartes's philosophy is found in the biomedical model of medicine. From this model stems the notion that all diseases are explained solely in biological terms - a virus, for example, a bacteria, or a wayward hormone. Within the strict biomedical model, psychological and social explanations for why people become ill or regain their health are not considered. Moreover, the impact of disease on the spiritual, emotional, and interpersonal lives of patients is not valued.

More than a century ago, however, Plato recognized the reality that physical illnesses affect us in non-physical ways. As human beings, we are indeed more than the sum of our parts. When our bodies are struck with illness, we do not simply notice the physical symptoms of the disease. We are affected mentally, emotionally, socially, and spiritually. We may even begin to question the very reason for our being.

In recent years, the biopsychosocial model, proposed by George Engel (1977), has encouraged the simultaneous consideration of biological, psychological, and social issues. According to the biopsychosocial model, biological factors must be understood as occurring in a human being, who is a complex, integrated mind-body organism. Indeed, "Body affects mind and mind affects body in such a way that neither notion makes sense alone." (Doherty & Campbell, 1988, p. 14). Furthermore, the biopsychosocial model recognizes that human beings exist within families and other social groups which provide the context for understanding the individual (please refer to Appendix A for further information about the biopsychosocial model).

Although there are countless illnesses, both acute and chronic, that are physically and emotionally crippling, Klagsburn (1984) argued that cancer holds a special position in medicine. He asserted, "To this day, the diagnosis of cancer dredges up in the minds of patients and families images of wasting away, hopelessness, and painful death." (Klagsbrun, 1984, p. 55). Falco (1998) noted that the word 'cancer' often conjures twin meanings. Not only is cancer seen as a deadly tumor and a terrible and deforming disease, it is also "a judgment, replete with recoiling and fear, an indication of lack of vitality." (Falco, 1998, p. 51).

While all cancers are emotionally and physically consuming, many argue that breast cancer is a uniquely devastating illness (Falco, 1998; Hall & Fallowfield, 1989; Ingram, 1988; Steele, 1997). Falco (1998) explained that breast cancer impacts more than just a woman's physiology, more than her body; breast cancer makes an indelible, new imprint on a woman's view of her femininity and her womanhood. Steele (1997) concurs that breast cancer not only threatens life, but also the core of a woman's self-image. She pointed out that, since the era of classic Greek art, the female breast has been a symbol of nurturance and femininity. And, to Western society, breasts are the primary symbol of femininity, motherhood, and sexuality (National Cancer Institute, 1984). Thus, "To discover you have cancer is to discover fear. But with breast cancer, fear has unholy dimensions, because treatment means mutilation, an assault on your womanhood, your body image, your very being" (Steinberg, Juliano, & Wise, 1985, p.).

At the present time, breast cancer is the most common form of cancer among women in the United States (American Cancer Society, 1999). Moreover, the incidence of breast cancer has been rising for the past two decades, while mortality has remained relatively stable since the 1950's. According to the most recent statistics published by the American Cancer Society, an estimated 1.9 million women are living with a breast cancer diagnosis. Today, a woman's chances of getting breast cancer at some point in her lifetime are 1 in 8. These numbers are quite alarming, in light of the fact that breast cancer affects not only a woman's physical health, but also her very essence (Falco, 1998). The numbers become increasingly disturbing when we begin to realize that, in addition to the impact that breast cancer has on the patient, it also greatly affects the lives of those who love her (Please refer to Appendix B for a review of the impact of illness on the family system).

While individuals with chronic illnesses such as cancer must reprioritize life values, adapt to their physical limitations, and create a new self-image, their families must simultaneously grieve the loss of their family member's health and accept a restructuring of the family (Doherty & Campbell, 1988). Shannon (1996) highlighted the fact that the illness of one family member inevitably impacts the entire family system. The author explained that chronic illness may lead to family disruption, changes in roles and financial status, and alterations in the family's social and emotional life. Families are also often burdened by uncertainty and unpredictability, and the wearing, constant care of the ill family member. Although it should be noted that physical illness may serve some positive functions within families (i.e, prompting families to "make the most" of potentially limited time together, bringing family members closer together, helping children to learn responsibility and gain independence), Armistead, Klein, and Forehand (1995) argue that, for most families, the stresses outweigh the possible positive side effects of illness.

Backman (1989) wrote about the changes in family dynamics that often occur in families dealing with chronic illnesses such as cancer. She stated, "Some family members may become overprotective or indulgent, fearing that the patient will die or become incapacitated" (p. 23). Family members may also resent the patient's special status, thinking that no one understands how their own lives have changed as a result of the illness. Furthermore, they may begin to feel neglected or unimportant in their own right, since so much attention is drawn to the patient.

Although all family members experience the psychosocial impact of chronic illness, many experts have suggested that children of parents who are chronically ill are at particular risk for psychological maladjustment, most commonly in the form of internalizing problems or negative affect (Armistead, Klein, & Forehand, 1995; Armsden & Lewis, 1993; Johnston, Martin, Martin, & Gumaer, 1992; Roy, 1990; Worsham, Compas, & Ey, 1997). Armistead, Klein, and Forehand (1995) outlined the following potential mechanisms accounting for this effect: (a) disruption of parenting (i.e., reduced parental support for the child, fewer efforts at discipline, neglect of the child due to reorganization of family around illness, changes in family routines, parental absence); (b) parental depression, (c) interparental conflict, and (d) parental divorce. Additonally, Johnston et al. (1992) commented on the strong likelihood of role reversal in which the sick parent may become the "child" and the school-age or adolescent child may become the "parent."

While dealing with parental illness is a struggle for any child, it is important to note that there is considerable variation in children's adjustment based on age or developmental level (Armistead et al., 1995; Armsden & Lewis, 1993; Johnston et al., 1992; Worsham et al., 1997). For young children, who tend to have primitive thinking and greater nurturance needs, "A parental illness can have an unsettling effect because of the disruption of family routines, an inability to understand the nature and complexity of illness, and the perception that parental inability or absence seems a personal rejection." (Johnston et al, 1992, p. 227). Older children are generally more cognitively complex and aware of the risks associated with their parent's illness and may be called upon to assume parental responsibilities that can no longer be performed by the ailing parent (Worsham et al., 1997). Additionally, older children may struggle with normal individuation efforts, since illness forces the family into a centripetal (centered on the family) rather than a centrifugal (centered away from the family) position (Rolland, 1994). At a time when adolescents would otherwise be gaining increasing amounts of independence, parental illness may keep them tied to the family by feelings of guilt over leaving their ill parent, or fear that they will lose their parent entirely. (Please refer to Appendix C for further information about developmental differences).

The fear of losing a parent to illness has been found to be especially salient in children dealing with parental cancer. Michielutte and Diseker (1982) discovered that children generally view cancer (regardless of the specific type) as higher in severity (except for heart disease), higher in susceptibility, and lower in benefits of treatment than other illnesses. Despite this finding, however, research on the psychosocial impact of parental cancer on children has been rather limited and inconclusive. (Please see Appendix D for a review of the available literature on the impact of parental cancer on children). The specific impact of breast cancer remains even more of a mystery.

Generally, the preliminary empirical evidence suggests that school-age children of mothers with breast cancer may be at greater risk for self-deprecating views, low self-esteem, less effective coping, and more behavioral problems than children of well mothers (Zahlis & Lewis, 1998). Furthermore, young children who have mothers with breast cancer have been found to experience anxiety about family stability and integrity (Lewis, Ellison, & Woods, 1985).

The remaining literature on the impact of maternal breast cancer focuses almost exclusively on the psychosocial functioning of female adolescents and adult women who have had a mother with breast cancer. Emotional themes among adult daughters of breast cancer patients have included: (a) fear of death and/ or identification with a mutilated maternal body image, (b) unresolved grief/ depression concerning the maternal figure, (c) guilt related to insufficient time spent with the mother, and (d) lowered self-esteem related to inadequate health practices due to immobilizing anxiety (Kelly, 1987). Gilbar and Borovik (1998) also found that, "Daughters of women who had breast cancer have less confidence that their internal and external environments are predictable and that things will probably work out as well as can reasonably be expected" (p. 120).

In a study comparing the psychological functioning of daughters of breast cancer patients to women without a family history of the illness, Wellisch, Gritz, Schain, Wang, and Siau (1991) found that daughters of women with breast cancer engaged in significantly less frequent sexual intercourse, had lower sexual satisfaction, and experienced greater feelings of vulnerability to breast cancer than controls. They could also identify a greater number of symptoms of breast cancer than women without a history of maternal illness.

In a follow-up study by the same researchers, it was discovered that younger women and women whose mothers actually died from breast cancer experienced significant alterations in long-term plans and greater role changes with their mothers during the mothers' illness (Wellisch et al., 1992). Additionally, the authors commented on the adolescent daughter's struggle to synthesize the image of a sick and potentially dying mother into her own sense of self, along with the preexisting image of an intact and healthy mother. They asserted, "These contrasting views of the mother, when fused with the daughter's nascent self-concept, form the basis for the daughter's ultimate self-representation that is carried into adult life." (Wellisch et al., 1992, p. 177-178). Finally, Wellisch et al. (1992) speculated that, "The adolescent daughter of a breast cancer patient may associate breast development and maturity with illness, body-image trauma, and even death" (p. 178).

Given the importance of the psychological issues faced by daughters of mothers with breast cancer, the research to date, focused almost exclusively on women, has indeed been warranted. Yet, it is reasonable to expect that sons of breast cancer patients may also be experiencing a unique set of intrapersonal and interpersonal concerns. This has not yet been addressed in the literature. (Please see Appendix E for information on gender differences in coping styles).

Hence, the purpose of this study is to not only expand the current literature on the psychosocial experiences of daughters of mothers with breast cancer, but also to provide the first glimpse into what it is like to be the son of a mother with this illness. Moreover, this study will provide a unique look at changes that occur within the family system as a result of a mother's breast cancer experience.

Since research on the systemic impact of maternal breast cancer is in its infancy, and because available quantitative studies have provided only limited information thus far, an exploratory, qualitative approach is proposed for the present study. According to Strauss and Corbin (1998), qualitative research refers to, "any type of research that produces findings not arrived at by statistical procedures or other means of quantification" (p. 10-11). They explain that a qualitative approach involves "a nonmathematical process of interpretation, carried out for the purpose of discovering concepts and relationships in data and then organizing these into a theoretical explanatory scheme" (p. 11). The advantage of using this approach lies in the way it allows the rich texture of a phenomena, an emotion, or an experience to unfold naturally and fully. Furthermore, qualitative methods can be utilized to explore substantive areas about which little is known, as is the case with the impact of maternal breast cancer on children.

Although there are numerous models of qualitative research (phenomenological, case study, ethnography, etc.), the grounded theory approach was deemed most appropriate for the current study. The use of grounded theory would allow: a) an exploration of the experience of having a mother with breast cancer at the level of data for emergent themes and categories that might have been missed in previous quantitative studies, b) an examination of the experience of having a mother with breast cancer from both nomothetic and phenomenological perspectives, and c) an acknowledgement and incorporation of personal and theoretical biases.

The ultimate aim of this study is to formulate a grounded theory that will capture the experiences of daughters and sons of mothers with breast cancer. And, in the end, it is hoped that this grounded theory will yield information that will be useful in the development of psychosocial interventions to help children of breast cancer patients.

METHOD

The Research Question

According to Strauss and Corbin (1998), the research question in a qualitative study is a statement that identifies the phenomenon to be studied. Although the initial question starts out broadly, it becomes progressively more focused as relevant concepts and their relationships emerge during the research process (Strauss & Corbin, 1998). The research question for the present study is: How are children affected by the experience of having a mother with breast cancer?

Evaluator Effect

In qualitative research, the primary investigator is the instrument used for both data collection and data analysis, thus inextricably linking the researcher with the data (i.e., the evaluator effect). It is because of this evaluator effect that it is critical to contemplate how the primary investigator could influence the results of the study. Generally, there are four ways the evaluator can impact the findings in a qualitative study (Patton, 1990, p. 473):

1. The evaluator is incompetent.
2. The presence of the evaluator may elicit reactions from participants.
3. The evaluator will have certain subjective biases.

4. There may be changes in the evaluator over the course of the evaluation (instrumentation effects).

In order to monitor the potential impact of the evaluator effect on the present study, each of the above points will be addressed. First of all, in reference to the competence of the primary investigator, the central issue was whether the researcher was capable of eliciting information about a sensitive, emotionally-laden topic. The primary investigator is a doctoral student in Counseling Psychology. At the time of data collection, she had completed the majority of her academic and clinical training and had been approved for an APA (American Psychological Association)- accredited internship. Therefore, she possessed the interview skills of a trained clinician and was capable of handling deep affect in a clinically and ethically appropriate manner.

Secondly, it is important to consider the influence of the evaluator on participants. To begin with, an area of potential influence was the fact that the interviewer was female. Because we live in a gendered society wherein women are seen as facile with emotions and relationships (e.g., nurturers, caretakers) (Falco, 1998), it is possible that the participants discussed their experiences differently with a female interviewer than they would have with a male interviewer. Additionally, due to gender-role expectations, the male participants may have reacted to the male (participant)/ female (interviewer) dyad differently than the female participants reacted to the same-sex interviewer. Finally, it should be noted that several participants mentioned that they felt comfortable talking to the interviewer. Moreover, they indicated that they would not have disclosed as much personal information if they had not felt validated and supported by the evaluator.

Another area of evaluator effect is the subjective bias of the investigator herself. It was inevitable that the investigator would conduct this study through the lenses of her own personal background and experience (i.e., female, Caucasian, mid- twenties, middle class, heterosexual, etc.). In an attempt to uncover her personal biases, the investigator underwent a bracketing interview which examined her experience with the phenomenon and her expectations for the study. It should be noted that, upon beginning the investigation, the evaluator had not directly experienced what it was like to have a mother or other family member be diagnosed with breast cancer. She became interested in the topic because she had several close friends whose lives were changed as a function of their mothers' breast cancer. For this reason, she was able to maintain some personal distance from the phenomenon under investigation. It should also be mentioned that the researcher had a long-time interest in women's health and body image issues (and had conducted previous clinical work and research in these areas), so she had expectations that the female participants might have been particularly affected by maternal breast cancer.

A final potential evaluator effect is change in the researcher's perspective over the course of the study. During the data analysis phase of the study, the investigator was informed that her paternal grandmother had been diagnosed with breast cancer. So, while the risks for heritability and the fear of personal loss had previously been at a safe distance, they became much more personally real for her at that time. This change, though difficult, seemed to be positive in the sense that it enhanced the investigator's understanding of the data and empathy for the participants who told their stories.

Participants

Research participants included thirteen adult children (11 women, 2 men) who have had a mother with breast cancer (Please refer to table 1 for demographic characteristics). Participants were all European American but varied according to their current age (19-65), their age when their mothers were diagnosed (6- 36), their mothers' treatment course (lumpectomy, mastectomy, chemotherapy, radiation), and whether or not their mothers survived breast cancer. Data collection was terminated at 13 participants since no new themes were emerging and the criteria for saturation of categories were satisfied. According to Strauss and Corbin (1998), theoretical saturation is reached when: a) no new or relevant data seem to emerge regarding a category, b) the category is well-developed in terms of its properties and dimensions demonstrating variation, and c) the relationships among categories are well established and validated.

Table 1. Demographics and Contextual Factors Related to Participants' Experience

(Please note that participants chose aliases to protect their privacy)

Name	Age, Gender	Age when mother diagnosed	Mother's age when diagnosed	Mother's treatment	Mother's Prognosis/ Outcome
Catherine	59 female	12	51	mastectomy	deceased
Anne 1	22 female	17	45	mastectomy	alive/ not in treatment
Claire	19 female	12	38	mastectomy	alive/ not in treatment
Anne 2	43 female	17	50	mastectomy/ radiation	alive/ not in treatment
Adriana	19 female	19	49	lumpectomy	alive/ in treatment
Rhonda	20 female	11	41	chemotherapy	deceased
Jeff	21 male	18	48	chemotherapy	alive/ not in treatment
Mabel	32 female	16	46	mastectomy	alive/ not in treatment
Jane	28 female	27	52	partial mastectomy	alive/ not in treatment
Jen	36 female	6	43	mastectomy	deceased
Andrew	26 male	21	53	chemotherapy/ blood transfusions	deceased
Olivia	65 female	36	72		died of other causes
Mary	20 female	10	38	partial mastectomy	alive/ not in treatment

Procedure

Sampling

The present inquiry employed a combination of convenience and criterion sampling (Strauss & Corbin, 1998). The criterion for selection (criterion sampling) was that the individual was over the age of 18 and has/ had a mother who had been diagnosed with breast cancer. It was expected that differences in data would emerge naturally because of the natural variation in individuals' experiences (convenience sampling).

Approval was obtained from the Human Research Committee prior to the commencement of the study. Participants were recruited through an advertisement in the university campus newspaper. All participants contacted the researcher voluntarily to set up an initial interview.

Data Collection

Participants were interviewed by the primary investigator in a private office. The primary investigator was a Ph.D. candidate in Counseling Psychology who had experience with counseling cancer patients and their families. The length of time for the interview was left open-ended, but ranged from 1 to 3 hours, with the average interview lasting 1 ½ hours. On a few occasions, follow-up interviews were scheduled because of time constraints during the initial interview. All interviews were audio-taped and then transcribed. Prior to the interview, participants signed informed consent forms and were instructed that they did not need to answer questions that made them feel uncomfortable. They were also apprised of the potential emotional consequences of participating and were made aware that referral sources for counseling would be provided if they wished to process any emotions that surfaced during the course of the interview.

The interview was semi-structured in nature, much like a clinical interview that begins with an open-ended question and is followed by a series of follow-up questions intended to explore certain areas in greater depth. The open-ended question asked participants to describe their experiences of having a mother with breast cancer. Follow-up questions explored changes in: (a) their relationship with their mother, (b) their relationships with other family members, (c) their own body image, sexuality, and health behaviors, and (d) general life plans. No psychological interpretations or attempts to conduct therapy were made. The interview was focused on elucidating descriptions and patterns of the individual's experience.

Data Analysis

The data were analyzed according to Strauss and Corbin's grounded theory techniques and procedures (1998). First, the interviews were audiotaped and transcribed, producing about 200 pages of single-spaced text. Next, the open coding phase of analysis began, in which interviews were broken down "line by line" in order to identify words, phrases, and phenomena that adequately described the data. After labeling and cross-validating the codes with a second reader, the codes were categorized and organized to describe the varying dimensions of the data. The second reader was a Ph.D. candidate with experience in qualitative research, as well as with counseling cancer patients and their families.

Open coding was followed by axial coding, which is the process of making connections between initial categories, in order to develop core themes and explanations about phenomena. This process is termed "axial" because coding occurs around the axis of a category, conceptually linking categories at the level of properties and dimensions.

At this phase of analysis, the investigator wrote reflective, analytical notes about the data. These notes were reviewed as a way of recognizing biases in thinking during data gathering and analysis. Although Strauss and Corbin (1998) believe that it is impossible to be completely free of our biases, they recommend this technique as a way of acknowledging biases so as to break through or move beyond them.

The final phase of data analysis was selective coding, which is the process of integrating and refining categories that ultimately leads to the formulation of the "grounded theory." During selective coding, the researcher moved from description to conceptualization. Techniques such as storyline memos (a rough sketch of the theory, or a memo that tells the "story" using concepts and their linkages) and diagrams were helpful in integrating the theory at this phase of analysis. Finally, the theory was refined by returning to the data to search for disconfirming evidence of the core themes and relationships.

Validity

Within grounded theory, there are validity checks inherent to each level of data analysis (Strauss & Corbin, 1990). At each stage, there is a continuous checking and re-checking to determine whether the code is actually reflected in the words of the participants. During the open coding phase, a second reader was consulted if there was confusion regarding the meaning/ interpretation of the participants' statements. If there was a discrepancy between the interpretations of the two readers, the difference in understanding between the two readers was discussed. In the end, the code reflected the readers' mutual interpretation of the statement made by the participant.

During the axial coding phase, a second validity check (i.e., a negative case analysis) was conducted that involved a search for statements in the data which both refuted and supported the understanding of the phenomenon. According to Strauss and Corbin (1990), discrepancies in the data provide the variation necessary to fully understand the complexity of the phenomenon under investigation. Therefore, had the researcher not looked for events in the data that varied from the original hypotheses, the analysis would have been incomplete.

Finally, during the selective coding phase, it was necessary to conduct an internal validity check by verifying the analysis against the data. In other words, statements posited in the theoretical model were examined to determine whether they had enough breadth to describe each participant's experience. If one person's story did not fit the model, then the model was reformulated to more accurately reflect that person's experience.

As recommended by Lincoln and Guba (1985) and Howe and Eisenhart (1990), two additional procedures were utilized to ensure the validity of the data analysis. First, the primary investigator underwent a bracketing interview to identify her biases related to the experience of having a mother with breast cancer. In order to examine the influence of her personal background on the data analysis, her assumptions and expectations were compared against the data during the axial coding phase of the analysis. Secondly, the data were compared against extant literature on breast cancer and related issues. This provided a broader context for interpreting and understanding the results of the present study.

RESULTS

The results of this study are organized into three sections. The first section describes the participants' experience of having a mother with breast cancer (this information was identified via open and axial coding). The second section discusses the influence of gender in dealing with maternal breast cancer. And finally, the third section integrates the emergent themes discussed in the first two sections into a theoretical model of children's experience with maternal breast cancer.

Section1: A Global Description of the Participants' Experience

Essentially, the first phase of data analysis consisted of a descriptive analysis of the participants' experience. By breaking down the data into themes and re-ordering the content of the themes, the experience of having a mother with breast cancer was organized into five categories that reflected the participants' experience. These five categories include: (a) the core aspects of the experience (i.e., the phenomena), (b) the contextual factors influencing the experience, (c) mediating factors, (d) coping strategies, and (e) consequences of coping strategies. This section of the results outlines the descriptive organization of the data.

Prior to describing the themes that emerged from the participants'stories, the reader should be reminded that there is overlap among the described experiences.

Indeed, no one theme stands alone, but instead, each represents a piece of a complex biopsychosocial phenomenon. Therefore, the reader should expect the content of the themes to blend together, since together they form a dynamic explanation of children's reactions to maternal breast cancer.

Core Aspects of the Experience

Feelings Associated with Having a Mother with Breast Cancer

Sitting with the participants and listening to their stories was both powerful and emotional. For some, the emotions were so raw that their experiences came to life right there in the interview room. For others, their emotional experience was a vague memory that had been dimmed by time. Some spoke of an unresolved and unremitting pain, while others spoke with a sense of resolution and wisdom bought by hindsight. For some participants, this study provided the first forum ever to talk about their experiences. Of course, one thing is certain, each participant had an important story to tell about how their mother's breast cancer impacted them- both then and now.

In reaction to their mother's breast cancer, the participants reported experiencing shock and disbelief; sadness, depression, grief and loss; fear, anxiety and uncertainty; guilt; anger; and feeling "different." Some participants experienced all of these emotional states, whereas others experienced only one or two of them.

Shock and Disbelief. Some of the participants expressed shock and disbelief when describing what it was like to be faced with their mothers' breast cancer diagnosis. Jeff, a 21-year-old, single, Caucasian male shared his experience:

> So yeah, it was kind of a shock. I really didn't know how to react at first. I was just kind of like, wow, um, you know, I can't believe this is happening. And they kind of explained to me all the procedures...you know, the chemotherapy- she had to have surgeries, and all that. So it was hard, but at the same time, I never

> really thought I was going to lose my mother. That just seemed impossible. So I was never, I never really worried about it like that. You know, I just... which was kind of naive of me to do, but I just didn't think it was possible. I just pretty much told myself that it- something bad, horrible- couldn't happen to me. So I guess I wasn't worried from that standpoint...

Adriana, a 19-year-old female, likened the initial experience of finding out about her mother's breast cancer to a bad dream. She further explained how the initial shock wore off once she witnessed changes in her mother's condition; yet, she described how a surreal quality still lingers when she thinks about her mother's illness:

> A few days after I found out I felt like maybe I dreamt it...maybe it was a bad dream. Then, when she went through her first chemo treatment it made it more real. I talked to her that night....I wasn't supposed to call, but I did, and I talked to her and she just sounded so exhausted. I mean she sounded more tired than anyone who has been tired....and that was her trying to be good on the phone...She's so young you know? To me she's still so young and she still looks young. I just can't believe that it happened.

Sadness, Depression, Grief, and Loss. Some of the female participants expressed feelings of sadness, depression, grief, and loss when describing what it has been like for them to have a mother with breast cancer. Adriana, a 19-year-old, single, Caucasian female described feelings of sadness, lowered motivation, and increased sensitivity:

> I'm always sad...I'm always sad and my boyfriend is like "Aren't you happy with me?" and I'm always complaining to him, and you know, I am happy with him- it's just that I've got other things on my mind. I want to be there for her, but I think it would be bad if I was there and was not going on with my life- and you know she'd be upset. It's just hard to think...you know you don't think that it's going to happen to your mom. It's hard to conceive of...I'm a little more sensitive I think. I get really sad and I don't mind talking about it. I think it's healthy to talk about it. I don't want it to eat inside of me. I want to be there for her but she doesn't want me there because she wants me to finish my education...I'm just not wanting to do anything. I'd rather, I don't know what I'd rather do but I just don't feel like doing anything.

Rhonda, a 20-year-old female, spoke of the feelings of sadness associated with watching her mother deteriorate during chemotherapy treatment:

> I watched her lose some hair, I watched her throw up and constantly be sick. You know she had a cane at the very end and she couldn't walk. That was very, very sad... I remember one day specifically. She was really....I don't know if this was from her treatment or the side effects or a combination. But it was really early in the morning and she just woke up screaming and screaming and she would not stop, like I guess she couldn't move any part of her body because she was so in pain everywhere. We had to call an ambulance to try and get her up out of her bed because she couldn't move. That was the most frightening part- when she was like that.

Rhonda also described feelings of grief and loss associated with her mother's death:

> I would be a totally different person. I don't know. I feel like if I had her now...like things with this year, figuring out what I want to do, figuring out my major...I feel like if she was here she would help. She knew a lot about me and she was the type of mom that would help with that kind of thing and would support me...I really think that she could help with that. Not so much tell me what to do but help me figure out what I want to do.

Fear, Anxiety, and Uncertainty. The most commonly described emotions were fear, anxiety and uncertainty. To begin with, Catherine, a 65-year-old, married, Caucasian woman summed up her experience:

> You know, it just felt like you were on a merry-go-round and you'd better hang on until it stops. Your world is spinning...

Adriana explained how her mother's breast cancer diagnosis led to a heightened fear of being personally diagnosed with the devastating illness:

> It's something that now scares me... you know it scared me before but more now. I'm afraid I'm going to get it.

Mabel, a 32-year-old, married woman described her fear of losing her mother and not being emotionally prepared to deal with that loss:

> And I think the other thing too is I'm just not ready to deal with losing a parent. I'm at the age where my dad lost his dad and I'm just not ready to go through that.......you know?

Jen, a 36-year-old married female, recounted how her anxiety manifested itself in her behaviors:

> I think I was a nervous...I bite my nails still to this day, which is kind of family nervous trait we have. I see my nieces and nephews biting their nails too, so I think it just runs in the family, but I was a nervous kid in that regard. I even had- sort of through this time and even after she died- I have a, I don't know if you can see it... I have a scar right here. But I've got this... I call it an itchy spot. It wasn't an infection or a fungus or anything, but I'd scratch it and it would make me feel better. I think the biting my nails and scratching the spot on my leg was kind of weird. So I wish I didn't have that, 'cause it was kind of embarrassing...I would scratch it until it would bleed, and people would notice what it was, and that sort of thing- and ask me about it, but that was just rough.

Jen also related what it was like to be a young child who felt responsible for her mother:

> And I can remember- it was in the summer, I was lying in bed worrying, what if the house catches on fire and I can't get mom out of the house? That kind of stuff. I wish I wouldn't have had to deal with that pressure. Not that anybody ever said you have to, but if something happens, you have to get your mom out of the house.

Rhonda described fear associated with seeing her mother suffer through her chemotherapy treatment:

> Oh, she did chemotherapy and she had horrible, horrible side effects which hurt so much. I've never seen my mom that weak and that sick. She's a strong woman. I had never seen her like that. I don't know... just seeing different sides of my mom was really scary.

Rhonda further explained how her mother's illness has caused her to question everything:

> You know at first- it was more so last semester- not knowing, not knowing the answers to really big questions that nobody knows. I was just questioning everything- down to what I learned in school, down to friends, my relationships, more so mainly me. Just questioning all my decisions or whatever I hold as part of me. I don't know, I realize more and more that I don't know much about anything- and it kind of scares me.

Guilt. Guilt seemed to be a predominant emotion for some participants when they looked back on their experiences with their ill mothers. Adriana, for instance, actually felt responsible for her mother's breast cancer diagnosis:

> My mother was diagnosed with breast cancer in December of 1999. I actually took her to a mammogram in November, so at first it was kind of like "Oh God," you know? I don't know, it was kind of stupid, but I felt kind of responsible

> somehow, you know? It was just strange.... Well, I felt like I had a part in it- you know because I took her. I mean I'm glad...It's stupid...but I'm glad she went because if she wouldn't have gone it would have gotten worse. But it feels uncomfortable to have played a part in something that is so wrong.

When talking about various health behaviors, Rhonda expressed a feeling of guilt because, in essence, she believes she should "know better" because of her mother's illness:

> I smoke, I drink every now and then, and more so, I eat very badly. Both my dad and I- we're just very unhealthy. I exercise every now and then but not as much as I should be, and I don't know about sexually-like how that comes into it but . . .I didn't really care about it- like in high school I got pregnant and had an abortion. I kept it a secret. I dealt with that in a worse way than with my mom- I just pushed that away. I'm just so ashamed of that. It's just so horrible. I didn't tell anyone. It was one of those things where it happened and was over with.

Jen discussed "unresolved issues" related to not saying goodbye to her mother before she died:

> As a kid I didn't... I just kind of assumed that she would get better. You know? She was in the hospital. She'd get better. She'd come home. Being a fairly naive seventh grader, or eighth grader, whatever it was... but now as an adult looking back I think it would have been better because I never said goodbye. The Sunday before she died I didn't get over to see her. They didn't take me. And I was getting tired of going to the hospital 'cause it was boring. You just sit there- me and my sister, maybe a relative, and my dad maybe, possibly. And it was boring when you're twelve and it's nice outside. You want to play basketball. Maybe I didn't understand what they were doing to her, why she was sick. And I would always- before and after church-and before we left to visit her- I would go outside and play basketball with my friends and my sister would call me in and we'd go. And then that day she didn't call, and I thought, cool, I'm not going to the hospital, and then she died that next week, so there were some unresolved issues there.

<u>Anger.</u> Another emotional response to having a mother with breast cancer was anger. Adriana related how she felt angry because her mother did not tell her about her breast cancer diagnosis right away:

> She didn't tell me about it- which made me angry- until after finals week, but I understood because I don't think I would have done very well in school if she would have told me.

Claire described the resentment she felt because she had to take on extra responsibilities and because her mother was not always there when she felt she needed her:

> I was a wreck; it was really, really hard for me...I was scared to death that she was going to die. I was over-worked for a kid my age- it is really a whole lot of work for a child my age, especially when I had never done anything like that before. I was really stressed out; I was really angry about having to do everything. There were parts of it that I loved doing- I loved being able to do it- but I really resented having to do it and not...it was years before my Mom said you know, you did a lot for me. She was so sick she couldn't really take care of me either.

Claire explained how she experienced anger related to changes in family dynamics:

> Sometimes it makes it hard for me to get along with my step-father because, being in the relationship he has with her and having to always take care of her...since they got married she has always been sick. One of the things that happened after her chemo was she developed clinical depression that is extremely severe at times. So he gets resentful at times and it is really hard for me to tolerate. Because it is like, I came into this as a permanent sort of thing- I didn't pick my parents or anything, but he picked her, and she is not the same woman that he married. And I know it is really hard for him that way, but at the same time it is like you married her, you are in this for the long haul, she loves you, you love her, deal with it. And it is really hard for me to deal with my sister a lot of times because she can be really rude sometimes. And the reason actually that she ended up going to Dallas, well the last straw sort of thing, was the night my Mom was in the hospital that night she had an infection and she was very, very ill. And I was taking care of the house... and my sister disappeared, ran off with some friends, and it took me hours to find her.

Claire further discussed how she utilized anger as a coping strategy:

> She [Mom] got remarried 6 months before she got diagnosed, but we were still flying to see my Dad every other weekend. He was pretty much supportive, he was kind of a vindictive sort of man, so he really helped me blame it all on my Mom, which was a dirty trick I think, but at the same time it helped me, it was a coping device. It was something I had to get over years later, but at the time it was like this is not my fault I shouldn't have to do this...

Feeling Different. Many participants described feeling uncomfortable or "different" than other children because their mother had cancer. Jeff, for example, related:

> It was real uncomfortable sometimes- just because I didn't know how to deal with it sometimes. I didn't know. I guess I'm the typical male. I don't show a lot of emotion. I'm not a real emotional person, and I was young so, I guess a lot of times I was real uncomfortable because I didn't know how to deal with it, and I didn't know what to say to my mother, or to other family members...it was definitely awkward for me even though it was my family... I just didn't feel comfortable with it a lot of time, talking about it- or just the whole situation.

Jen shared:

> And so there were even things that- probably because she didn't feel well- that I wasn't able to do...like I wanted to play volleyball my seventh grade year and she didn't want to drive me cause we lived in the country- just stuff like that. So I think that affected me some too. So that was hard, and the house wasn't kept up well, and so I didn't have friends over 'cause she... and I don't know if it was cause she was sick or... but I think that added to it probably. It wasn't bad dirty. It was just cluttery, and sort of pack rat. Sort of not organized and that sort of thing- so I didn't have friends over and things. In some part of me, I think it's probably because she wasn't well, but things weren't as neat and clean as they might be.

Mabel summed up her experience:

> You're just trying to be a teenager. And, I think one thing was, you know, you're different than other kids because you know, your mom's just had cancer.

Contextual Factors Influencing the Experience

As with any other experience, having a mother with breast cancer does not occur in a vacuum, but it is subsumed in the broader, complex context of life itself. The biopsychosocial experiences described by the participants were undoubtedly influenced by other life circumstances and stressors that occurred before, during, or after their mothers' illness. Depending upon what was happening in their lives at the time of their mothers' diagnoses, participants had varying reactions. Some life circumstances appeared to provide a buffer to the experience of maternal breast cancer, while others seemed to magnify its emotional intensity. Anne, a 43-year-old, married female recalled feeling "insulated" by being away at college at the time of her mother's diagnosis:

> At the time my mother was diagnosed, I was just a college freshman, so I was somewhat removed from the whole thing. I had my own life and my own concerns, and my own interests, and my own worries. And of course it was not easy to have that concern. It was right after I had gone to school. It was not like a week or two weeks or a month, but within about two days of the time that I moved to campus. In fact, my mom had the mammogram right before I came to campus and then the doctor called her on a Sunday or Monday and wanted her to come back to the hospital to do another mammogram. I was insulated from that because I was gone, and I think that she kind of wanted to protect me because she knew that I was dealing with my own new things in my life, and my own changes.

Mabel's mother had always been especially healthy, so she experienced her mother's illness as particularly shocking:

> She made us eat soy, you know, tofu in the 70's when it was still like liquid. You know what I mean? She's just always been so healthy. So I think that from my perspective it's intimidating because she's like stellar healthy person and yet it still happened to her.

Mary's mother, on the other hand, had been ill frequently, so the experience of having a mother with breast cancer did not stand out as much for her:

> My mom has been sick all my life, pretty much. I've always known she's sick, because she has another disease as well...she has breast cancer, and then she also had cysts on her ovaries. It was always something. And I was really young. I was like in fourth grade, and it was just like one more thing. But I don't think I ever dealt with it because I was just a little kid and now I think it would be a lot harder on me because of what's going on. Then, I was just like it's just something else, oh she's having surgery again.

Jeff revealed that it was especially difficult for him to see his mother, who had a doctoral degree, undergo cognitive changes as a result of her treatment:

> Well, I think sometimes I was really understanding, and sometimes I'd just get real frustrated. You know, I would lose patience with my mother, you know. I probably shouldn't have, but I mean...I don't know. I'd just get real frustrated

> with her sometimes- I'd be like mom, you already asked me this, come on. And she'd say, I'm sorry Jeff. So it was kind of trying, you know... to keep your patience. I mean, she's my mother. What is so unbelievable is that she has her doctorate and she's a professional...she's a real smart woman, so that made it especially hard.

Andrew, a 26-year-old, single, Caucasian male shared what his experience was like, having his romantic relationship end around the same time of his mother's illness:

> It was a real interesting time 'cause I was also supposed to get married two weeks after my mom's death and that fell through, actually the day of my mother's death...it was a hard time. And that caused an interesting dynamic as well, because my ex-fiancée didn't get along with my father and my sister and so that caused friction between us all. So, it's sort of hard to separate it some of it, you know? It's hard to filter it out- if it was just my mom's death or if it was just the relationship thing. So if we were to have arguments or conflicts- which my family has never dealt with that well- it wasn't clear if it was a conflict because of the lacking of my mom- she was sort of a mediator- or if it was due to my ex-fiancée not getting along with them.

Jen had a unique experience, in that her father was a truck-driver, so she went to live with her older sister during her mother's hospitalization and after her death. She described her experience:

> I was living with one of my older sisters at the time. She was a young, married person. She's quite a bit older than me and had small children, and mom was in the hospital for a long time, like a whole winter and then she died in the spring. It was a neat old house, but didn't have central heating, and I lived upstairs. So the heat had to come up through the vent in the floor. So I can remember we had some really bad winters those years and being cold and bundled up in my room. They were struggling monetarily and my dad gave them a credit card basically to take and use, and he gave them money for groceries, more than probably it would require to feed me. So he was giving them a lot of money to keep me cause he couldn't because of his work hours and driving a truck. He couldn't be there to help me through school or practices or school activities, or even be home to make sure I'm okay 'cause he would work at four or five in the morning and not get home 'til six or seven at night because of his truck driving hours.

Catherine recalled a number of other life stressors that, in combination, led her to feel that her mother's illness was just "one of life's many struggles."

> Well, my life was miserable, to be 16, married, then, let's see, two weeks after we were married, I had this terrific pain in the middle of the night. They took me to the doctor, and he said it was either kidney stones, a kidney infection, or I was pregnant. And I thought ahhhhh, two weeks married and I'm pregnant... what a shock that was, that's the way life happens for me. And then six weeks later- that's when they told us mom had less than a year to live. So that was that summer and then she died after that...and well, my husband and I had separated...he had a drinking problem. He was young and I was young, and I would have taken it a lot different now than I did then. That's just my life. So I really don't know how I feel about Mom. It's just another part of life I think.

Mediating Factors

Some common mediating factors that seemed to influence the participants' perceptions of their experience of having a mother with breast cancer included: (a) participant's gender, (b) participant's age at the time of mother's diagnosis, (c) the mother's physical response to her illness and its treatment, (d) the mother's emotional response to her illness and its treatment, (e) the amount of information shared with the participants, (f) the nature of the participant's relationship with his or her mother, (g) the nature of other family relationships, and finally (h) the cultural and generational context.

Gender

Although the present study did not include as many male participants as expected, there were nevertheless some noticeable gender effects based on the experiences of the available participants. Overall, it appeared that female participants differed from male participants in two ways (please note that these differences may be a product of the small sample size of male participants). First of all, females and males generally differed in terms of their preferred coping styles. The male participants had a tendency to cope through avoidance strategies (i.e., distraction, physical and emotional removal from the situation, etc.). In contrast, the female participants were more likely to emotionally approach the situation (i.e., accessing support, expressing emotions, etc.). Secondly, females and males seemed to differ in terms of their emotional proximity to the experience of having a mother with breast cancer. For example, female participants often reported having to assume the roles previously held by their mothers (e.g., household chores, child-care). They were also more likely to equate their mother's breast cancer to a personal threat against their own bodies and their health. The two male participants seemed to be able to hold these threats at a safer distance.

Claire described what it was like for her being female and the oldest of three siblings:

> I am the oldest of three children. My sister is four years younger than me and my brother is eight years younger than me, and when my mom got sick and had to do chemotherapy and radiation therapy I was the one that took care of the kids. I kind of did everything that she did- in a 12 year old's capacity- keeping the house clean, I did most of the cooking, looking after the two younger ones- especially my little brother because he was four or five then....so, it was a big change in my perspective on responsibility.

Age

The ages of participants at the time of their mothers' diagnoses ranged from age six to age thirty-six. It was clear that an individual's age had a significant impact on his or her perceptions, understanding, and ability to cope with the experience of having a mother with breast cancer.

In general, it appeared that the participants who were young children at the time of their mother's illness did not have the cognitive or emotional resources to understand and to cope effectively with what was happening. It seemed that those who were adolescents at the time of their mother's diagnosis had a greater intellectual understanding of the illness; however, they appeared to wrestle with how to cope emotionally. They often described an "internal battle," characterized by sadness, fear, and a desire for comfort on the one hand, and a developmentally-appropriate need for separation and individuation on the other hand. Participants who were young adults at the time of their mother's illness generally referred to their age and independence as emotional buffers which served as protection against their mother's cancer.

Jen, who was six when her mother was initially diagnosed with cancer, stated:

> When she was first diagnosed, I was young enough that I didn't understand what was going on. I was in first grade, so six. So I didn't really know...I don't even know if anybody even said cancer to me. They just said she had to go the hospital and have an operation or whatever.

Rhonda explained how it was difficult as an 11-year-old to understand what was happening with regard to her mother's illness:

> I always look back and think I would have dealt with it a little better if I would have known exactly what was going on. I don't know. At that time I just didn't understand what was going on at all. Cancer- wow- that was just hard for me to grasp at that age- there was so much medical terminology that I didn't understand.

Catherine, a 12-year-old at the time of her mother's diagnosis, described what it was like for her to go through puberty without her mother:

> I think at the time what was more scary for me was that mom had never talked about periods...so I had to stay all night- when mom went into the hospital for when she had her surgery- with an aunt I had never stayed with before...And I wasn't about to talk to my dad, I wasn't' about to talk to... anyone else but Mom.

Mabel, who was 16 at the time of her mother's diagnosis, talked about her struggle to "just be a teenager":

> I played ice hockey and I had been to an ice hockey camp in Canada...And I'm from Vermont, and my parents picked me up at the Montreal airport... my parents had a business trip to go on soon... And so, of course, my friends were going to come over and we were going to party. So, you know, like your parents are away. You're sixteen. What else are you going to do in the summer? And, actually I've told this story to my parents now, and my mom just laughs, but I remember going under the bridge leaving the Montreal airport and my mom saying, "well we're

> not going on vacation. I'm sick." You know, and I was like, god, there goes the party. You know? And that was my initial reaction.

Andrew, 21 and in college at the time of his mother's breast cancer diagnosis shared:

> I was in college so it wasn't...it was probably different than it would be for a high school student or younger children because I was removed from it a lot of times.I only had to deal with it in terms of being there and seeing the effects at like Christmas time or summertime and stuff like that.

Andrew further explained:

> I don't think I realized the implications of it. You know? It was sad and I realized it was...and I'm sort of a more... I don't necessarily show my emotions that much or think about things as much as the rest of my family...and being twenty-one, I was probably caught up in stuff that just, you know, I didn't think about it that much. So I didn't realize the impact it was going to have.

Olivia, who was 36 at the time of her mother's cancer diagnosis expressed:

> Well, really, I guess it hasn't been a great problem to me. My mother didn't get breast cancer until she was 72. I just realize that I am still seven years from that myself. I am 65. So, I guess it hasn't been a real difficult thing for me. It would have been much more scary, much more scary- it would have felt much more threatening if I were younger and if my mother had been younger.

Mother's Physical Response to Breast Cancer and its Treatment

Another mediating factor which clearly influenced the experience of having a mother with breast cancer was the severity of the mother's breast cancer- and her response to its treatment. Not surprisingly, participants whose mothers had more advanced (terminal in some cases) breast cancer seemed to struggle more emotionally than those participants whose mothers had cancer that was more easily treated. Likewise, participants whose mother's experienced more debilitating side effects from their treatments appeared to be affected to a greater extent emotionally. Mabel reflected on what it might have been like if her mom had not survived:

> I definitely don't mean to diminish its importance, but it's definitely been a positive experience. And I think it's been positive only because my mom brought

> it to be. I had another high school friend whose mom didn't survive, and she died when we were in ninth grade. It would have been a totally different experience if my mom had died.

Olivia explained that her mother's positive response to treatment made it easier for her emotionally:

> I don't think I panicked, you know at all. She had a mastectomy, and they felt comfortable about the result, and she responded real well. Then later on she had x-ray treatment but she didn't have chemo. She got through the x-ray quite comfortably- some nausea and so forth but nothing drastic and so that again made it fairly easy for me. You know, to not get worried about it and so forth.

Rhonda, on the other hand, described what it was like to witness her mother's rapid deterioration and eventual death:

> I was 11 and she was 41. She had breast cancer for seven months and she died after that seven months, so I don't know, it was really fast. You know, even during that time I watched her physically- I watched, you know. What was going on at that time? At 11 years old I had no idea that she was going to die. I never expected that. So even when she did die, that was...I don't know...very unexpected. I remember we all found out one day...

Mother's Emotional Response to Breast Cancer and its Treatment

Participants seemed to use their mothers' emotional reactions as a compass to assist them in understanding and navigating their own emotional experiences. For this reason, it appeared that the children had a tendency to cope better emotionally when: a) their mothers were also coping effectively and b) their mothers' coping style closely matched their own preferred style of coping. Olivia described a sense of feeling comforted by her mother's emotional response:

> She took it rather matter of factly. And my mother- she wasn't a particularly humorous person, and she was very modest...and I was just amazed at her responses to this because I would have expected something much more reserved and much more oh... just almost prudish. But she would say, "Oh, its not so bad- it is just like having a flat tire." And then she used to say, "I am just so old and tough it can't grow any faster in me." She just took it, you know- as I say it was very out of character for her- but she took it very comfortably it seemed to me.

Olivia later stated:

> I think the fact that- as I mentioned she was extremely modest- and the fact that she took it as lightly and as well as she did, I think did perhaps make me somewhat more comfortable... and although she didn't change the way she dressed or she didn't change a whole lot of herself at all... but just the fact she could take a mastectomy as lightly as she did in terms of her body was surprising, and I think probably just a little reassuring to me.

Adriana, on the other hand, reported that she did not respond well to her mother's and father's jokes, perhaps because it did not match with her preferred coping style:

> She gets sick and you know she makes jokes of it. She calls herself "baldy," which I don't think is funny. I mean my dad jokes about it but...when he first found out ...you know he wouldn't do anything to talk to her...that's kind of the way he is...You know he knows that she wants to feel like she can do stuff. She even made the comment "I'm strong enough to punch you so now so..."

Mary spoke of the impact that her mother's emotional strength had on her:

> ...And that's why I still feel like she's a very strong person and it's taught me....all of it has taught me that I can get through anything. So it was kind of like I was never really that worried because they never put it across to the kids that there's...that we need to worry about this.

Claire shared that her mother's depression had more of an impact on her than the cancer itself:

> I don't think the cancer has really impacted me much. The depression has really impacted my relationship with Rob, just because I have a tendency to be the same way. She had mild depression for most of her adult life, but after chemotherapy, there are some studies that are real preliminary that show that chemotherapy affects brain chemicals that exacerbates depression. But I have a tendency towards depression myself and I am hyper aware of it and it effects my relationship.

Amount of Information Shared

The amount of information that parents shared with their children about their mother's condition seemed to be influenced by the child's age, the child's cognitive and emotional capacity to understand the illness, and the family's level of comfort in sharing the information. Lewandowski (1996) speculates that this filtering of information may also be related to the degree of guilt that the patients feel about "burdening" others with their cancer-related problems.

By and large, most participants reported that they wished they would have been more informed about their mother's illness and her treatment. Many of them felt that they would have coped better if they had had more information. Those participants who felt adequately informed reported feeling more emotionally in control of the situation. Rhonda, for example, noted:

> I always look back and think I would have dealt with it a little better if I would have known exactly what was going on. I don't know. She's the kind of person that kept things from us just for protection in a way...I don't know. If I'd known, I would have told her all the things that I wanted to say for a long time since after her death...just tell her everything. I would have been there for her and helped her more. I would have done all sorts of things. At that time, I just didn't understand what was going on at all. Cancer- that was just hard for me to grasp at that age- there was so much medical terminology involved.

Jen recalled feeling surprised by her mother's death because she had not been informed about what was happening:

> I don't know if anybody ever told me she might die and so that was kind of a big thing. Now looking back, I just wish people would have been more candid. I always blamed that on my mom being from a good Midwestern rural farm family- you know they tried to gloss things over- not real open about communicating....And again, if they just would have been more open about what was happening, what were they doing to her and that sort of thing. 'Cause I mean, we'd go and visit in the hospital, I had know idea what... you know, how she, I don't even know. Was she getting treatment? Was she just dying? I don't know, and I've never really bothered to go back and ask 'cause to me it kind of seems pointless at this time to bring up- well, why was mom in the hospital? Was she getting chemo, radiation, or was she just dying? I don't know.

Mabel speculated that her mother shared more with her than she did with her brother because she was female and the older sibling:

> I think being the daughter she probably also shared more with me- as well as being the older sibling- than with my brother...I mean, I can't say for sure, but I can't imagine her telling my brother as much as she told me.

Olivia reported that, because her mother was open with her about the breast cancer, she too was able to be open with her own children:

> You know, we always talked very openly, we didn't make a big point of it, but there was certainly discussion...my children were all aware that Grandma had had breast cancer and so forth. Of course the little ones were too little to understand at that point but...Oh, let's see. At the time, my twins were probably about a year and a half and then the next child up was three and a half, and the next one up would have been going on ten and the next one twelve. And so, the ten and twelve year olds- you know I think told them in simple terms what was going on at the time of her surgery and everything. It was always something we were very open about and as the kids got older you know, I think they realized that that it was something to watch out for within our family, especially the girls, of course but although not omitting the boys. And then, as I am older and they're full adults, you know they are glad that I take care of myself properly.

Relationship with Mother

A critical mediating factor that influenced the participants' experiences was the nature of the relationship with their mothers. Anne (age 22) painfully recalled what it was like to feel that her mother was not there for her when she needed her most:

> I remember we definitely had problems, but it really divided my sister and I, and that was a real vulnerable time for us too because we were going through our own issues...and having a mother that couldn't be there to help us- and wasn't able to- I just remember all the pain...

Anne went on to describe the discomfort she feels to this day in her relationship with her mother:

> I still don't feel comfortable talking about issues with her- and we have never talked about the breast cancer. But she does such weird such weird stuff now- she will like whip off her shirt and show us the scar, and we are like "okay mom,"- you have not even shared this with us. And now she is so like open about

> it but in a weird way, still not talking about it, but she will just like show us the scar - show us her fake breast that she uses and her bras- and it is so uncomfortable, because I am like wait a minute I don't even know about this...

Adriana explained how the mother-daughter dynamics changed after her mother was diagnosed with breast cancer:

> I am more careful about what I say. I don't want to upset her. We never fought before, we've always had a great relationship, but I just want to cater to her you know? Whatever she needs I'll get. All she needs to do is tell me and I'll find a way. Money is not a problem. She won't blame anything on me. It was hard for her when I went to see her in January and she showed me her scars. My father comes in and was like, "why are you crying?" you know?

Olivia shared how she gained admiration for her mother as a result of the way her mother handled the breast cancer experience:

> She didn't usually make light of things, and yet she did with this. So, it was easier for us to take it, comfortably. I think the experience probably enhanced an area of admiration for her that I really didn't have before. I almost felt like my mother oh, probably sold herself short in life. She was the kind of person who was always the secretary but never the president, you know, this kind of thing? And she didn't ever have a career- she didn't have education past high school and so forth- I know that given today's world she would have been capable of much much more, and I kind of resented that in some ways because my role model was that way for me. But you know... the way she handled this was very gracious, and I think it enhanced my appreciation for her.

Relationship with Family

The broader family context also provided a backdrop against which the participants' stories unfolded. Generally, it seemed that participants with close, united, supportive family systems fared better emotionally than participants whose families were wrought with conflict and lacked a supportive quality. Although some participants mentioned receiving support from individuals outside of the family, it emerged repeatedly that it was the family relationships which were most central to the participants' experiences. Claire commented on the way her family pulled together during her mother's illness:

> So, there was just a really strong sense of connectedness in my family after she got sick because of all of the things that we had to work through together, all of the work we did together- especially the kids- we did so much that we never did before that it just really heightened the balance and how connected we are.

Olivia also spoke of the connections with her family members and the way her siblings helped out when Olivia was not able to be there herself:

> I have always lived further away from my parents- after I went away to college, I have always lived much further away from my parents than either of my siblings did. So, I was always grateful to my siblings- that they were there, and I knew they were reliable and stood by Mom...

In contrast, Anne (age 22) described her perception that her mother's breast cancer engendered a chasm in the family unit:

> I guess the biggest thing I remember is how it just totally split our family. I think at the time, not immediately at the time but shortly after- when she was recovering- my mom and my dad started going to counseling together, started doing their own thing. And my sister and I who hated and loved each other at the same time- we were kind of like bonded together just to get through it. So, it was just that my dad and mom were doing great, they were getting counseling together; they were dealing with this issue, working through it. But my sister and I weren't included in any of that- and maybe they thought we shouldn't be because we had other things to deal with- but we just kind of had to bond together as sisters and just kind of work through it and help each other. I just don't remember very much family interaction during those years at all... I mean never did we ever have dinner together or do anything together at all.

Andrew recounted how his family's dynamics were impacted by the death of his mother:

> They didn't change until she passed away...And then it was real...she was sort of the glue of our family. Like all three of us would go to her, not to each other. So it was a pretty... it was a scary time for all us. We realized, oh wow, I have to now deal with my father or my sister directly, and not confide in my mom or go to her. So, there was a stormy period of like, oh my gosh. It's sort of like the empty nest syndrome where two adults realize, oh my gosh, we have to start talking to each other again and not have this child in common. Same thing with my family.

> We were like, oh god, we have to start dealing with issues that actually happen to you guys- we were no longer able to just go through my mother.

Cultural and Generational Context

To date, there is a paucity of literature describing the impact of ethnicity and race on the experience of parental cancer. It is likely that cultural differences impact healthcare beliefs and attitudes, access to healthcare, incidence rates, and survival rates (Meyerowitz et al., 1999), all of which in turn impact the experience of family members and of the family system as a whole. Although all of the participants in the present study were Caucasian, it should not be ignored that their lives and their backgrounds were rich and unique in a number of ways. Participants were raised in all regions of the country- and at varying points in our country's history. The zeitgeist of the time was much different in 1951, when Catherines' mother was diagnosed with breast cancer, than it was in the year 2000 when Adriana's mother was diagnosed with the illness.

Jen shared her belief that her family's coping style was shaped by the context of the Midwestern rural society where she was raised. She said:

I always placed the blame on the fact that my mom was from a good Midwestern rural farm family and that they tried to gloss things over- not real open about communicating... Midwestern rural and the style of parenting that my mom had been raised in, there wasn't a whole lot of asking about feelings. And even now, I struggle to try to do that more and express my feelings with my husband or my siblings or whatever because we weren't modeled that. You didn't talk about your feelings.

Jen also commented that her dad was from a "different generation," which she perceived to have an impact on how her mother's illness was handled:

> He, I think, tried really hard but did not always know how to be...anyway, he certainly wasn't a today's kind of dad. It was more, I'm the dad. You do what I say- that sort of thing. I mean, it was a whole different generation. I mean, you have to consider- I was really young. I was born in '63. You know, after they'd

> already had kids and it was just a whole different way, different style of parenting than I see, like my friends parent their children.

Catherine recollected that she was not informed about breast cancer, because it was not as visible in the media as it is today:

> It wasn't all the news and everything like it is today with the Race for the Cure and all...Well, I don't think there was anything in the media about it now that I think about it.

Coping Strategies

Participants generally described two styles of coping used in dealing with the experience of maternal breast cancer: approach and avoidance. Approach strategies were characterized by an active attempt to effect emotional change with regard to the core experience of having a mother with breast cancer. Examples of approach strategies included information gathering, care-taking, changes in personal health behaviors, seeking support, finding meaning, and emotional expression. Avoidance strategies could be described as physical, mental, and emotional efforts to shift the focus from the core experience to something else that is not as difficult to handle. Examples of avoidance strategies reported by participants included physical or geographical removal from the situation, distraction, denial, and, in some cases, humor. It is important to note that although participants generally tended to gravitate more heavily towards one certain style of coping, it was not uncommon to hear them talk about employing a combination of approach and avoidance strategies over time.

Jen recalled her avoidance reaction when she found out about her mother's death:

> ... So I went upstairs to change clothes and Suzy came up and told me. And I think I cried and I ran as fast as I could to the basketball court and pretended like nothing was wrong. I played basketball with some of the guys, and they knew actually. And one of them tried to talk to me about it- an older guy. He was like high school age, and I didn't really want to talk about it. And then, the next day I

> tried to go to school. I went to school. I got on the bus. I went to school. Except the whole time I was avoiding...I just wanted things to be normal.

Jeff said that he did not want to know about his mother's illness. He wanted to be involved to the least extent possible:

> There was really nothing that I... there wasn't a whole lot I could do to help. I didn't really participate much at all. You know, I was pretty much just- I mean they would tell me what was going on- and I just would say, "okay." I'd visit my mom at the hospital, I'd spend some time with her, that was about it- that was my involvement...And to be honest with you, sometimes I didn't want to be that involved. I didn't like, want to know.

Jane, in contrast, wanted to be involved but was not able to be to the extent desired. She related what it was like to feel a natural tendency towards approach strategies when that style was not congruent with the climate of her family:

> My family tends to be...well, my parents are divorced and they are both remarried. My mom and my step-dad both tend to not- well I think they dealt with it differently than I did. I wanted to find out as much as I possibly could about it, how to treat it, and I think I approached it sort of in that way. They approached it as maybe in more of a denial way. So I think at the beginning we sort of had some conflicts.

Claire noted that it was important for her to strike a balance between approach and avoidance:

> Well, I did some counseling that winter when I was a freshman. One of the things that I figured out was how to be helpful but not be so involved. So, right now it is like I go there and help out when they need me, but I don't feel the obligation I used to, and I don't have the feeling that I can never do enough. It is like I do what I can and I help whenever I can, but if I can't then everyone is going to be okay without me...drawing limits has been very good. I have my own place now and I am much- I am still really involved with my family but on a different kind of level- and not taking care of them because I should but helping out because I can.

Rhonda stated that she utilized avoidance strategies around the time of her mother's death; but now, ten years later, she is using approach strategies to work through the painful memories:

> I've dealt with my mother's death for so long. But right away I didn't deal. This year is a very big year for me as far as dealing emotionally. I mean my mother has been dead for almost ten years now and I'm just now reflecting on every aspect of it. In a way, this year has been like a self-reflection. I just remember first dealing with it...I really did not...It was almost like it was a dream. It just was not real. You know? It's really hard to accept. After a while my dad and my sisters moved on with their lives. It was almost as if I pushed it aside- or inside- so deep somewhere that I haven't really dealt with it. I never really talked about it, I never really did much to cope. But this past couple of years- this year especially- I've had feelings about it.

Rhonda went on to explain how approaching her own emotions has allowed her to reconnect with her mother in ways that she did not think possible:

> I used to always just look back on the experience and only think of her death and that is it. I don't know...now, I just want to learn more about her. I want to learn more about her life. What she was like? I want to talk to my dad more- and her sisters. I want to learn more about her and about what was going on at the time she was sick- and about her death.

Consequences of Coping Strategies

The consequences of employing different coping strategies varied within and between participants. Thus, the consequences should not be viewed as endpoints to the experience of having a mother with breast cancer, but as part of a dynamic, ever-changing and ever-developing process. Despite the transactional nature of the theory, certain themes did seem to emerge as a function of the experience of having a mother with breast cancer and the coping strategies used to deal with it. The impact on the following areas will be discussed: (a) life views and plans, (b) health views and behaviors, (c) body image, (d) romantic relationships, and (e) sexuality.

Life Views and Plans

As a result of their attempts to cope with the experience of having a mother with breast cancer, a number of participants reported an increased sense of self-reliance, both practically and emotionally. Jen depicted the experience of losing her mother as a child and remarked on how this loss has shaped her life views:

> I think as a result I'm a lot more independent than a lot of people. Being a girl, losing your mom, having a dad who's kind of checked out because of his job... So I'm very independent because I didn't have anybody else I could turn back to. Yeah, there were family members, but in the long run it was just down to me- what do I want to do? And there's part of me- you know you never really want to say you're glad somebody died- but in a way I think I'm a stronger person because of it. By not having a parent- and yes my family was supportive, but I really was making my own decisions- It wasn't like I was going to people saying, 'what should I do?'

Mary also became increasingly independent as a result of her mother's illness:

> I became really independent. I raised my sister, not because I had to, but I took on that role as the caretaker because my brother was on the way. I started cooking my own dinner...that's the biggest thing that happened...she (mom) didn't do stuff around the house, and it has kind of always been like that because she's been busy and my dad was busy... no one cooked, no one cleaned, no one did things, so we just did it on our own. And I always cooked dinner and we took care of ourselves. That's because... she just couldn't.

Claire reported that she too took on extra responsibility as a function of being a daughter of a mother with breast cancer:

> I was the one that took care of the kids. Yea, I kind of did everything that she did- in a 12 -year-old's capacity- keeping the house clean, I did most of the cooking, looking after the two younger ones- especially my little brother because he was four or five then. Yea, so, it was a big change in my perspective on responsibility. Now, I am totally overly responsible about most things. I still do a lot of taking care of things at home. I went to college here because I didn't want to be too far from my family. I think it really made me be the kind of person that takes care of others, especially other people.

Rhonda summed up her experience of losing her mother to breast cancer in only a few words. She said:

> I had to grow up in an instant.

Participants also revealed how the experience of having a mother with breast cancer has impacted the way they plan their lives. Anne (age 43) described the "carpe diem" philosophy that she has donned since her mother's illness:

> More of living for now... I hope that I live a long, happy, active life, but there is every possibility that I won't. Some of the decisions that I might make- like for example I am going to Puerto Vallarta on Tuesday- and I wouldn't normally do that kind of thing. But I am going to take advantage of the moment.

Jen explained that she does not worry a great deal about planning for the future because she has a sense that she can make it through whatever life throws at her:

> My planning involves- I don't want to say the path of least resistance- but I just sort of follow things I'm interested in, and the doors seem to open up- and I don't know why. And everything, everything's always worked out even though maybe when I started something I'm not sure where I'm going with it. So maybe again the independence to say, hey, I want to do a Ph.D. in education. I'm not sure what I'm going to do with it, but I'm happy doing it and I'm sure that the door will open when I get there. Maybe it's given me a sense that things have always worked out, even in the face of tough times, whether it's a mom dying, stepmother problems, whatever. I just make the best of whatever and do a good job.

Health Views and Behaviors

Health behaviors seemed to be distinctly related to the particular coping style used by the participants. Those participants who utilized an approach style of coping seemed to engage in an increased number of health behaviors (frequent health checks, healthy eating, exercise, etc.), whereas those who employed an avoidant style of coping tended to engage in fewer health-promoting behaviors.

Rhonda, for example, described her tendency to maintain distance from anything that would remind her of the frightening realities of cancer:

> The way I treat my body physically is not good. I don't take good care of my body at all....I don't do anything that I should be doing to prevent cancer or just to lead a healthy life in general. I eat horribly. I smoke. I drink every now and then. For a while, I got really, really into drugs....In high school, I got pregnant and had an abortion...I don't exercise as much as I should be....My mom did all the healthy things and she died of cancer anyway so what's the point?

Both male participants commented that they had a heightened awareness of mortality due to their mothers' illness, but they reported that they did not increase their health behaviors as a result. Jeff explained that he is able to superficially acknowledge the importance of healthy living, but he is not able to translate his awareness into personal action:

> Well, I don't eat that healthy. I'm not the most healthy person. I guess I live the college lifestyle. I'm on the run a lot. I guess it hasn't scared me enough. I guess I need to realize that health is the most important thing, you know? When you see someone debilitated like that you realize that nothing else matters if you're not healthy. Well, I guess I understand that- but not fully- because it's ever happened to me. I've never been faced with... I've never lost my health, or faced the obstacle of dealing with that. So I guess I have just kind of avoided it... I probably can't understand fully until it happens to me.

Andrew also shared how he distanced himself from the reality of his mother's cancer:

> When she was diagnosed, I didn't really understand the implications. The whole time through college I was a recreational smoker while my mom had breast cancer. So it doesn't really make sense, you know? Why would you watch your mom and your family go through this awful thing, but yet you still fill your lungs with this crap. So that's sort of an embarrassing thing to me, that I still did that.

In contrast, Claire, who tends to use an approach style of coping, actually expressed anger at individuals who do not practice health behaviors:

> I get almost resentful of people who are close to me when they do reckless things, because it is like everybody is so interconnected in their lives; it is like everything I do effects several people very significantly, and it is the same way for everyone. I think when you are reckless with yourself, it is selfish-it is not taking into account what other people experience when you are sick or get hurt.

Referring to her mother's breast cancer, she said:

> I think it just makes me a lot more aware and a lot more grateful about everything… and probably a little bit paranoid about health issues, my own and other people's.

Body Image

Depending upon their coping styles (as well as their gender), participants' body image was impacted negatively, positively, or neutrally. It appears that Jeff and Andrew's gender may have served a protective function in terms of their body image. They did not report being affected either positively or negatively as a result of having a mother with breast cancer. They speculated that this was because they were unable to personally relate to the experience of having breasts. Andrew noted that his body image might have been more affected if his dad had had prostate cancer.

The female participants seemed to have divergent experiences based on their personal coping styles, as well as their mothers'. Those participants who utilized more approach techniques tended to report a positive impact on their body image, while those who used avoidant coping strategies seemed to experience a more negative impact on their body esteem. Likewise, participants whose mothers were more forthcoming with information (approach) seemed to fare better with respect to their body image. Reflecting this trend, Anne (age 22)- whose family utilized avoidant coping mechanisms- spoke of the fact that both she and her sister were diagnosed with eating disorders around the time of her mother's illness:

> Well, both my sister and I had eating disorders. She was bulimic and I was anorexic, and it just kind of like all happened at the same time. It was just horrible, a crisis situation in our family...I mean I definitely know that I just kept getting deeper into my disorder. I mean one of the biggest issues that both my sister and I had was that we didn't have a strong family support system. I mean they were definitely there, but my mom was always real distant. I think it definitely increased my confusion of life and thus made me probably more depressed and sink deeper into the disorder.

She further described how the emotional distance from her mother augmented her fears about her body:

> Well, I was really scared of my own body. I am scared of my breasts, and I didn't want to lose them, you know. I think that I was just really confused about just being a woman and all the things that went with it, and as you can imagine my mother never really explained any of that to us...she just kind of gave us a book and that was it.

On the other hand, Mabel, whose mother was open and approach-oriented, reported a positive impact on her body image:

> Everyone has a sense of their body, and I think mine is more from the- 'is everything working?' versus the 'do I look good?' point of view, because really what is looking good? You know? I mean, that's all relative ... you have to have a healthy look at your body with it as the whole picture, knowing that you may lose a piece of it and it doesn't really mean that you're any less of person. You just have a different body. Having two boobs is not the reason for being here on earth. I mean there's more to life beyond that.

Relationships

The impact on participants' romantic relationships seemed to differ according to their individual styles of addressing their experience. Jeff, for instance, explained that he does not feel personally threatened by the idea of breast cancer, but he expressed a heightened awareness of the risk for the women in his life:

> It's not something that I'm worried about...I don't really think about it much. I mean, I guess because I'm young, you know, and I guess I feel like I just couldn't

> have cancer right now because I'm so young, but, it's something that I know that I'm probably going to have to deal with again. You know? Either with my mom again, or my sister, or my aunt, or if I ever have a wife, my wife.

Anne (age 43) commented that the experience of having a mother with breast cancer has made her increasingly aware of her choices of mates. She explained:

> If breasts are that important to a man, then he is probably not someone that I am interested in. Granted breasts are part of your sexuality and everything, but a person in your life needs to know that they are just objects and when they are gone that you are still much more important.

Rhonda reported that she maintains emotional distance in significant relationships in the same way that she kept herself distanced from her mother's illness:

> I've noticed in past relationships, like with my boyfriend this past year... Like in a way I could deal with things on my own and I didn't really need him the way he needed me. But there is distance definitely. People feel like I'm not totally open with them. That I'm withholding...

Catherine described how she struggled with knowing how much emotional energy to put into taking care of her mother versus how much to put into sustaining her marriage:

> Carl was drinking and running around, and maybe he was doing that because he wasn't getting affection and love, or whatever it was he needed at the time. Because he did tell me, he said, your first duty is to your husband, then to your kids, and then to your mother. He explained that your parents usually die. Your kids grow up and marry and go away from home. Then it's you and your partner. Made good sense to me, but every time my mother was real sick and she needed someone to help her and she had no one....

Anne (age 22) said that having a mother with cancer actually brought her closer to her husband, because she realized that he was there to support her through emotionally difficult issues:

> It has probably affected my relationship with my husband positively. ..Just because we have definitely talked about all of these issues together and he is really supportive and wants me to get all of my exams and check ups when I need to...he wants me to take care of myself. He is a vegetarian in the house, he goes

> out for his steak but he is really supportive of everything that I do to keep healthy and I think that strengthened our relationship.

Sexuality

Effects on sexuality were primarily noted by female participants and not males. The effects ranged from self-consciousness within sexual relationships to an increased awareness of one's body and sexuality. It also appeared to be the case that individuals with a propensity towards avoidant coping strategies may have "avoided" the potential negative consequences of unsafe sexual practices.

To begin with, Mary represents an example of someone who experienced self-consciousness within sexual relationships:

> I'm definitely self-conscious about the size of my breasts. My mom- not to go into details- but she's never had small breasts. She said that they used to be a lot bigger, you know, because she's lost about a quarter of them or half of them. But she still makes comments about how small they are...and mine are obviously smaller than that. So I have a complex, definitely...and that gets in the way...I'm self-conscious about it and it doesn't help when she thinks hers are small when she's lost part of them. That's all I can think of.

Mabel described how she both she and her husband have become more in tune with her body since her mother's illness:

> I think I'm probably more in tune with my body and everything that happens to it since, you know, I do do exams. And as well as- I mean Jay- he knows my boobs as well as I know my boobs, you know? It's interesting because he's a climber and so his fingers are callused. They're very sensitive. Sometimes I think that if I did actually have a lump he'd probably be the first one to feel it, just because his fingers are the much more sensitive than mine... So in that way I think that it has changed because I think if my mom hadn't have gotten breast cancer, then whatever guy I was with- it wouldn't occur to him to feel for a lump.

Jen speculated that she was perhaps more sexually active than she might have been if her mother had been around to discuss sexuality with her:

> I was fairly- I don't want to say promiscuous- but you know, I certainly in high school had what I would consider a typical sex life. And I don't know if it was so much the having a mother with breast cancer, but not having anyone talk to about sex...and it was sort of up to me to decide what was right and what was wrong because no one ever sat down and helped me think it through.

Section II: Gender and its Relationship to the Experience of Maternal Breast Cancer

One of the motivations behind the present study was to elucidate the experiences of both male and female children of breast cancer patients. This second section will discuss: (a) the meaning behind the limited number of males who volunteered to participate and (b) the observed differences between the male and female participants in this study.

Limited Number of Male Participants

Participants were recruited through advertisements posted in the University newspaper. The first advertisement called for "Adult Children of Mothers with Breast Cancer"- in other words, gender of participants was not specified. This first advertisement yielded eleven female volunteers and one male volunteer. The second advertisement specifically requested male participants, and this also yielded only one male participant. Possible explanations for the low number of male volunteers could include: (a) males may view any "breast"-related topic as being irrelevant to them as a function of their gender, (b) males may utilize more avoidant coping mechanisms which would be incompatible with responding to an advertised opportunity to "discuss" their experiences, and (c) societally-prescribed gender roles do not encourage males to express their feelings openly.

To begin with, it may be the case that "breast"-related topics are immediately associated with the female gender. Males, then, may have discarded a study dealing with maternal "breast" cancer as being fundamentally and experientially irrelevant to them. Although statistically it is certain that there were more males out there with mothers who had breast cancer, it is possible that they felt they should not have been affected by the experience because they personally do not have- and could not relate to having- "breasts." Both of the male participants in the present study suggested that they were not as emotionally affected by the experience of maternal breast cancer as were their sisters. Andrew, for instance, noted:

> I'd be interested to see how my sister would answer these questions, because I know she would answer them a lot differently- like in regards to sexuality or her personal health. I know she is a lot more scared, and concerned about having breast cancer- more conscious about that. So it would be interesting. You know, it seems like a gender thing.

He continued:

> Yeah, because you know if my dad would have prostate cancer and pass away from it, then I'm sure it would affect me a lot differently than it did...but my mom passed away from breast cancer...For whatever reason, if my dad had prostate cancer, it would be more of a reality that it could happen to me.

It is possible that males truly are less affected by the experience of having a mother with breast cancer. Indeed, their gender might serve a protective function in the sense that it emotionally distances them from the fear that "this could happen to me." Moreover, the potential of heritability might not be as frightening for males, since their chests do not seem to be as inextricably linked to their masculinity and sexuality in the way that breasts are so closely tied to femininity and sexuality for women.

Another possibility is that the medical field, in conjunction with the media, has provided insufficient information about the veritable risk of male breast cancer. In other words, it may be the case that men have not been adequately informed that they too are at risk for developing the illness. It is interesting to note that American Cancer Society's "Breast Cancer Facts and Figures" (1999-2000) does not once mention statistics for male breast cancer....One might also notice that the stories on the news tell the tales of *women* with breast cancer...open almost any self-help book for breast cancer patients (found in the *women's* health section) and read suggestions for *women* struggling with the illness...enter the doors of almost any breast cancer support group and be greeted by *women*...notice that the leaders of the war against breast cancer are mostly *women*...and finally, remember that the color representing the cause is pink- the color which, in our culture, symbolizes *womanhood* and *femininity*. It seems then that men receive the clear message that breast cancer is a *woman's* illness...and therefore, "nothing to be afraid of."

In addition to the fact that the risk of male breast cancer is virtually invisible in our society, it is also communicated that males are not emotionally impacted by the experience of having a mother with breast cancer. This is promulgated by the growing body of literature on daughters of mothers with breast cancer, coupled with the paucity of research on sons of mothers with the same illness. So, the question remains...does the limited number of male participants in the current study suggest that males are truly unaffected by maternal breast cancer?... Or that they *feel* they should not be based on the messages espoused within our culture?

Another potential explanation for the limited number of male volunteers is the finding that males have a tendency to utilize avoidant coping strategies more frequently than females (e.g., Kavsek & Seiffge-Krenke, 1996). This *avoidant* coping style is incompatible with the action of *approaching* a study that would require them to further *approach* an emotionally-laden subject matter. Even with the men who did participate in this study, it is interesting to note that their transcribed interviews each consisted of only seven pages, whereas the women's transcribed interviews ranged from nine to 21 pages long. It appears that the female participants generally spoke more freely about their experience.

A third reason offered for the paucity of male participants is the male gender role prescribed by our society. From a very young age, boys are taught to be "strong," and "stoic"; emotional expression is seen as being virtually synonymous with weakness. The saying "big boys don't cry" has certainly been heard on more than one occasion. Furthermore, it may be that males are especially discouraged from expressing emotion regarding their mothers. The label "Mama's boy" frequently has a negative connotation and is used to describe a male who is "weak," "needy," and "dependent" upon his mother. The label "Daddy's boy," in contrast, is thought to describe a man who more closely parallels the gendered expectations for a male in our society. Based on these ideas, it would be interesting to see how many males would volunteer to discuss paternal prostate cancer instead of maternal breast cancer.

Observed Gender Differences

Observed gender differences will be delineated according to the following domains: (a) life views/ plans, (b) health views/ behaviors, (c) body image, and (d) relationships and sexuality. The reader is once again asked to keep in mind the small sample size of male participants.

Life Views and Plans

There were similarities and differences between genders in terms of the impact of maternal breast cancer on their views of life in general. Both males and females expressed an increased awareness of the importance of interpersonal relationships as a function of their mothers' illness. It is worth noting, however, that females exhibited a heightened awareness of their own mortality, whereas males expressed a growing awareness of the mortality of others (i.e., the women in their life). Mabel, for instance, described feeling resigned to getting cancer at some point in the future:

> It's just one of those things that I know...statistically I will get cancer. My doctor's already told me that. And that's okay. I mean it's one of those things that you'd rather know...you'd rather know that information and then you can deal with it. But, um, it's still just a little- well obviously- it's just a little bit emotional.

Jeff instead spoke of his heightened fears of losing one of the women in his life to cancer:

> I mean, it's something that I know that I'm probably going to have to deal with again. You know? Either with my mom again, or my sister, or my aunt, or, if I ever have a wife, my wife.

Health Views and Behaviors

Gender differences in the domain of health views and behaviors were probably confounded by the style of coping used by the participants. As mentioned previously, participants who employed an avoidant coping style typically engaged in fewer health-related behaviors than participants who utilized an approach-oriented style. So, although the male participants described engaging in fewer health promoting behaviors than female participant, it is uncertain whether this difference is related to gender or simply to differences in coping style.

Body Image

The male participants did not report changes in their personal body image as a result of having a mother with breast cancer. The female participants, on the other hand, reported both positive and negative changes in their body image as a result of their mothers' illness. One possible explanation for this observed gender difference is that females in Western culture are more strongly encouraged from a very young age to be cognizant of their body size, shape, and appearance. It is also possible that daughters of mothers with breast cancer experience vicarious effects on their body image as a function of their biological similarities to their mothers.

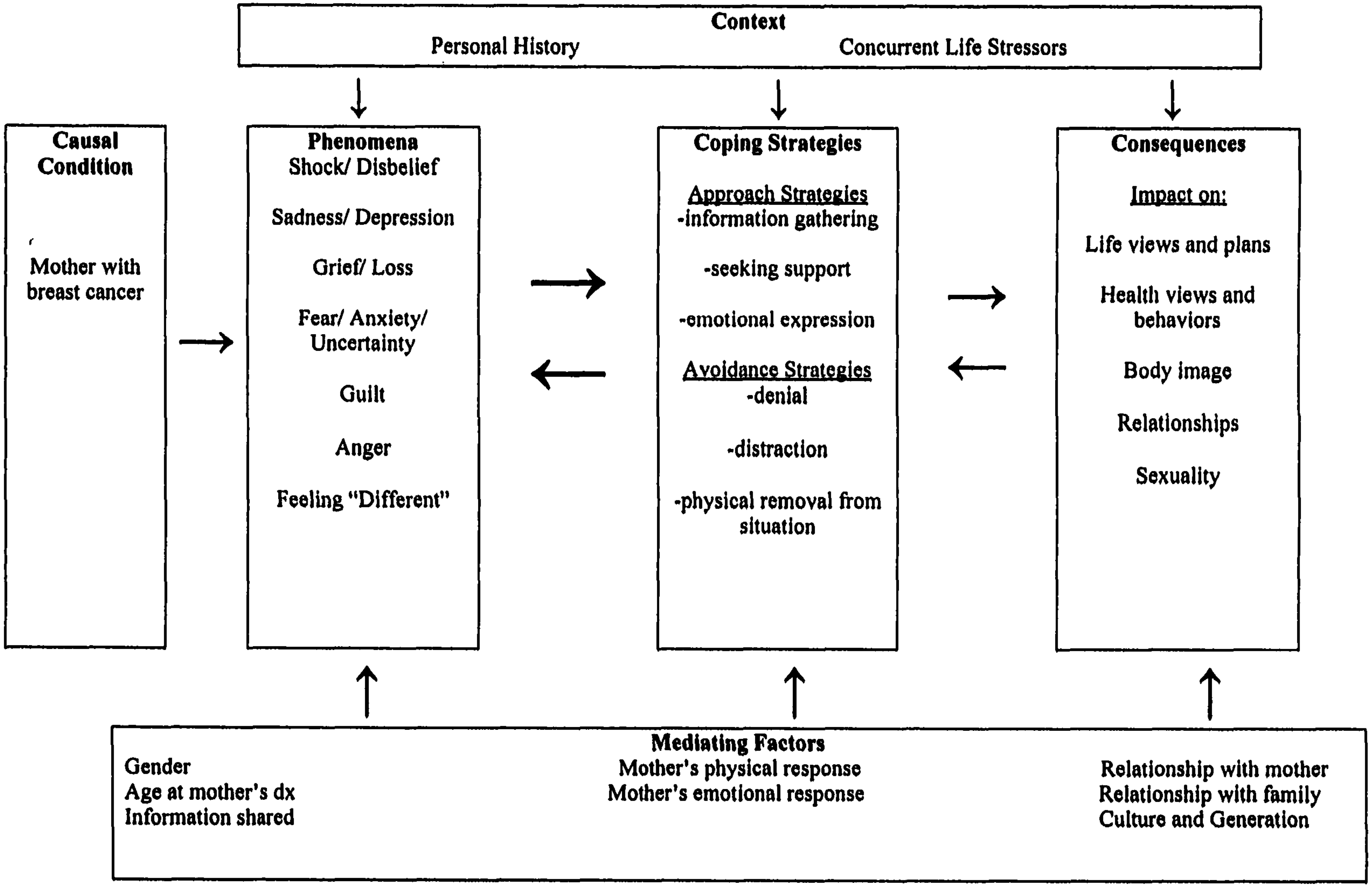
Relationships and Sexuality

Both males and females generally remarked on a greater awareness of the value of significant relationships spurred by their mothers' illness. However, male participants tended to express concern for their romantic partners, while female participants were more likely to relate personal stories of the impact of their mothers' cancer on their own experience of sexuality and romantic relationships.

Section III: Developing a Model of Children's Experience with Maternal Breast Cancer

The previous sections delineated and described the experiences of the 13 participants, according to each individual category of the model. The description of these categories is critical to understanding the phenomenon, but the purpose of grounded theory is to go beyond mere description and to provide a conceptual, theoretical, and cohesive understanding of the phenomenon being studied. The grounded theory model for children dealing with maternal breast cancer is presented in Figure 1.

Figure 1. A Transactional Model of Children's Experiences with Maternal Breast Cancer


Context
Personal History
Concurrent Life Stressors
Causal Condition
Mother with breast cancer
Phenomena
Shock/ Disbelief
Sadness/ Depression
Grief/ Loss
Fear/ Anxiety/ Uncertainty
Guilt
Anger
Feeling "Different"
Coping Strategies
Approach Strategies
-information gathering
-seeking support
-emotional expression
Avoidance Strategies
-denial
-distraction
-physical removal from situation
Consequences
Impact on:
Life views and plans
Health views and behaviors
Body image
Relationships
Sexuality
Mediating Factors
Gender
Age at mother's dx
Information shared
Mother's physical response
Mother's emotional response
Relationship with mother
Relationship with family
Culture and Generation

A Transactional Model of Children's Experience with Maternal Breast Cancer

Viewing the Model as a Transactional Process

This model was formulated to explain the process that children may go through when their mothers have breast cancer. It is important to remember that the experience of maternal breast cancer is not a fixed process with set endpoints, but instead it should be viewed as a process that is cyclical and dynamic in nature. The flow of the model is as follows: When children's mothers are diagnosed with breast cancer, they are confronted with the immediate circumstances surrounding the illness (i.e., the context). In addition to their personal histories and concurrent life stressors, the children are also differentially affected depending on the following mediating factors: the children's gender, their age at the time of their mother's diagnosis, the amount of information shared with them, the mothers' physical and emotional response to breast cancer and its treatment, their relationship with their mothers, and their relationships with the rest of their family members. Depending upon these mediating factors, the children will select certain strategies to cope with the situation. These chosen coping styles will then, in turn, moderate the impact on the following areas of functioning: life views and plans, health views and behaviors, body image, romantic relationships, and sexuality.

Central to understanding the above-described model is realizing that any change in the context, the mediating factors, or the coping strategies will shift the emotional and behavioral outcomes of the experience. For example, an individual who is depressed in response to their mother's breast cancer diagnosis may find (or access) new social support which allows her or him to engage in expressive, approach-oriented coping which then results in a decrease in depressive symptoms. Likewise, a person who is coping relatively well could experience another loss (e.g., divorce, or death of another family member), start isolating from others, and then begin to engage in avoidant coping strategies. In this particular situation, the emotions associated with the mother's breast cancer might resurface or become magnified and the individual may enter a period where he or she becomes depressed. Thus, one can see that an alteration in context engenders an alteration in experience. And so, considering the frequency with which changes occur over a lifetime, the reader should attempt to visualize a child's experience with maternal breast cancer as a dynamic, constantly changing, and ever-evolving process.

A more detailed explanation of specific components of the Transactional Model of Children's Experience with Maternal Breast Cancer is as follows:

Causal Condition

For the purposes of this study, the causal condition was simply defined as having a mother with breast cancer.

Phenomena

The phenomena which emerge from the experience of having a mother with breast cancer include a variety of psychological experiences and mood states. The core emotions expressed are: shock/ disbelief, sadness/ depression, grief/ loss, fear/ anxiety/ uncertainty, guilt, anger, and feeling "different."

Context

The psychological/ emotional phenomena are directly impacted by the context that serves as the backdrop to the experience of maternal breast cancer. This context consists of the child's personal history (e.g., previous experience with illness in mother, mother's level of premorbid cognititve functioning, etc.) and other life stressors that occur around the time of their mother's illness (e.g., financial problems, moving, relationship problems, etc.).

Mediating Factors

In addition to their broader life context, children's experience with maternal breast cancer will be influenced by the following mediating factors: gender, age at the time of mother's diagnosis, amount of information shared with the child, mother's physical and emotional response to breast cancer and its treatment, the child's relationship with their mother, their relationship with the rest of the family, and the cultural and generational context.

Coping Strategies

As mentioned previously, the two major styles of coping with the experience of having a mother with breast cancer were approach and avoidance. Approach strategies generally seemed to be most beneficial to participants and included the following kinds of techniques: information-gathering (e.g., asking their mothers questions, asking medical providers for information, doing research on the internet, reading books about breast cancer), seeking support (from family, friends, medical providers, counselors/ therapists), and emotional expression (crying, verbalizing emotions, etc.). Avoidance strategies- when used consistently over time- were more often associated with negative outcomes. Examples of avoidant techniques included: emotional denial, distraction (mental, emotional, and behavioral), and physical removal from the situation.

It should be noted that approach and avoidance are not mutually exclusive strategies. In fact, many individuals described using both styles of coping at different points in time. Avoidance was more commonly described as a strategy used early on, just after the participants were told of their mothers' breast cancer diagnosis. Approach strategies were more commonly employed later, after the participants had had a chance to prepare themselves for the emotional sequelae of their mother's illness. It seemed that those participants who employed approach strategies- or a combination of approach and avoidance strategies together- fared best with respect to emotional and behavioral outcomes. Those participants who utilized avoidance strategies, to the exclusion of approach strategies, described the greatest number of negative consequences.

Consequences of Coping Strategies

As a result of context, mediating factors, and coping style, children experience a variety of emotional and behavioral reactions to their mothers' breast cancer. Some change their views on life; others do not. Some change their views on health; others do not. Some experience disturbances in body image; others do not. Some describe sexual and interpersonal sequelae; others do not.

Suffice it to say then, the response to maternal breast cancer is not a linear process with one predictable outcome. The experience is influenced by an infinite number of factors that when combined together, result in rich, complicated stories that are unique to the individuals that tell them.

Based on the results of the present study, however, it appears that the following contextual and mediating factors place individuals at highest risk for negative consequences:

- being female
- being adolescent at the time of mother's diagnosis
- having parents who are not open about mother's illness and prognosis

- having a mother who experiences significant physical deterioration and perhaps ultimately dies
- having a mother who does not cope effectively and perhaps has depressive and/ or anxious symptoms
- having a strained/ distant relationship with mother
- having a strained/ distant relationship with other family members
- having multiple concurrent life stressors and a tumultuous life history.

Furthermore, it seems that individuals who utilize avoidant coping strategies to the exclusion of approach-oriented strategies are at greater risk for developing physical and mental health problems in response to their mothers' breast cancer.

DISCUSSION

"A mother laughs our laughter, sheds our tears, returns our love, fears our fears. She lives our joys, cares our cares, and all our hopes and dreams she shares."

(Summers, in Exley, p.1)

Limitations of the Research

Before interpreting the meaning embedded in these findings, it is useful to reflect on the limitations of qualitative research. To begin with, one potential limitation is small sample size. The present study interviewed thirteen participants- eleven women and two men. The number of male participants is particularly limited, perhaps because of a male tendency to utilize avoidant coping strategies, or because males do not feel that breast cancer is relevant to them. Whatever the case may be, the generalizability of the results is limited to the experiences of the thirteen individuals interviewed. A second limitation of the research is the limited ethnic diversity in the sampling of the participants. All of the participants were European American; therefore, the present findings cannot be generalized to other ethnic groups. A third limitation is that the study is retrospective for the most part, meaning that participants' experiences were told through the filters of time and memory. Although some participants' mothers had just recently been diagnosed with breast cancer at the time of interview, for most it had been years since they were told of their mothers' illness. Finally, the generalizability of the results may be limited by the self-selection of participants. It is possible that the thirteen participants who volunteered for this study were different in some way from other adult children of breast cancer patients (e.g., in coping style, phase of grief, etc.), thus leading them to respond to the advertisement while others did not. The results should be interpreted with these four caveats in mind.

However, despite limitations in generalizability, small sample size can be an advantage in that it allows for a deeper exploration of participants' experiences. In fact, qualitative researchers often purposefully utilize small samples, in order to allow for a deeper understanding of the phenomenon under investigation. Creswell (1998), for example, notes that whatever qualitative investigation may lack in breadth is counterbalanced by the depth and richness of the inquiry.

Indeed, qualitative researchers view generalizability differently than quantitative researchers. More specifically, the purposes of the qualitative paradigm are to define, in depth, the unique aspects of a phenomenon and to explore how these aspects link together. In contrast to quantitative research, the goal is not to claim a universal truth about the applicability of the findings to other populations; however, it is considered appropriate to make thoughtful, yet speculative extrapolations from the data set (Patton, 1990).

In line with the qualitative paradigm, the results of the current study should be viewed primarily as an explanation of the "lived experiences" of the thirteen participants who told their stories. Although, in the ensuing discussion, the researcher does offer speculative comments about the utility of the results, these extrapolations should be considered working hypotheses which may have relevance in some contexts but not in others. Furthermore, because the intent of the current study was to stimulate thought about sons and daughters of mothers with breast cancer and to generate clinically relevant ideas that might assist in the treatment of these children, the reader is invited to make their own interpretations about the data presented.

Evaluation of Qualitative Research

Despite its limitations, one must remember that qualitative research is evaluated on a different set of criteria than quantitative research. Howe and Eisenhart (1990) recommend that readers ask two important questions when evaluating qualitative research. First, does the research question have utility for professionals in the field? And, second, does the researcher make effective use of the data collection and analysis techniques (e.g., identify biases, conduct adequate interviews, etc.)? Eisner (1991) suggests that another way to evaluate qualitative research is to examine its usefulness in expanding and deepening the understanding of the phenomenon under investigation.

Based on these evaluative criteria, the remainder of the discussion will focus on synthesizing the present findings and identifying how they might be useful in the development of future research and clinical interventions for children of mothers with breast cancer.

A Synthesis of the Transactional Model of Children's Experience with Maternal Breast Cancer

A mother's breast cancer does not occur in a vacuum; indeed, it is well-known that its effects reach far beyond the identified patient. Maternal breast cancer is a complex, biopsychosocial phenomenon that has been found to have particular effects on the children of breast cancer patients. Certainly, the impact of a mother's breast cancer is influenced by the contextual and mediating factors that envelope the child as they live through the experience of maternal breast cancer. Based on the results of the present study, it appears that children at particular risk for biopsychosocial dysfunction are those who are female, adolescent, and generally uninformed about their mothers' illness. Children who have strained familial relationships (with mother, father, and/ or siblings) and children whose mothers have marked physical and emotional symptoms related to their breast cancer also seem to be in the high-risk category. Finally, children who have a tumultuous life history and multiple life stressors that occur around the time of their mothers' breast cancer also appear to be at increased risk for developing biopsychosocial problems.

In addition to the contextual and mediating factors that may place a child at higher risk for developing a variety of problems, it also appears that an avoidant style of coping with their mother's illness further increases the likelihood that they will experience negative effects resulting from maternal cancer. On the other hand, the present findings indicate that approach-oriented coping strategies may provide a buffer against long-term negative consequences (e.g., disordered eating, relationship dysfunction, etc.). Although, approach-oriented strategies are likely to increase emotional distress in the short term (e.g., fear at "not knowing what to say" to their mother, anxiety at seeing their mother's scar, etc.), it seems that the long-term outcomes are more positive when this style is used. Examples of approach-oriented coping strategies involve taking some sort of action that directly addresses the mother's illness (e.g., information- gathering, care-taking, emotional expression, etc.). It is likely that this style of coping creates a sense of control for the children- and this sense of control is invaluable, especially in light of the fact that breast cancer is, by nature, beyond their control. It is also possible that, by addressing their mothers' illness directly, children are able to find meaning in the experience.

Support for Existing Research

The results of the present study lend support to existing research in two distinct ways. First of all, this study provided additional support to the notion that female adolescents are at greatest risk for developing biopsychosocial problems in relation to their mothers' breast cancer. And, second, the current research is in line with other studies which have shown that approach-oriented coping strategies are generally more effective than avoidant coping strategies in dealing with life stressors.

Extension of Existing Research

The present research expands the available literature in three primary ways. To begin with, it offers a unique opportunity to explore the virtually uncharted territory of male experience with maternal breast cancer. Also, for the first time to date, the current study applies ideas about approach- and avoidance-oriented coping styles to the experience of maternal breast cancer, in particular. And finally, this study takes a distinctly broader view of the myriad of contextual and mediating factors that may influence a child's ability to cope effectively with their mother's breast cancer.

Future Research Directions

The present study was intended to be an exploratory study that would open up the doors for future research endeavors. Based upon the ideas that have begun to emerge with regard to gender differences in dealing with maternal breast cancer, it appears warranted to embark on future studies which include greater numbers of male participants. Because of the difficulties encountered in recruiting males for the present study, it is recommended that alternative selection strategies be employed. For instance, it may be helpful to recruit participants through an oncology clinic, rather than a university newspaper.

Moreover, it may be interesting to conduct a study which would compare sons' responses to paternal prostate cancer with daughters' responses to maternal breast cancer. First of all, males might be more likely to volunteer to participate in a project that is congruent with their own gender. And, second, it is possible that sons are affected to a greater extent by their fathers' prostate cancer than they are by their mothers' breast cancer.

Finally, it is critical that efforts are made to include diverse samples of participants when studying the impact of maternal breast cancer (or parental cancer in general) in the future. Because cultural factors can significantly influence the ways in which people think of / respond to illness, it will be important to include individuals of various ethnic backgrounds, religions, and sexual orientations.

Clinical Interventions

Only recently have researchers begun to examine the impact of interventions directed at children coping with parental cancer. Available programs include: "For Kids Only" (Bedway & Smith, 1996), "The Bear Essentials" (Greening, 1992), "Quest" (Heiney & Lesesne, 1996), and "Kids Can Cope" (Taylor-Brown et al., 1993). These programs target the needs of children and adolescents by providing education about cancer, exposure to the oncology setting and staff, activities to facilitate emotional expression, and instruction in coping strategies.

Although the aforementioned programs have been shown to have some benefits, the results of the present study suggest that interventions aimed at the entire family system would be most helpful to the children of cancer patients. Unfortunately, programs that include all family members and address parental cancer from a family systems perspective are exceedingly rare. One available program that incorporates the entire family system is called, "We Can Weekend" (Walsh-Burke, 1992). This is a weekend retreat geared for families (i.e., patient, spouse, and children) to address family communication, coping with cancer, social support, and informational needs. "Building Bridges," a program proposed by Cooper et al. (2001), has also been recently designed with the entire family system in mind. "Strengthening Family Ties" is a combined workshop and support group program open to families in which one parent is undergoing cancer treatment and at least one child is under the age of 18 years. In this program, opportunities are afforded for addressing patient needs, spouse needs, marital concerns, and child/ adolescent needs in appropriate forums. Perhaps most importantly, the entire family is able to address the impact of cancer on their lives and work through issues together.

Further work in developing and assessing programs to help the children of cancer patients is needed. Moreover, the present research indicates that children of mothers with breast cancer have unique concerns related to body image and sexuality that might be best addressed in specialized programs.

In closing, the individuals who participated in the current study offer the following words of advice and support to other children of mothers with breast cancer:

> Don't let it overrun your life, but certainly don't let it not be a part of your life, because I think there is so much to learn from it...Especially, don't be afraid to

look at her scar....once, I was looking at my mom's scar and I couldn't help but stare. I mean she has a huge red scar and no nipple!...but it really made me realize that it's still her body. It's still my mom... So I'll look at the other nipple. You know? That is one way of reaffirming that it's still your mom. No matter how or what she's been through, or what her boobs look like, she's still your mom. *– Mabel, 32*

I guess I could tell them what to expect. Say, you know, your mom's going to be a little out of it sometimes. Your mom's going to lose her hair. There's going to be days where she's just going to be real sick, and she's going to be in bed, and she may be throwing up, and it's not pleasant. You know? It's not going to be pleasant at all, but remember, it's not going to be like that all the time. There will be good days too. *–Jeff, 21*

Let your moms know how much you love them. Let them know how you feel. Ask your mom what's going on. It helps to know what's happening.
– Rhonda, 20

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Appendix A

The Biopsychosocial Model

"We can envision in chronic illness and it's therapy a symbolic bridge that connects body, self, and society. This network interconnects physiological processes, meanings, and relationships so that our social world is linked recursively to our inner experience."

(Kleinman, 1988, p. xiii)

Kleinman (1988) writes of the "intimate and manifold ways by which illness comes to affect our lives" (p. xi.). The author differentiates between the terms "disease" and "illness." He explains that disease is that which physicians have historically been trained to view through the lenses of the biomedical model. Essentially, he defines disease as the measurable alteration in biological structure or functioning. In contrast, he describes illness as "how the sick person and members of the family or wider social network perceive, live with, and respond to symptoms of disability" (p. 3). "Illness problems" would include being unable to walk upstairs to our bedroom because of weakness, pain, or fatigue...experiencing low back pain while sitting at work...impossible headaches that interfere with schoolwork, ...impotence that leads to divorce...anger because no one can objectively see our pain and know that our disability is real...the loss of hope that we will get better...an altered body image because of the loss of a breast...(p. 3).

The biopsychosocial model is a "general systems" framework that describes the *experience* of the "illness" and not the *symptoms* of the "disease." This model was developed by George Engel in 1977 and has since begun to challenge the medical field to look through a broader lens that views the mind as well as the body, the emotional as well as the physical, the family as well as the patient, and the larger social context as well as the affected family.

Weisman (1984) emphatically agrees that "cancer creates problems beyond the tumor itself"(p. 107). Thus, in order to shed light on the broader picture, the author presents a model to delineate the psychosocial phases of the cancer experience. He suggests the following phases: (a) existential plight, (b) accommodation and mitigation, (c) recurrence and relapse, and (d) deterioration and decline. (Please note that not all patients experience the third and fourth phases).

The existential plight begins at the time of initial evaluation and diagnosis. Existential plight may be divided into early impact distress (immediately after diagnosis) and a more protracted "plight proper." Impact distress is commonly associated with life and death concerns and the realization of mortality. Advanced staging at diagnosis often means a higher level of emotional distress, but not necessarily. Plight proper refers to the more extended period of time when the individual and his or her family deals with the symptoms of the disease, the treatment and its side effects, prolonged disability, unemployment, financial strain, and family troubles.

The existential plight is often followed by a ripple effect of non-medical problems such as impaired parenting, sexuality, and socializing and not being able to resume work or other activities with the same vigor as before. The accommodation and mitigation phase refers to "a broad range of adaptive efforts and tactics for alleviating or coming to quiescence and equilibrium with the residual effects of cancer" (p. 116). Certainly, there is a wide array of individual differences in this phase; however, someone who receives only original treatment (i.e., surgery) may have a more manageable time than someone who receives supplementary or adjuvant therapy (chemotherapy or radiation) for a protracted period.

The next phase is the recurrence and relapse phase. According to Weisman (1984), relapse is the term used when cancer returns during treatment. Recurrence refers to the return of the cancer long after treatment. Usually, more treatment is given during this phase, but with a grimmer outlook. This phase can be described as a secondary existential plight. Pessimism in the patient is often evident and levels of vulnerability typically rise. Patients who were once resistant about follow-up treatments often become more cooperative out of fear and desperation.

The fourth and final psychosocial phase of the cancer experience is termed deterioration and decline, which may be insidious or abrupt. The defining characteristic of this phase is the professional opinion that the purpose of further treatment is palliative and not curative. Psychosocial problems become more evident as deterioration progresses, at least in the sense that many individuals experience an increased urgency to resolve "unfinished business" with important people in their lives. On the other hand, certain problems tend to recede for the patient, "as if the acceptance of the outcome provides a sense of distance which reduces distress" (p. 118). Ultimately in this stage, physical changes coalesce and patients become exhausted, confused, episodically depressed, and very sick. The main psychosocial task is to help bring about the least physically and emotionally painful death possible.

Freidenbergs and Kaplan (1993) concur that cancer can indeed have a profound effect on a person. They explain that cancer may interfere with any number of daily activities and that the patient may react with anxiety, depression, loss of self-esteem, and a disruption of coping strategies. They list the many different types of fears that can be activated, which include fears of loss of control, loss of independence, loss of privacy, loss of normal bodily functions, mutilation, isolation from family and friends, loss of income, pain and death.

With regard to breast cancer in particular, Falco (1998) writes: "Many women experience their cancer diagnosis first and foremost as a threat. The threats can be multiple, including a threat to her sense of self, to her body's integrity, to her lifestyle and activities, to her dreams, and to relationships" (p. 48). Thus, in an application of the biopsychosocial model to breast cancer, the following affected areas will be discussed: (a) body image, (b) sexuality, (c) mood, and (d) relationships.

Body Image

"I am in a small boat floating along the inside of my body. My body is a river. The river is burning. The territory on the banks has been pillaged and razed. I assess the damage: sexless organs intact- lung, liver, kidney. But there's a hollow where the breast should be...In the shallows, I moor the boat, hear the dead calling: 'You belong with us. Come.'"

(Dine, 1999, p. 254)

In Western culture, a great deal of emphasis is placed on a woman's body. In fact, when describing societal views on female physical appearance, Falco (1998) states, "If her appearance is deemed desirable, then so is she, and she is treated accordingly. If her body is not deemed desirable, then she is worth less- even worthless" (p. 21). Falco maintains that only thin, firm, youthful, *double-breasted* bodies are considered attractive in this society. And, since, according to Western culture, a woman "*is* her appearance" (Falco, 1998, p. 22), then when a woman has breast cancer, the very crux of her identity is threatened and perhaps destroyed.

Authors point out that the breast has been a universal symbol of womanhood since recorded history (Kincaid, 1984), making us a "breast-fixated society" (Weatherly-White, 1980). Some even say that mastectomy is equivalent to castration in the male (Renneker & Culter, 1952; Small, 1982). Thus, the breast is undoubtedly a vital part of a woman's sexuality, her feminine self-image, and her body image in particular.

Carver et al. (1998) define "body image" as the patient's perception of what her body is like. They make a subtle distinction between "body image" and "concern over body image," explaining that the latter pertains to the level of an individual's investment in her body image. They speculated that women with a higher level of concern about their appearance would be more vulnerable to various forms of body image disturbance after surgery. Schain (1988) concurs that a woman whose self-esteem stems primarily from physical beauty and traditional values of femininity is more likely to be devastated by mastectomy.

Hopwood and Macguire (1988) describe body image problems with women who lose a breast through mastectomy. The authors relay how their study participants described themselves as "feeling like a freak" or "feeling like half a woman." They explain how this body image disturbance can lead to avoidance behaviors such as removing mirrors, dressing and undressing in the dark, avoiding taking a bath, and avoiding looking at the chest wall. They relate that the participants described feeling very self-conscious of their "lop-sided body" and restricted in the kind of clothes they could wear to conceal it. Many of the participants found themselves unable to look at magazines or television where attractive women were displayed, without becoming distressed and jealous at seeing other women with two normal breasts. The authors conclude that "For some women then, mastectomy- particularly if combined with radiotherapy- is not just a question of losing a body part but a real sense of permanent change to their remaining body" (p. 47).

When examining the psychological reactions specific to mastectomy, some researchers postulate that it is the related fear of death which evokes emotional turmoil in women (e.g., Aaronson et al., 1988; Goldsmith & Alday, 1971; Kenney et al., 1988; Margolis et al., 1990). The vast majority of researchers in the field, however, maintain that a woman's psychological reaction is more closely tied to the loss of her breast and the importance she places on this body part in defining her femininity (e.g., Clifford, 1979a; Colette et al., 1984; Margolis & Goodman, 1983; Mock, 1993; Schover, 1991). Reaby and Hort (1995) compare the attitudes and experiences of women who wear external prostheses postmastectomy to those who undergo breast reconstruction surgery. They suggest that an external prosthesis is never incorporated into a woman's image of her own body. It is said to be experienced as a foreign object, a nuisance, and a reminder of the disease and the feelings of vulnerability associated with it. According to the authors, a prosthesis may even be associated with a fear of death.

Mock (1993) compared the impact of the most common types of treatment for breast cancer: mastectomy, mastectomy with delayed reconstruction, mastectomy with immediate reconstruction, and conservative surgery. The findings of her study showed significant differences in body image according to type of surgical treatment experienced. Apparently, women treated with conservative surgery reported greater satisfaction with their bodies than women treated either with mastectomy or immediate reconstruction. Thus, Mock concludes that it is the loss of a body part which is so significantly related to feminine identity (i.e., the breast) that results in a negative alteration in body image and self-concept.

Sexuality

"I want you to know that at the very moment in time when my identity as a female is threatened, my ability to be sexual may be limited. Not only do I feel tired and less attractive, but my chest is sore and intercourse has become painful. I fear being rejected and, if you are my intimate partner, you fear hurting me." (Becvar, 1996, p. 85)

Among the biopsychosocial treatment sequelae of breast cancer are changes in sexual functioning and intimacy- very important areas of patients' lives which are often neglected by health care providers. As one survivor of cancer noted, "It is normal for us to put sexual issues in the back our mind while we are responding to the diagnosis and...cancer treatment" (Kaufman, 1989, p. 173). Indeed, sexual intimacy can be considered a "luxury" when survival has been the primary issue (Schover, 1987). Meyerowitz et al. (1999) report that most breast cancer survivors, even those who are not at risk for overall psychosocial distress, continue to experience difficulties in some areas of sexuality for at least three years after diagnosis.

Burbie and Polinsky (1992) point out that, while all cancers may impact sexual functioning, cancers which involve anatomical sites associated more directly with sexual activity not only have a psychological impact on sexuality but often have a physiological impact as well.

Andersen and Jochimsen (1985) state that two groups at especially high risk for sexual difficulties are women with breast cancer or gynecologic cancer. In comparing the two types of cancer, the authors reveal that women treated for breast cancer reported a significantly lower frequency of kissing their partners than did the women treated for gynecologic cancer. They speculate that the alteration in body form produced by the mastectomy may engender a reluctance among women for any type of intimate behavior that includes close body contact, such as partners holding one another while kissing. Additionally, sexual partners of breast cancer patients may feel constrained when wanting to embrace and kiss there spouse for fear they might hurt their partners physically (at the surgery site) or emotionally (by reminding her of the change in form).

Meyerowitz et al. (1999) review the multiple contributors to sexual difficulties among breast cancer survivors. The authors point out that certain aspects of treatment, such as the extent of surgery and the need for chemotherapy or hormonal therapy have been linked to sexual problems and sex-related physical symptoms. They discuss how chemotherapy has been found to be particularly disruptive to sexual functioning, perhaps in part because it causes ovarian failure and leads to a premature menopause in premenopausal women. Ovarian failure also results in decreases in estrogen and testosterone, which can lead to vaginal atrophy, decreased vaginal lubrication, and decreased libido.

Falco (1998) maintains that changes in energy, sexual desire, and physical discomfort with sexual activities can be the result of chemotherapy and radiation, feeling sick, being in pain, and taking pain medications. Referring to changes in breast sensitivity in particular, she explains that many changes in breast sensation are possible after the various treatments for breast cancer. The author points out that surgical scars can either be painful or numb, and that erogenous areas are often lost through surgery. She adds that radiation treatment can also change the skin's response to touch, sexually and otherwise.

A study on the factors influencing the sexual life of women affected by breast cancer suggested that the subjective sexual experiences of women with breast cancer are influenced by the patient's age (Ghizzani et al, 1995). For the younger women, adjustment to the illness and the needed treatment appeared to depend on the quality of the marital relationship, and, for the menopausal patients, on a more extended network of emotional support.

Numerous researchers note that marital strain- including sexual difficulties- has a negative influence upon child functioning (e.g., Armsden & Lewis, 1994; Lewis et al., 1989; Lewis et al., 1993). Kemper and Reichler (1976), for instance, found that marital difficulties have been associated with more frequent punishment of children and less effective parenting.

Mood

Breast Cancer

"She haunts my optimism and flaunts her ghostly figure of reality at my days. She lingers on horizons in dreams, where hope sees her as someone else. Perhaps just a figure of my

imagination. My illusion is transparent. Her off-white gowns flutter in morning breezes. And I whisper: Don't come back wearing gowns of black..." (Knowles, 1996, p. 141)

According to Ingram (1988), "Cancer of the breast may have a significant impact on the emotional and psychological constructs of the individual" (p. 23). The author notes that a diagnosis of breast cancer is often psychologically equated to death itself. It is not surprising then that emotional symptoms such as anxiety and depression frequently accompany the physical symptoms of the disease. In a popular self-help book for women with breast cancer (Phillips & Goldstein, 1998), patients are indeed warned that they may encounter shock and disbelief, anger, denial, depression, uncertainty, and fear when faced with their diagnosis. In addition, they are cautioned that they may experience a disruption in self-esteem, changes in their body image, self-blame, and negative thoughts.

Many experts suggest that it is also highly likely that cancer patients will experience diagnosable psychiatric conditions ranging from mild adjustment disorders to chronic major depression (Baider & Kaplan De-Nour, 1984; Barraclough, 1994; Maguire, Faulkner, & Regnar, 1993; Massie & Holland, 1989; Northouse, 1988, 1992). In fact, some researchers have estimated depression to be four times more common among cancer patients than in the population at large (Barraclough, 1994).

In a psychological treatment manual for breast cancer, Haber and her colleagues (1995) list panic, guilt, disappointment, difficulty adapting to the illness, and feeling overwhelmed as expected psychological reactions to diagnosis. The authors state that psychological reactions to the treatment itself may include increasing levels of anxiety, depression, fear, and social withdrawal. In the post-treatment period, they suggest that a woman may experience feelings of loss that come in many forms. She may experience loss of the regular contact with/ support of medical providers, loss of a sense of normalcy as she discovers that she is different than she was prior to the breast cancer experience, loss of trust in her bodily experience, loss of or change of the breast, loss of or change in sexuality and fertility, and loss of or change in the experience of motherhood as she is acquainted with the risk of death and leaving her children alone in the world.

Yes, women with breast cancer are plagued with concern not only for themselves, but also for friends and family. Guilt and self-blame for the suffering experienced by others and the burden one's healthcare places on family members- both financially and emotionally- are frequently reported by patients with cancer (Barraclough, 1994).

Relationships

"A person does not live alone, uninfluenced by anything in the present, but rather lives in a very real and dynamic context, usually that of a family or other intensively relating group." (LeShan, 1994, p.76)

In a study that asked women to disclose their concerns about having breast cancer, it was found that breast cancer patients were most concerned about the effect of their illness on people close to them (Pistrang & Barker, 1992). Weihs (1996) hypothesizes that this is in part because women are socialized from a very young age to care for others. The author asserts that "caring for themselves can seem like a disavowal of an appropriate concern for other people" (p. 90). Moreover, she maintains that when women with breast cancer need to request time and specific types of attention from others, this may represent a loss of role as "manager of family" and/ or "provider of emotional sustenance."

Haber et al. (1995) write of the numerous ways that a woman's relationships are impacted by the breast cancer experience. To begin with, the authors point out that women with breast cancer require emotional support, someone to help her make treatment decisions, and someone who can assume various caretaking roles (e.g., driving her places, helping her figure out the finances of treatment, cooking, laundry, etc.). They explain that families vary in their responses to the illness- some deteriorate, some may improve in their functioning, but most will experience considerable strain as a result of the illness and its consequences.

Families may encounter communication problems that may take the shape of arguments or of a "conspiracy of silence" in which family members maintain an attitude of forced cheerfulness. Husbands may experience emotional difficulties when their wives have breast cancer because in this culture their wives are often their sole confidants, and the illness can powerfully change this relationship. And, although various children may be differently affected by their mother's illness, they are all affected nonetheless (please refer to Appendices B, C, D, and E for information about the impact on children). Depressed parents typically have restricted response repertoires, or withdraw and reduce the frequency of their interactions with their children (Webster-Stratton & Hammond, 1988). The tendency of the cancer patient to withdraw may in turn cause others (including their children) to feel awkward and frightened, afraid to mention the illness, and afraid to approach the patient (Spiegel, 1996). Thus, isolation becomes bidirectional within the family system.

Outside of the family system, friends may feel the pressure to "say the right thing." As noted by Haber and her colleagues (1995), this can be quite difficult in that giving advice or encouraging recovery may be experienced by the patient as presumptuous, and identifying with a patient's plight (e.g., "I know exactly how you feel") may be seen as alienating or belittling.

Appendix B

The Impact of Illness on the Family System

"Mothers are the pivot on which the family spins...Mothers are the pivot on which the world spins." (Brown, in Exley, p. 8)

Doherty & Campbell (1988) describe the family health and illness cycle to include "family illness appraisal," "family acute response," and "family adaptation to illness and recovery." They explain that family illness appraisal refers to family beliefs about the illness of a family member and to family decisions about how to deal with the illness. Depending on the family's cultural and/ or religious background for instance, it may be necessary to decide whether the individual who is ill should seek professional attention or be cared for within the family's lay network. The family's acute response refers to "the immediate aftermath of illness for the family." (p. 25). This phase concerns the immediate adjustments that the family must make to deal with the illness. Especially in the case of disabling or life-threatening conditions, the family will likely undergo a period of disorganization when its normal coping patterns are not sufficient to handle the new demands. Finally, the family adaptation to illness and recovery refers to how a family unit reorganizes itself around a chronic illness of a family member, and to the ways that a family adapts after the recovery of the family member.

Danielson, Hamel-Bissell, and Winstead-Fry (1993) offer a model that describes how families meet the demands of cancer in particular. In essence, they suggest that the cancer represents a stressor. They posit that different families may be more or less vulnerable to that stressor based on the degree of life changes and other concurrent stressors. The family's level of adjustment is then mediated by their already established patterns of functioning, the nature of their appraisal of the illness stressor and its severity, their abilities to problem solve and cope effectively, and their available resources (i.e., support network).

Lewis, Hammond, and Woods (1992) developed and tested an explanatory model of family functioning with newly diagnosed breast cancer in the mother. The authors found that higher levels of experienced illness demands (i.e., illness-related thoughts, concerns, and events that the individuals experience in response to health problems) increased the patient's depressed mood, which, in turn, negatively affected their marriage. Poorly adjusted marriages then negatively affected the family's ability to problem solve and alter their behavior as the need arose. Moreover, it was discovered that the mother's level of marital adjustment directly affected the quality of her relationship with her young child. Not surprisingly, then, it was found that this negatively impacted the overall psychosocial functioning of the child.

In a study on the transgenerational development of chronic illness meanings, Seaburn, Lorenz, and Kaplan (1992) assert that there are four factors which may potentially aid in the adjustment of family systems. First of all, they argue that well-adjusted families tend to construct some positive meaning out of the illness experience. Examples of positive meanings might include a greater appreciation of life, learning to live in the present moment, and achieving a better balance between work and other aspects of one's life. Second, they suggest that families who pass positive illness meanings from one generation to another (i.e., parent to child) may benefit from the spiritual, political, or cultural elements inherent in these meanings. Third, the authors remark that stories from the past regarding illness experience create a structure for current experiences. The fourth and final idea is that illness meanings passed through families provide influences and guides for daily functioning. In sum, the authors argue that "those families who construct meanings from stories of strength and triumph find chronic illness to be less burdensome" (p. 325).

Appendix C

Developmental Differences

"The child's developmental level influenced the nature and extent of the explanations given to the child by their parents, the nature of the child's understanding, and the nature of the other demands on the children and the family."

(Hilton & Effert, 1996, p.102)

Haber and her colleagues (1995) delineate the different types of emotional experiences that may be expected of children at various developmental levels. Drawing from Haber et al.'s work, as well as others', children's common emotional responses to maternal breast cancer will be reviewed according to the following developmental stages: pre-school children, latency age children, pre-adolescence and adolescence, and young adults.

Pre-school children

Developmentally, children of this age are extremely egocentric- that is, they perceive that everything that happens in their world is either related to or caused by them (Harpham, 1997; Vasta, Haith, & Miller, 1999). Therefore, when faced with parental cancer, young children often conclude that the illness resulted from their own thoughts or behaviors (Adams-Greenly & Moynihan, 1983; Armsden & Lewis, 1993; Bedway & Smith, 1996; Couldrick, 1988, 1991; Koocher, 1974). Children not informed of the cancer-related causes of their parents' fatigue, irritability, and anger may interpret their parents as being upset with them. Moreover, it is not unusual for a pre-school aged child to feel overwhelmed by feelings of guilt and shame due to misconceptions that their own behavior or thoughts caused parental distress (Adams-Greenly & Moynihan, 1983; Amato & Ochiltree, 1986; Armsden & Lewis, 1993).

Additionally, children of this age will experience separation anxiety which may be exacerbated by the mother's own anxiety in leaving for treatment and being parted from a very young child. They may have depressive reactions to the mother's incapacity and unavailability, which may be perceived as lack of love and interest. They may exhibit resistance or over-attachment to new caretakers. It is possible that they will reject their mother because of her absences or physical changes such as bandages, new body odors, etc. They might have odd or magical fantasies about the cause of the household disruption. And, finally, they may experience anger at the changes in routine and relationship patterns. (Haber et al., 1995)

Because of the limited cognitive abilities of children of this age, they are frequently confused about the nature of their mother's illness. Prior to the experience of having a parent with cancer, the extent of most children's contact with disease has been with contagious illnesses (e.g., colds, chicken pox, etc.). Hence, young children tend to incorporate the concept of contagion as central to illness, and as a result, they believe that it is possible to "catch" their parent's cancer (Hergenrather & Rabinowitz, 1991; Lewandowski, 1996).

Furthermore, children are often confused by the seemingly contradictory nature of cancer treatment. In general, their mothers look quite healthy and normal at the time of diagnosis, but later look and feel sick as a result of treatment (e.g., hair loss, fatigue, and nausea resulting from chemotherapy). Because of this, children may attribute their mother's illness to the doctors and the treatment, believing that healthcare providers are causing- or at the very least, maintaining- their parent's illness (Armsden & Lewis, 1993; Harpham, 1997).

Latency Age Children

Strong emotional states in latency-aged children may diminish the child's ability to cope with thoughts and emotions related to their mother's cancer, and may increase the degree of threat they perceive. Temporary regression in maturity level may in turn reduce the child's capacity for self-soothing, problem-solving, or effectively utilizing available support systems (Armsden & Lewis, 1993).

Children at this developmental stage may experience helplessness, and perhaps eventual depression, when the need for mastery is thwarted by the powerful family crisis of maternal breast cancer (Haber et al., 1995). They could have guilt and anxiety about "bad thoughts" and perceive such thoughts as a betrayal of their mother, an impediment, or even destructive of her. They might experience emotional isolation due to difficulty in verbalizing feelings or in finding adults to listen to them. In addition, it is possible that children of this age might feel embarrassed at the attention that the mother's illness draws. And, finally, Haber et al. (1995) note that middle-aged children might have particular trouble dealing with doctors, nurses, hospital rules, or machines.

The empirical literature has revealed that middle-aged children face a number of fears including (but not limited to): fear of cancer symptoms, fear of treatment and its side effects, and most of all, fear of the potential death of the parent (Bedway & Smith, 1996; Brazy & Ircink, 1999; Burton & Watson, 1998; Christ et al., 1993). Additonal fears include concern for the well parent's health (Couldrick, 1988, 1991), concern for the child's own health (Couldrick 1988, 1991), fears of abandonment (Lewandowski, 1996), worries about treatment outcomes (Grandstaff, 1976; Michielutte & Diseker, 1982), and fears about expressing their feelings openly (Call, 1990).

Pre-adolescence and adolescence

Although adolescent-aged children are faced with similar concerns as younger children, their more advanced level of cognitive and emotional understanding yields distinct responses to their mother's cancer. While children of both ages experience heightened levels of anxiety, the manner in which the anxiety is expressed can differ greatly. Children are more likely to candidly express concerns, exhibit anxious behaviors, and report anxious feelings, while adolescents, on the other hand, are less likely to express their emotions in any direct or observable manner (Compas et al., 1994; Grant & Compas, 1995; Heiney et al., 1997). Similarly, both children and adolescents report experiencing anger directed toward the ill parent; however, children are more willing to try to explain why they are angry, while adolescents may instead make statements such as "I hate you" with no real explanation as to the cause of their anger (Peters & Esses, 1985; Pitzele, 1985).

Despite the "detached" and "unaffected" exterior, investigators have documented the following adolescent reactions to parental cancer: heightened aggression (Roy, 1990), greater sexual promiscuity (Harpham, 1997: Roy, 1990), increased alcohol consumption (Harpham, 1997; Roy, 1990), increased drug use (Harpham, 1997), a greater tendency to run away from home (Wellisch, 1985; Lichtman et al., 1984), marked drop in school performance (Lichtman, 1984), and increased rate of theft (Lichtman et al., 1984).

According to Haber et al. (1995), with pre-adolescents and adolescents, power struggles, anger, guilt, and feelings of abandonment may result from changes in supervision (more or less) that result from their mother's illness. They might experience a sense of infringement or unfair burden, due to the addition of new chores and responsibilities for sibling care.

There may be changes in family dominance patterns because the mother's incapacity may leave teens in a new role with their father and their siblings. This may be particularly uncomfortable for girls if they are encouraged to take the mother's former role (when the mother recovers, the return to normal may also present problems). Pre-adolescents and adolescents may feel embarrassment because of sexual associations to the breast. Additionally, they could potentially experience discomfort with the increased focus on the parent, when the teen is simultaneously striving for more distance and autonomy. They will likely feel angry at the inconvenience or disruption of social activities. This is particularly pronounced when the teen must rely on the parents for transportation.

Adolescents might experience anger at reduced financial resources and support for their extra-curricular activities. They may feel lonely or have a sense of being an outsider if friends withdraw due to their discomfort with the illness or changed routines. They could be preoccupied with their own physical appearance and may reject their mother because of changes in her appearance. They will also likely experience uncertainty about the future, especially if the mother is single.

Young Adult

Haber et al. (1995) recognizes that young adults may exhibit resistance against the perceived threat to newly developing independence from the family. On the other hand, individuals at this more advanced developmental level could display over-attachment and difficulty with separation of identity and development. They may have guilt about neglecting the parent in need. And finally, they may engage in denial in the forms of minimizing, forced cheerfulness, or refusal to acknowledge their mother as a suffering adult.

Appendix D

When a Parent Has Cancer

"A mother is she who can take the place of all others but whose place no one else can take."(Cardinal Mermillod in Exley, p. 8)

Children perceive cancer as having a unique stigma when compared to other chronic illnesses (Michielutte & Diseker, 1982). Perhaps, this in part because of the lack of control that they experience with regard to this illness. Indeed, Compas et al. (1996) reveal that children consistently reported that their parents' cancer was controlled more by external factors than by their own personal control. The authors suggest that this lack of control seems to limit children's options in terms of available coping strategies. They assert that this is reflected in low levels of problem-focused coping. In other words, with little opportunity to exert control, children engaged in very few active, problem-oriented types of coping. Instead, the researchers found that children were more likely to engage in emotion-focused coping with regard to their parents' cancer. Unfortunately, however, this type of coping was found to be largely ineffective in managing the emotional stress associated with the illness of their parent. Apparently, emotion-focused coping was related to perceptions that the cancer was more serious; that is, children who used this coping style believed their parents' cancer to be significantly more advanced in terms of stage and prognosis. Essentially, it appears that children employ emotion-focused coping as a way of disengaging from the stress of parental cancer, but these disengagement efforts may actually increase rather than decrease levels of distress.

Heiney et al. (1997) discovered that children who have a parent with cancer report significantly higher state and trait anxiety levels as compared to a normed population sample. It was found that, while adolescents manifest anxiety directly, latency-aged children seem to internalize their anxiety and express it as somatic complaints and depressive symptoms. And, according to the investigators, as parents' state anxiety increases, they are less likely to correctly judge the inner emotional state of their children and may not perceive them as being anxious.

Lewandowki (1996) notes that there is indeed cause for concern about a child's emotional adjustment when a parent has cancer. Since parental cancer poses unique threats to a child's security, it should be expected that children will be emotionally affected (albeit to varying degrees). Lewandowski points out that having a parent with cancer leads to a number of changes in the family and the child's routine. Even if children stay in their own homes, family members are often required to take on new roles and assume additional burdens. Additionally, research has found that families tend to report more difficulties in managing household tasks when the ill parent is the mother (Cohen et al., 1977).

Over time, financial concerns may be experienced in the family because of the treatment costs and because of lost income when the ill parent is unable to continue working or when the well parent takes time away from work (Lewandowski, 1996). Decreased physical and psychological availability of the parents may also have a detrimental impact on the child's sense of security. Furthermore, the child's feelings of safety and security are threatened when significant adults are extremely anxious, unavailable, and/ or change their styles of interacting with the child and family. Finally, there is substantial empirical evidence that cancer diagnoses and treatment interfere with the parents' ability to provide support, discipline, communication, predictability, attention, and empathy for their children (Armistead, Klein, & Forehand, 1995; Armsden & Lewis, 1993; Maccoby & Martin, 1983; Siegel, Nesagno, & Christ, 1990).

Christ et al. (1993) lists common fears and concerns of children of cancer patients. To begin with, children are likely to have a fear of their parent's symptoms of cancer and its treatment. As indicated by the authors, "Especially frightening to the children were the vomiting, bleeding, disfigurement, panicked shortness of breath, and mental confusion they saw in their ill parent" (p.419). Side effects of such treatments as surgery, chemotherapy, and radiation, which included loss of hair, weight, and energy were also quite distressing. It is important to note that, "because identification is such a powerful process during latency, the disturbing nature of such symptoms often resulted in somatic reactions" (p. 419).

Christ et al. also report that children are likely to experience a fear of their ill parent's death. Although children may utilize denial as a coping strategy during the early phases of their parents' cancer, it becomes increasingly difficult for children to sustain this denial when the parent develops more (and more severe) symptoms of the disease. In addition to their fear of their ill parent dying, children may also experience a fear for their well parent. According to Christ et al., children often express great concern about the vulnerability of the well parent, upon whom they come to feel increasingly dependent as the ill parent's condition deteriorates. Their anxieties are likely to be heightened by their observation of the well parent's sadness, fatigue, irritability, and anxiety.

Researchers have investigated the factors that will influence how and to what extent children will be affected by their parent's cancer. Some of the factors that have been found to be important in determining a child's emotional adjustment include: age and developmental stage, gender, cognitive abilities, individual strengths and weaknesses, previous behavioral or emotional problems, family communication patterns, number and type of other stressors experienced, reactions of significant adults, perception/ understanding of the situation, and the amount/ quality of social support available (Hoke, 1996, Lewandowski, 1992; Lewandowski, 1996; Siegel et al., 1992).

In general, negative reactions of children to the stresses engendered by their parent's cancer may include anti-social or attention-seeking behaviors, changes in school performance, physical symptoms, regressive or anxious behaviors, changes in socialization, and changes in mood (Lewandowski, 1996). Other behavioral consequences may take the form of changing interactions with family members, peers and teachers at school, and individuals within the community (Christ et al., 1993). More severe reactions to parental cancer could potentially include strong, frequent, and persistent bursts of anger, sadness, and anxiety; suicidal thoughts; severe and prolonged decline in schoolwork or school behavior; severe and prolonged conflict with parents; and intense somatic symptoms (Christ et al., 1993).

Appendix E

Gender Differences in Coping Styles

> *"Indeed, we humans are all both strong and weak...Occurring at the same time, or during different waves of our lives, we are strong and we are weak."*
>
> *(Falco, 1998, p. 15)*

From the moment children are born, they are both literally and figuratively wrapped in a blanket of gender stereotyping. Girls are wrapped in pink and boys in blue, and from then on they begin to learn what it means to be a girl or boy. According to Bem's gender-schema theory (1985), children use gender as a cognitive organizing principle in order to structure and guide their perceptions of reality. In other words, they are particularly likely to organize information about themselves and the rest of the world according to the definitions of femaleness and maleness that are found in our society. From a very young age, children learn that males are supposed to be "strong" and females are supposed to be "weak." They learn that females are supposed to be "nurturing" and males are supposed to be "tough." They learn that men are supposed to be guarded and that it is acceptable for women to discuss their feelings at length with others.

Moos and Schaefer (1984) review the major types of coping skills available to both males and females: appraisal-focused coping, problem-focused coping, and emotion-focused coping. Appraisal focused coping may include logical analysis and mental preparation, cognitive redefinition, and cognitive avoidance or denial. Problem-focused coping is said to take the form of seeking information and support, taking problem-solving action, and identifying alternative rewards. Finally, emotion-focused coping typically entails affective regulation, emotional discharge, and/ or resigned acceptance. It has been discovered that females, on average, tend to utilize more emotion-focused coping strategies than their male counterparts. Males, on the other hand, are more likely to utilize problem-focused or appraisal-focused styles of coping.

Another useful way of categorizing coping strategies is through an "approach-avoidance" distinction. According to Roth and Cohen (1986), approach and avoidance are "simply metaphors for cognitive and emotional activity that is oriented either toward or away from threat." The authors posit that there are costs and benefits to both approach and avoidant styles of coping. In regard to avoidance (denial, repression, blunting, etc.), they maintain that such strategies can serve to reduce stress and anxiety and allow for gradual recognition of threat. In other words, if one "doses" oneself with threatening material, in a way, that prevents it from becoming overwhelming. Furthermore, they argue that partial, tentative, or minimal use of avoidance can lead to increased hope and courage to deal with threatening material in the long-term. Essentially then, the benefits of avoidance are those effects that work to facilitate approach-style coping strategies. The costs of avoidance strategies include interference with appropriate action/ problem-solving, emotional numbness, disruptive avoidance behaviors (e.g., restricted activity, avoidance of certain stimuli, etc.), and a lack of awareness of the relationship between psychological symptoms and the threat or stressor.

The positive opportunities offered through the use of approach strategies (i.e., seeking information, seeking support, problem-solving) include the ventilation of affect, the assimilation and resolution of the trauma or threat (i.e., maternal cancer in this case), and the ability to problem-solve and select an appropriate action to address the source of the stress. Negative consequences associated with approach strategies could be increased distress and/ or nonproductive worry.

In general, researchers have found that individuals who rely more on approach strategies and less on avoidance strategies tend to experience better health and well-being (Moos, 1997) and have generally been found to be better emotionally adjusted overall (Ebata & Moos, 1991). Although it has been found that girls have significantly higher values in approach-oriented coping than boys (Kavsek & Seiffge-Krenke, 1996), research has also indicated that girls tend to employ emotion-focused coping strategies more commonly than boys- a technique that some experts suggest is ineffective when dealing with a stressor such as parental cancer (Compas et al., 1996).

In a review of the literature, it has been found that adolescent daughters experience higher levels of distress (Compas et al., 1994), more symptoms of anxiety and depression (Grant & compass, 1995), more strain on the parent-child relationship (Brazy & Ircink, 1999), greater hostility (Lichtman et al., 1984), and a higher incidence of adjustment problems (Wellisch et al., 1992) than do sons of cancer patients. Experts have posited a number of plausible explanations for these findings:

1) A large proportion of parental cancer is breast cancer; therefore, heritability concerns may induce heightened levels of distress in daughters as they become aware of their own risk (Armsden & Lewis, 1993; Compas et al., 1994; Harpham, 1997).

2) Social mores dictate that daughters should take on additional household responsibilities, such as housework and care for younger siblings, thereby leading to

increased levels of distress (Armistead, Klein, & Forehand, 1995; Compas et al., 1994; Lewandowski, 1996).

3) Females are more likely than males to employ ruminative coping strategies (i.e., emotion-focused), which are correlated with increased rates of depression (Compas et al., 1996).

4) Daughters are more frequently expected to provide emotional support to both the ill parent and the well parent than are sons, leading to demands that the daughters may feel unable to meet (Lichtman et al., 1984; Wellisch et al., 1992).