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Daughters of Women With Breast Cancer:
Living In Fear

by

Debra Carolyn Walsh ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of Master of Science

in

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ABSTRACT

This qualitative phenomenological study discussed the experience of daughters of women with breast cancer. In-depth interviews were conducted on 6 women interested in sharing their "stories". A descriptive interpretive phenomenological approach was utilized. The overall themes were described as: *The fear that never goes away* and *More fear: the second diagnosis.* The sub-themes included: *Keeping it together for mom, Experiencing vulnerability: What if it happens to me?, Breast exams: The terror of finding something, Feelings of terror: Mom might die,* and, *Changing of roles: It feels so backwards.* Two additional themes reflected the daughters' experience from a more positive perspective. *Moments of intimacy: Mom and me,* and finally, *Admiring mom: How can she be so strong?* Implications for practitioners and health professionals are discussed. Particular attention was given to the immediate needs of daughters during their mothers' diagnosis and treatment.

This thesis is dedicated to……

Nate and Jayna, whose patience has been unending not only through this masters degree but also my undergraduate degree.

Doug, whose belief in me has propelled me to push on at times when I've wanted to coast.

My loving friends and family who believed I could do this.

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CHAPTER I

Statement of the Problem

Breast cancer diagnosis among women has risen over the past three decades, yet mortality rates have declined steadily since 1986 and particularly since 1990. This may be due to many factors including the benefits of screening programs and improved treatments. During their lifetimes, 1 in 9.5 Canadian women are expected to be diagnosed with breast cancer. This is up from 1 in 13 in 1977. Of those women afflicted, 1 in 26 are expected to die of breast cancer (Canadian Cancer Statistics, 2001*)*. It is the most common cancer for women (excluding non-melanoma skin cancer). Twenty-three percent of breast cancer cases occur in women under age 50, 46% occur in women aged 50-69, and 32% in women aged 70 and over (Canadian Cancer Statistics, 2001).

Women, as well as other members of society such as partners, husbands, moviemakers, and novelists, attach significance to women's breasts, particularly in our North American culture. Thus it is not just a personal matter to be concerned about breast cancer and its effects. Simply hearing the term breast cancer often elicits a wide range of distressing thoughts and feelings for women. As one woman hears of another woman diagnosed with breast cancer it may trigger her own sense of vulnerability. She may question whether the woman had a history of breast cancer, whether she followed good self-care practices and whether she conducted self-breast examinations. It seems that many persons search for reasons and explanations for the occurrence of breast cancer for others or for themselves. If we have not ever been diagnosed with breast cancer, we may secretly hope that it will never happen to us.

Breast cancer does not just have a personal impact; it also has a family impact. Researchers have identified many family aspects of the disease including the impact on intimate partners, children and even siblings of the patient (Hilton, 1996; Lewis, 1996; Lichtman, Taylor, Wood, Bluming, Dosik & Leibowitz, 1984; Wellisch, Gritz, Schain, Wang, & Siau, 1991, 1992). Because of the increasing number of women who delay childbearing until later in life, more young children are likely to experience the effects of their mother's breast cancer (Howes, Hoke, Winterbottom, Delafield, 1994). According to Canadian Cancer Statistics (2001), a woman's risk increases across all ages until age 80. There is also considerable evidence that the risk of breast cancer increases for women who have a family history of the disease, particularly a first degree relative, thus it is not surprising that daughters of women with breast cancer may be particularly affected (Canadian Cancer Statistics, 2001; Gilbar & Borovik, 1998; Lichtman, et al., 1984; Wellisch, Hoffman, & Gritz, 1996).

The mother-daughter relationship creates natural interpersonal links. There is not only a genetic link, but a daughter has other anticipated connections to her mother. Her mother models the female role such as helping her daughter take on life changes like menstruation and childbirth. Her mother provides the anticipatory socialization for aging and the changes associated with aging such as the acquisition of gray hair, weight gain, hot flashes and other life changes. Mothers also may become the model for care-giving and as daughters age themselves they begin to anticipate that some day, usually long in the future, they will be able to return that care-giving to their mother.

These natural links between mother and daughter may provide the sources of a wide range of responses when a mother is diagnosed with cancer. For example, when breast cancer affects a mother in the family, daughters may respond with fear because they are reminded of their own vulnerabilities. We often live as if we have many tomorrows, yet, there are no guarantees. We may expect good things to happen, yet breast cancer can interrupt the hoped for expected life. The glaring realities of life challenges such as unexpected illness continue to bombard us with the fact that life never stays the same. We are not as safe as we thought we once were.

I am mindful of these vulnerabilities as I face the second half of my life. I cannot deny the possibility that I might be faced with some type of life challenge with my own mother. Just observing the realities of breast cancer for other women provides a sense of vulnerability to me. There seems to be a sense of vulnerability that was not there before. Considering the complexities and the power of the mother daughter relationship I continue to wonder: What is it like to be a daughter of a woman who has experienced breast cancer? What kind of responses and feelings does this experience generate in the daughter?

A research topic emerges in various ways. During the time that I was doing my masters degree course work I had the opportunity to be involved in a practicum where I explored the support systems available to women who had been diagnosed with breast cancer. I was involved in a weekly support group where women shared their experiences of having breast cancer and how they personally coped. This was the start of a personal journey of my wondering about the experience of breast cancer for the daughters as well as the mothers. The realities of the many family impacts of breast cancer led me to reflect about the manner in which a life threatening disease like breast cancer may affect family members who are closely connected to that patient.

It was within this support group that I had the opportunity to meet a woman in her twenties who had been diagnosed with breast cancer. This was of particular concern for her as both her mother and grandmother also had experienced breast cancer. I listened weekly as this young woman endeavored to sort through the fact that what had happened to her mother and grandmother was now actually happening to her. Her greatest fear had now beset her. She had opted to have a double mastectomy due to her strong familial pre-disposition. While I had met her after her own diagnosis, I wondered week-to-week how she coped with her mother and grandmother's disease both before and after her own diagnosis. As the weeks passed, I listened to her story and wondered again what it was like to be a daughter of a woman with breast cancer.

As I explored this question further, I discovered that there were few resources for daughters of women with breast cancer to handle such an experience. This concerned me as I pondered what I would do if I were a daughter whose mother had breast cancer. I wondered how this would affect my life and my relationship with my mother. How would I love and care for my mother during this experience, and still have the emotional energy to handle my concerns?

The research literature provided some insight about daughters' reactions to mothers' experience of breast cancer. Some of the topics that had been explored included: 1) daughters' psychological stress (Wellisch, et al., 1991; Wellisch, et al., 1992; Wellisch & Lindberg, 2001),

2) daughters' overestimation of risk to breast cancer (Black, Nease, Tosteson, 1995; Esplen, Toner, Hunter, Glendon, Liede, Narod, Stuckless, Butler, & Field, 2000; Gagnon, Massie, Kash, Gronert, Simkovich Heerdt, Brown, Sullivan & Borgen, 1996; Lerman, Lustbader, Rimer, Daly, Miller, Sands & Balshem, 1995; Phillips, Glendon, & Knight, 1999; Lichtman, Taylor & Wood, 1984; Wellisch, et al., 1991; Wellisch & Hoffman, 1992; Wellisch & Lindberg, 2001), 3) daughters' uncertainty (Hilton, 1987, Hilton, 1989; Hilton, 1993; Kash, Holland, Halper, & Miller, 1992; Lewis, 1986; Rees, Fry & Cull, 2001), 4) daughters' beliefs that things will work out for themselves in the future (Gilbar & Borovick, 1998; Wellisch, et al., 1992; Wellisch & Lindberg, 2001), 5) daughters' dealing with intrusive thoughts (Baider, Ever-Hadini, Kaplan & De-Nour, 1999; Bowen, McTiernan, Burke, Powers, Pruski, Durfy, Gralow & Malone, 1999; Lerman, et al., 1993; Zakowski, Valdimarsdottier, & Bovbjerg, 1997) and 6) the nature of the mother-daughter relationship (Lichtman, et al., 1985; Wellisch, 1979; Wellisch, et al., 1991). The methods for these research studies tended to be quantitative with data collected through surveys. The literature was often limited to studying a daughter's reactions to their mother's breast cancer. Daughters were rarely allowed to tell their own stories and to focus on their own interests and concerns.

There appeared to be a gap in understanding daughters' everyday experiences after their mother had been diagnosed with breast cancer and in particular studying them from an emic perspective. After reviewing the literature I concluded that more insight was needed on the everyday experiences, views and responses of daughters of women with breast cancer. Such insight would best be provided by allowing daughters to tell their own detailed stories about their beliefs, fears, joys, and sorrows of living with this situation. Such information is not only important to the women themselves, but to the educators and health care providers who can potentially assist daughters in handling these situations. By listening to daughters and their stories we will gain greater understanding of their experiences. As family and health practitioners continue to gain insight into these daughter's experiences, they will be able to offer more responsive support and educational programs.

Statement of the Problem

The purpose of this study was to explore the real life experiences of daughters of women who have been diagnosed with breast cancer using a phenomenological approach that allows a rich exploration of the thoughts, feelings, and experiences of these women. A small group of daughters shared their stories about living with the circumstance of breast cancer of their mother. The research question that guided this study was as follows: What is it like for a daughter to have a mother with breast cancer? The following chapter will include a detailed review of the relevant literature related to the familial impacts of breast cancer with special consideration of research dealing with daughters' experiences.

CHAPTER II

Research Review

A literature review was conducted to examine existing research regarding daughter's experiences of women with breast cancer. Because some experiences of daughters may be similar to other family members, the discussion begins by reviewing the literature that explores family and spousal reactions to cancer. The following section includes a description of relevant literature dealing with daughters of mothers with breast cancer. The majority of the research focused on psychological risk and coping of daughters. These risks included studies of psychological distress, overestimating risks, increased vulnerability and uncertainty, depression, loss of a sense of coherence and disturbed long range life plans, coping processes and increased intrusive thoughts. Literature dealing with coping processes for daughters is also discussed. The final section includes a discussion of literature related to changes in the mother daughter relationship as part of the breast cancer experience.

FAMILY REACTIONS TO CANCER

Having a family member with a life-threatening disease such as breast cancer can be a stressful experience. In fact, cancer may become an interpersonal crisis for patients and for those who love them (Biegel, Sales, Schultz, 1991; Hilton, 1994; Hilton, Crawford, & Tarko, 2000; Hough, Lewis, & Woods, 1991; Sales, Schulz, Biegel, 1992*)*. There has been a large body of literature that has explored the impact of different types of cancer on the family system (See for example, Balogh, 1999; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hilton, 1993; Holland & Lewis, 2000; Lewis, 1986; Lewis, 1996; Lewis, Woods, Hough, & Southwick Bensley, 1989; Rolland, 1993; Sales, 1991; Sales, Schulz, & Biegel, 1992; Weingarten & Weingarten Worthen, 1997*)*. This literature has been generated from researchers within the medical community, (e.g. nurses, doctors and other health professionals) as well as from family scholars (e.g. psychologists, human ecologists, family scientists and sociologists). The following summarizes some of the key findings from this broadly based literature.

According to Rolland (1993), mastery is maintained in the face of uncertainty by acknowledging possible losses, sustained hope, building flexibility, and adjusting major goals. A common and difficult situation that cancer patients and their families must face is learning to live with cancer and the uncertainties it effects. Cancer disrupts normal family equilibrium and life no longer is predictable. Family disruption and perceived life threat have a negative affect on usual patterns of family life (Hilton, Crawford, & Tarko, 2000). Where family members once felt somewhat in control of their lives, they suddenly feel a sense of helplessness as worry sets in (Hilton, 1993). Family members strive to give support to the patient yet they often find they too need support.

Cancer poses enormous physical and psychological challenges from the moment it is first suspected (Hilton, 1994; Northouse, 1992). Learning to live with a loved one's cancer may be more difficult than living with one's own diagnosis of cancer. Depending on their perceptions of stressful situations, cancer patients and their families may react in various ways to the cancer's extended and unpredictable disease course (Balogh, 1999 & Biegel, Sales, Schultz, 1991; Hilton, 1993). Denial, anger, depression and fear are often predictable crisis reactions (Biegel, Sales, Schultz, 1991). Life goes on and daily issues still need to be handled. Family members often endeavor to make their lives more certain and more manageable (Ben Zur, Gilbar, & Lev, 2001; Hilton, 1994; Hilton, Crawford, & Tarko, 2000; Hough, Lewis, & Woods, 1991; Leventhal, Leventhal, & Van Nguyen, 1985). According to McCubbin and McCubbin (1993), families often face a life-threatening disease with an "innate reaction to fight, to remain stable, and to resist changes in the family's established patterns of behavior" (p. 59). They face the challenge of adjusting and adapting to cancer.

Coping with uncertainty and demands associated with cancer may draw families together or push them apart (Hough, Lewis, & Woods, 1991). Coping for family members becomes more difficult as it interferes with their abilities to assess situations (Hilton, 1993). For example, some individuals may focus only on cancer and ignore other issues and responsibilities. The opposite is also true where family members may choose to ignore cancer and its effects and focus on issues that are less threatening. Families who are able to view breast cancer in a positive light tend to adjust better (Hough, Lewis, & Woods, 1991; Rolland, 1993). When individuals are able to construct positive meaning from the illness experience they also tend to adjust better (Hilton, 1994; Hough, Lewis, & Woods, 1991). Family members may also begin assessing their own priorities and meaning of their lives under these circumstances.

It is important to realize that family members' responses to crisis are interactive and dynamic with each member actively seeking to control their environment and meet their day-to-day responsibilities. The impact of cancer on the day-to-day activities within the home depends somewhat on which family member is the patient. When the patient is the mother, cancer may have a major impact on the home as the woman may be forced to relinquish or share household or child-care responsibilities because of cancer treatment. This may be particularly true when dependent children are at home.

Lewis (1986) conducted a critical analysis of the research literature to that date regarding the impact of cancer on the family. He found that families were effected in the following ways: physical demands, emotional strain, fear of the patient dying, uncertainty, altered roles and lifestyles, financial stress, ways to comfort the patient, altered sexuality, altered roles and lifestyles, perceived inadequacy of services, existential concerns, and non-convergent needs among household members. Although the analysis of the literature is not recent, it seems that the issues families face are similar even a decade and a half later.

FAMILY REACTIONS TO BREAST CANCER

The family of a woman with breast cancer experiences a variety of psychological and social challenges as well as interpersonal challenges (Given & Given, 1992; Lewis & Hammond, 1992; Northouse, 1992; Northouse, 1994; Weingarten & Weingarten Worthen, 1997; Zahlis & Shands, 1993). At diagnosis the demands of breast cancer are superimposed on the normal demands of family life (Lewis, 1996; Northouse, 1994). The effects of breast cancer on family members are experienced in various ways. The impact of breast cancer is reported to be equal if not greater on the family caregiver as on the patient, in particular when examined over time (Balogh, 1999; Given & Given, 1992; Hilton, 1993; Hilton, 1994; Northouse, 1992).

Not only do family members deal with the disease itself, but also with the contemplation of losing the woman to breast cancer (Balogh, 1999; Northouse, 1992). Family members may often feel a lack of social support and isolation as the focus tends to be primarily on the woman with breast cancer (Balogh, 1999). Family members also find themselves adapting their lifestyles to meet the daily pressures of the woman's breast cancer which includes balancing home and work responsibilities (Balogh, 1999; Lewis, 1996; Northouse, 1992; Northouse, 1994) and also in being sensitive to the woman's emotional needs (Northouse, 1992; Zahlis & Shands, 1991).

Although research shows that over time families experience significantly lower levels of illness-related demands, the levels of the woman's depressive moods negatively affect family functioning (Lewis, 1996; Lewis & Hammond, 1992). Family members face the challenge of not only managing their own lives during the crisis but also responding to the demands placed upon them because of the woman's breast cancer (Lewis, 1996).

Family members identified normalization as a major family coping strategy (Hilton, 1996). Normalization is viewed as a process of developing strategies that are used to minimize the effects of the impairment while still recognizing the seriousness of the situation and the possible dangers. Hilton

(1996) proposed to describe the process of normalization as it emerged from a study of families coping with early stage breast cancer. She conducted qualitative research with fifty-five women diagnosed with breast cancer and their families using a grounded theory methodology. Hilton found that daughters of women with breast cancer identified normalization as a major family coping strategy in dealing with breast cancer.

Several authors also suggested normalization may assist in reducing family stress (Hilton, 1993, Hilton, 1996; Holland, 1998; Rolland, 1993; Rowland & Holland, 1989). The families' sense of normalcy was dependent on family factors such as life stage, experiences with illness, and flexibility. They described normalization as "being normal", "getting back to normal," and "doing normal things". Families varied in what normal meant to them yet there was a common theme of wanting things to return to every day life (Hilton, 1996). Perception of the cancer and intrusiveness of treatments were also important factors in determining families' use of coping strategies. In general, families were seeking a desired state that was stable, safe, and free of health problems.

Hilton's findings suggested that having a positive attitude is important in maintaining some sort of normalcy and reducing stress for family members. It was proposed that what was normal for one person may not be normal for another. In most cases, family stress was reduced by maintaining a positive attitude and by keeping things as similar as possible or getting them back to normal.

Rolland (1993) also suggested that families who viewed problems as normal rather than "problem-free" had a distinct advantage in maintaining a positive identity in the face of chronic illness. This positive view may also be useful in obtaining outside help. Families with high standards and strong beliefs in high achievement may find a loss of control and are not able to apply their high standards to a situation of chronic illness. In situations of long-term adversity, hope is sustained through developing flexibility in one's definition of normality (Rolland, 1993).

SPOUSAL REACTIONS TO BREAST CANCER

Most literature in the past fifteen years that has studied specific family members' reactions to breast cancer has focused on the reactions of the spouse (See for example, Ben-Zur, Gilbar, Lev, 2001; Biegel, Sales, Schultz, 1991; Hilton, 1994; Hilton, Crawford, & Tarko, 2000; Hough, Lewis, & Woods, 1991; Northouse, 1989; Sales, Schulz, Biegel, 1992; Samms, 1999). Cancer has a major effect on husbands that is magnified when wives require aggressive chemotherapy and when dependent children are involved (Hilton, Crawford, & Tarko, 2000; Wilson & Morse, 1991).

Husbands find themselves actively engaged in fighting cancer as well as dealing with family life challenges. Men often put their own needs on hold, in an attempt to keep family life as normal as possible (Hilton, Crawford, & Tarko, 2000; Wilson & Morse, 1991). Their focus is on their wives and families. Often it is frustrating, as they would love to fix the situation, but are unable to do so. Spouses face juggling most or all of the family responsibilities that include:

household, childcare, work, and finances, while usually holding down a full-time job (Holland, 2000).

These studies concurred that breast cancer can have a very stressful impact on the spouse's emotional well-being. The studies indicated that husbands of breast cancer patients reported such things as sleep disturbances and eating disorders (Wellisch, Jamison, & Pasnau, 1978) as well as increased distress, anxiety and depression, sometimes at levels similar to that of their wives (Northouse & Swain, 1978, Maguire, 1981). One of the most difficult aspects of handling a wife's diagnosis of breast cancer for husbands was to help their wives deal with the emotional impact of the disease (Zahlis & Shands ,1991; Gotay, 1984, Wilson & Morse, 1991). Maintaining a "brave front" to protect their wives took an emotional toll on husbands (Sabo, Brown & Smith, 1986). It took extra work to maintain a less than real facade, and communication between partners was limited about essential aspects of the disease and their relationship.

Fewer studies have focused upon younger aged women and their partners (Baider & Kaplan-DeNour,1988; Northouse & Swain, 1987; Northouse, 1989; Lewis, et al.,1989). Of the few studies conducted with this group, they have tended to suggest that age alone does not make a difference in the husband's reaction to a wife's breast cancer. Younger husbands, however, may have very different stresses in their lives and less "family history and support" to buffer them from the challenges of this situation (Northouse, 1994).

An increased number of qualitative studies are providing insights into the daily experiences of spouses of breast cancer patients. For example, in a recent qualitative study, Hilton, Crawford, & Tarko (2000) explored men's experience of their wives' breast cancer. The husbands shared how their wives' breast cancer impacted them and their families. Hilton et al. (2000) interviewed 11 male partners to find what facilitated and hindered the family members' coping. Men were found to have reacted to their wives' cancer with shock, disbelief, depression, fear, anger, and feelings of being overwhelmed and consumed by the situation. The two themes that were identified were focusing on the family to keep life going and focusing on a wife's illness and care. The first theme tended to focus on the men's children while the second focused on their wives. Nine sub-themes were identified: relying on health care professionals, being there, being informed and contributing to decision making, helping out and relying on others, trying to keep patterns normal and family life going, being positive, adapting work life, managing finance, and being positive.

The men in the Hilton, Crawford, & Tarko study experienced their children as worried, anxious, sad and often more dependent. School-age children tended to be of the most concern. Adult children were also fearful and concerned. One father recalled his daughter's response to her mother's diagnosis, "Oh, my God, that increases my chances of getting cancer." Overall, most men in the study felt unprepared, and struggled with not knowing what to do or how to behave. They faced dealing with their mates' emotional and physical needs while performing usual tasks in the family and assuming new responsibilities (Hilton, 2000).

Some research on marital relationships of breast cancer patients was generated on a belief that there would be severe strains to the marriage and sexual relationship and that this might result in divorce. Research on marital relations of breast cancer patients has not supported this view (See for example, Northouse, 1994; Lewis & Hammond, 1992; Morris, Greer, & White, 1997; Carter, Stoddard, & Silliunas, 1993). Couples who were experiencing breast cancer are no more likely than couples in the normal population to divorce (Northouse, 1994). This does not mean that there are no strains in the relationship that are exacerbated by breast cancer. It is estimated that about one quarter of couples experience some sexual problems following a breast cancer diagnosis (Wellisch, et al,, 1978; Maguire, 1981). Those couples with sexual problems before a diagnosis report the greatest strain. Another area of marital strain reported in the literature was communication problems, particularly those dealing with communicating about the illness.

There are many areas with respect to spousal responses to breast cancer that remain to be explored including the exploration of younger couples, those couples who have been married for a second time, and those who have been married for a short time. Northouse (1994) suggests that more research is needed to address the developmental stage of the marriage and how that affects adjustment to the impacts of breast cancer.

IMPACT OF BREAST CANCER ON CHILDREN

For a long time breast cancer was viewed as a disease that affected older women, who if they had children, were no longer responsible for their care. This probably contributed to the fact that it is only within the past 20 years that research on the impact of cancer on children has emerged (Armsden & Lewis, 1994; Balogh, 1999; Howes, Hoke, Winterbottom, & Delafield, 1994; Issel, Ersek, & Lewis, 1990; Lewis, 1996; Lewis & Hammond, 1992; Lichtman, et al., 1984; Northouse, 1994). The research included a study of the relationship between mother and child (Lichtman, et al., 1984), and psychosocial effects of breast cancer on children (Armsden & Lewis, 1994; Howes, 1994). Children tended to adjust behaviorally (Armsden & Lewis, 1994; and Howes, et al., 1994) and yet experienced lower self-esteem as a result of their mother's breast cancer (Armsden & Lewis, 1994).

Lewis, Ellison and Woods (1985) studied the impact of a mother's breast cancer on children at three age levels: 7-10 years, 10-13 years and 14-19 years. Not surprisingly, they found that there were differences in children's response depending upon their age and developmental stage. Younger children were more concerned about their family staying together; whereas older children worried about how the illness disrupted their family life and added household chores to their tasks. Adolescents had struggles about seeking independence while feeling responsible for helping their parents.

Issel, Ersek and Lewis (1990) explored the ways in which school-age children coped with their mother's breast cancer. Eighty-one children were interviewed aged 6-20 years of age whose mothers had been diagnosed with breast cancer within the past two-and-a-half years. Children used four types of strategies in dealing with their mothers' breast cancer: they acted as though they were “in their mothers’ shoes”, they carried on “business as usual”, they “tapped into group energy”, and they “put their mother’s illness on the table” (talking about their feelings).

When acting as if they were in their mothers’ shoes, children tried to anticipate what their mothers would want if they were in the mother’s shoes. Business as usual included many strategies of doing activities in the usual and customary manner along with putting the mother’s illness out of their minds and to carry on with life as best as possible. The children tapped into others as resources during their mother’s illness, which was having some form of family time where this aided them in coping. And finally, the children shared their getting their thoughts and feelings out in the open. Both personal reflection as well as family discussion maintained this response. Many of the children in this study expressed the importance of normal family activities during their mother’s illness.

The research review thus far has explored both general family, spousal and children’s overall reactions to breast cancer. Next, I will focus on the literature that deals specifically with daughters of breast cancer patients and how they face similar, if not more difficult challenges.

DAUGHTERS REACTIONS TO BREAST CANCER

Daughters of women with breast cancer are a heterogeneous group of women with a variety of family circumstances, a variety of pre-dispositions, risk factors, and family experiences. As this group of women is heterogeneous, it is not surprising that research completed to date notes a variety of responses. The research regarding daughters' reactions to breast cancer has included studies about coping with psychological distress, overestimating personal risk, dealing with vulnerability and uncertainty, handling long range life plans, coping processes and managing intrusive thoughts.

Psychological Distress

One characteristic response of daughters that has been reported consistently is psychological distress. Daughters who have a family history of breast cancer show more signs of psychological distress than do women with no history of breast cancer (Wellisch, et al., 1991; Wellisch & Lindberg, 2001).

Psychological reactions of daughters to mother's breast cancer have included these four themes: 1) a sense of guilt in not devoting sufficient time and attention to the mother, 2) unresolved grief/depression, usually in regard to the mother, 3) fear of death or identifications with a mutilated body image, and 4) a decrease in self-esteem when failing to conduct effective breast health practices resulting in immobilizing guilt or anxiety (Kelly, 1987). Other reported psychological responses were ones directed to external sources such as anger towards the medical profession regarding latency in diagnosis and treatment outcomes, and denial (Kelly, 1987).

The daughter's age at the diagnosis of her mother's illness has been reported to be one important factor in understanding her responses. Some of the research dealing with children's responses to breast cancer has touched on the responses of adolescent daughters specifically. Women who were adolescents when their mothers were diagnosed reported significantly more emotional upset than younger or adult aged daughters (Wellisch, et al., 1992). These greater feelings of discomfort about their mothers' illnesses may be due to two potential factors. The first factor may be that adolescents are emotionally vulnerable because of separation/independence issues. Another factor is that the daughters' emerging sexual development may coincide with the mothers' illness. Thus, Wellisch and colleagues (1992) speculated that the adolescent daughter might associate breast development and maturity with illness, body image, and possibly death. The mother's disease may also be a threat to the daughter's self-esteem, emotional growth and identity.

For example, Lichtman and colleagues (1984) reported that adolescent daughters experienced more relationship problems with their mothers who had breast cancer than did older daughters. These adolescent daughters were more distant, more defensive and more argumentative than were sons. One reason suggested for the more frequent and diverse problems of daughters as compared to sons was that daughters felt more at risk by their mother's breast cancer than sons. Another possible reason for a greater frequency of mother-daughter strain was that mothers might lean on their daughters for support more heavily than they do on sons. These researchers viewed the mother's demands on the daughters for support as well as her fear of inheriting breast cancer as a major contributing factor to the difficulties experienced by adolescent daughters. Apparently the adolescent girls' reactions to their mothers' breast cancer involved excessive fear for their mothers' lives rather than withdrawal and hostility that was evident in older girls.

Overestimation of Risk

Past research showed that daughters of women with breast cancer demonstrated a high level of breast cancer worries and a persistent overestimation of perceived risk for breast cancer (Esplen et al., 2000; Lerman, et al., 1995; Phillips, Glendon, & Knight, 1999*)*. Women who perceived themselves to be at high risk of developing breast cancer tended to overestimate rather than underestimate their risk of breast cancer (Black, Nease, Tosteson, 1995; Esplen et al., 2000; Lerman et al., 1995; Wellisch et al., 1991; Wellisch & Hoffman, 1998; Wellisch & Lindberg, 2001).

Daughters' beliefs and attitudes were affected by whether or not they had a family history of breast cancer. For those daughters who were high-risk, there was a tendency to actually over-estimate this risk (Black, Nease, & Tosteson, 1995; Esplen et al., 2000; Lerman et al., 1995; Wellisch et al., 1991; Wellisch & Hoffman, 1998; Wellisch & Lindberg, 2001). Daughters at high-risk (when she had at least one first-degree relation: (daughter, sister, or mother) diagnosed with breast cancer) as compared to low-risk women (those without a history) had greater feelings of susceptibility to breast cancer (Wellisch, et al., 1991). Women who were at high-risk reported the most psychological difficulties and reported feeling like a "walking time bomb" (Gagnon et al.,1996).

This overestimation of risk may continue over time, even when counseling is attempted to help women more accurately determine their risks. Lerman and colleagues (1995), in a quantitative study, examined 200 women aged 35 years and older who had a family history of breast cancer. After 3 months of individualized breast cancer risk counseling they found that two thirds of women continued to overestimate their risks of breast cancer. The counseling was found to be less effective for women who experienced frequent and intrusive thoughts about breast cancer. Those women who were most preoccupied with breast cancer were the least likely to improve their personal risk comprehension following the receipt of more accurate risk information. Lerman and colleagues suggested that the women's high levels of mental stress interfered with their comprehension and attention to the risk information as well as they did not believe the risk data that was presented to them.

In another quantitative study, Gagnon et al. (1996) examined perceptions of breast cancer risk and distress in 94 women at high risk of developing breast cancer. Women completed 3 self-reported questionnaires. It was found that 76% of the group of high-risk women overestimated their risk of developing breast cancer by at least doubling their actual risk as measured with empirical risk tables. Risk perception was found to be dependent on a person's myths and beliefs about cancer, heightened media attention, an anxious and preoccupied coping style, intrusive thoughts about developing breast cancer, and the familial experience of cancer (Esplen et al., 2000).

The women at high risk for breast cancer (one or more first-degree relatives with breast cancer) may be affected in regards to their breast cancer risk and the impact of this information on their surveillance behaviors and psychological stress. Kash, Holland, Halper, and Miller (1992) studied 217 women with a family history of breast cancer regarding psychological distress and their surveillance behaviors. The participants completed a questionnaire regarding health beliefs and behaviors, psychological distress and social support. The researchers found that women who perceived their risk to breast cancer as being high felt that they could do little about developing breast cancer and had high anxiety. They suggested that being at high risk may deter a woman from initiating surveillance behaviors and may increase women's fears of breast cancer. Kash et al. (1992) suggested that women who think they will definitely get breast cancer have a sense of powerlessness and believe that there is little they can do to decrease their chances of developing the disease.

Uncertainty

Uncertainty is another psychological challenge reported by daughters of breast cancer patients. Hilton (1993) defined uncertainty as a cognitive state where an event cannot be adequately defined or categorized due to lack of information. Life threatening situations may be ambiguous because information is incomplete, unclear or not understood. Uncertainty is a major source of stress for critically ill individuals and their families (Hilton, 1996). Uncertainty relates to the patient's prognosis, the outcomes of the disease's treatment or recurrence, future vulnerability, and the family member's inability to predict the future disease course (Lewis, 1986).

Uncertainty may also relate to being in doubt, not feeling safe, being undecided and not being able to rely on someone or something (Hilton, 1993). Uncertainty increases a sense of helplessness and limits the individual's sense of control. Hilton (1993) proposed that when a person felt out of control and resolution of a problem seems unavailable, excessive worrying, fear, rumination and anxiety might result.

For daughters of women with breast cancer, their worlds may no longer appear as predictable as they once were (Hilton, 1993). Without a strong sense of control, women felt unsure and uncertain about the outcome of their lives due to their perceptions of the situation. The daughters' uncertainty about their particular situations may also interfere with their ability to assess coping strategies. The impact of cancer may be an ongoing experience that causes a continual sense of upheaval. Daughters reported facing much uncertainty in different aspects of their lives and often this uncertainty made them feel that they were not able to count on others (Hilton, 1987; 1989). Daughters reported pondering if and when cancer would develop and how they would manage this risk (Rees, Fry, & Cull, 2001).

The daughters' experiences of breast cancer in their families affect how they think and feel about their own risk (Rees, Fry, & Cull, 2001). For example, daughters who experienced a high uncertainty in dealing with their mother's disease, had more emotional and logistical difficulties in managing their own lives compared to those who viewed their mother's breast cancer as short term (Rees, Fry, & Cull, 2001).

Another aspect of the daughters' vulnerability was in the area of depression. Wellisch and Lindberg (2001) explored the psychological reactions of depression in daughters. They examined depression in 430 daughters of women with breast cancer. Participants completed baseline questionnaires assessing anxiety and depression. Semi-structured clinical interviews were also conducted to provide psychosocial background information regarding daughters' thoughts and feelings regarding health practices and behavior.

Daughters scoring high in depression were younger, had more relatives with breast cancer, reported more symptoms of anxiety, and had more self-perceived vulnerability to breast cancer. Also, it was found that the younger a woman was at the time of her mother's diagnosis, the more likely she was to report depression later in life (Wellisch & Lindberg, 2000).

Wellisch and Lindberg's clinical results also indicated that the younger the daughter was at the time of exposure to a relative's breast cancer the more likely an unexpected high level of vulnerability and unpredictability. The authors suggested that such vulnerability affected the daughter's sense of trust and safety and may also have altered many of her later life expectations (Wellisch & Lindberg, 2001). Wellisch and Lindberg's research revealed that "the more, the sadder". Thus, the number of relatives affected with breast cancer makes a key difference in the daughters' experiences and the level of depression of at-risk women. Women with higher symptoms of depression also had higher symptoms of anxiety.

Sense of Coherence and Long Range Life Plans

Having a mother with breast cancer constitutes a traumatic event that triggers extreme fear and a feeling of helplessness (Wellisch & Lindberg, 2001). The daughter's perception of her mother's breast cancer may alter her long-range life plans (Wellisch et al., 1992). This may take the form of the daughter's career choices, her choice of a marriage partner and where she may choose to live (near or far from mother). Sense of coherence is defined as whether the person believes that there is a high probability that things will work out as well as can be expected (Gilbar & Borovik, 1998).

In a quantitative study where sense of coherence and involvement in medical settings were evaluated, Gilbar and Borovik (1998) discovered that daughters of breast cancer patients had a lower sense of coherence (defined above) as compared with women with no history with breast cancer. The level of coherence and attitude toward the medical treatment was predicted by the age of the daughter when her mother was diagnosed, the age of the daughter when her mother died, and whether the mother was still living (Gilbar & Borovik, 1998).

Not only was a daughter's sense of coherence affected, but also there were reported challenges to her long-range plans. Wellisch and colleagues (1992) in a cross-sectional study studied 60 daughters whose mother had breast cancer. A common theme that emerged for the daughters was their perception that their mother's breast cancer altered their long-range life plans. This was found to be evident for both younger and adult daughters of breast cancer patients. The data seemed to suggest that the daughters were caught in an emotional closed loop. That is, they felt that their mothers' illnesses had altered their life courses and they were unable to put this behind themselves emotionally. This lack of emotional resolution may further alter their life courses (Wellisch et al., 1992). Practically speaking, this may affect the partner a daughter chooses, where she will live (close or far from mother), and how she feels about herself overall (Wellisch et al., 1992).

Coping Processes

Not all of the research dealt with problems. Some of the research looked at how daughters actually handled these concerns. Coping becomes a necessary strategy for these women. Daughters facing the breast cancer of their mother struggled in adjusting to their stressful situations. Coping processes and personality traits contributed to the woman's adjustment to the continuing threat.

Gilbar and Borovik defined coping processes as the ways in which a woman involved herself in the medical setting, her preferences regarding medical information, the source and frequency of referrals, and time lapses since the discovery of symptoms. Other contributors toward coping strategies are personality attributes and a sense of coherence (Gilbar & Borovik, 1998; Holland, 2000; McCubbin & McCubbin, 1993).

Holland and Lewis (2000) suggested that individuals coped better with various types of cancer when they faced a problem or crisis head-on rather than trying to avoid the inevitable or hoping that it would go away. They proposed that successful copers tended to perceive an illness as a challenge. They suggested that rather than being defeated by the problem successful copers tended to believe that it could be mastered. They suggested several factors that may help individuals cope with cancer and its treatment: being optimistic and generally positive toward life, being able to take one day at a time, being able to meet a challenge head-on, possessing a fighting spirit, and being able to see the humorous side of things.

Developing coping strategies was not always easy for daughters of mothers with breast cancer. They were found to have less confidence that their external and internal environments were predictable and that things would out for them. Although daughters of breast cancer patients were less convinced that things would work out, they still tended to take more initiative in the medical setting as compared to women whose mothers were cancer free (Gilbar & Borovik, 1998).

Intrusive Thoughts

Another psychological response of daughters mentioned in the literature is the presence of intrusive thoughts. Intrusive thoughts may be described as unwanted and uncontrolled thoughts and feelings as well as breast cancer worries (Lerman et al., 1993). Daughters of women with breast cancer have been noted to be laden with many breast cancer worries and intrusive thoughts (Bowen et al., 2000; Lerman et al., 1993; Zakowski, Valdimarsdottier, & Bovbjerg, 1997).

Lerman et al. (1993) in a population-based study found that 53 percent of first-degree relatives of breast cancer patients reported intrusive thoughts about breast cancer and 33 percent were impaired in their daily functioning because of thoughts and worries regarding breast cancer. Intrusive thoughts or "uncontrolled thoughts and feelings", impairments in daily functioning, and sleep disturbances were reported by the women. It was also noted that some daughters tended to think constantly about breast cancer, to dream about it, and to experience general psychological distress and elevated anxiety (Baider et al., 1999).

Daughters of women with breast cancer also experienced high levels of worry regarding breast cancer (Bowen et al., 2000; Gilbar, 1998; Lerman et al., 1993; Wellisch et al., 1991; Wellisch & Lindberg, 2001). "Cancerphobia," or the fear of cancer often troubled daughters of women with breast cancer (Holland, 1989). Increased attention to breast cancer may have affected the women's perceptions of risk and worries regarding breast cancer. Overall, intrusive thoughts and worries are issues that daughters dealt with on an ongoing basis.

The Mother-Daughter Relationship

It was not only mothers and daughters individually who were affected by the presence of breast cancer. The nature and quality of the mother daughter relationship may change as well when a mother is diagnosed with breast cancer. The severity of the illness (the greater the severity the greater the impact) and the chronicity of the illness (a chronic illness has greater impact than an acute illness) were noted as important factors in determining how the mother daughter relationship changed (Lichtman, et al., 1984).

Explanations for disturbances in the mother-daughter relationship were suggested by Wellisch et al. (1979). Each relationship has associated expected roles and role expectations and responsibilities associated with those expectations. Breast cancer may affect how those roles, role expectations and behaviors are carried out. Wellisch and colleagues (1979) suggested that breast cancer might precipitate both overt and covert role changes for daughters. Overt changes may be in such issues as role overload as the daughter takes on more responsibilities for the mother. Role reversal may also occur when the daughter is expected to carry out what was her mother's role and the mother takes on a more child like place in the relationship. The daughter may suddenly find herself in a position to provide nurturing support for her ill mother that is far beyond what she ordinarily expected to do as a daughter.

In a study of 78 breast cancer patients, mothers reported specific types of problems with daughters (Lichtman et al., 1984). The mothers reported deterioration in 12% of their relationships. Some daughters were viewed as having extreme fearfulness over their mother's prognosis. The most dramatic and rejecting responses reported were by adolescent daughters who had moved out of the house. Post adolescent daughters also experienced difficulty adjusting to their mother's cancer in the areas of becoming more distant and avoiding discussion of cancer. This was demonstrated by argumentiveness and irritability, which commonly was reported by mothers.

Lichtman et al. (1985) also suggested three factors that may predict strain upon the mother-child relationship: 1) poor prognosis of mother, 2) poor adjustment of the mother to her cancer, and 3) more severe surgery such as mastectomy and lumpectomy. They found that problems were more likely to occur in daughters rather than sons when their mothers were ill (Lichtman, et al., 1984). The mother-daughter relationship may be strained due to mothers' tendency to rely more on daughters than on sons. Because of the increased tension created by greater demands upon the daughters, this may have added additional strain on the mother-daughter relationship.

Not all mothers and daughters reported a change in their relationship. Lichtman et al. (1984) found that approximately one-half of the women interviewed reported that the mother-daughter relationship remained the same after breast cancer. For most relationships that changed, they were more likely to have overall improved rather than deteriorated. Improved relationships took the form of greater understanding and closeness. For those relationships that changed for the worse, the women tended to have a worse emotional adjustment to cancer, a worse prognosis and a more severe type of cancer (necessitating a mastectomy).

CONCLUSION

While the body of research on daughters of women with breast cancer is increasing, the research studies conducted to date tended to be quantitative studies. While these studies provide us with a framework to view the possible responses of daughters to breast cancer there has been a distinct emphasis on psychological reactions to the experience. It is evident that there are still many gaps in the research.

Many factors can affect a daughter's response to her mother's illness. The issues of age and developmental stage of daughters when mothers are diagnosed needs to have greater attention. The quality of the mother-daughter relationship at the time of diagnosis and the ordinal position within the family may also be factors that would extend our understanding. Also, the affects of her mother's breast cancer on the daughters' relationships with her significant others are issues needing attention.

Methodologically there have been more quantitative studies than qualitative studies. Both of these methods are important to help us understand the experience of daughters. Qualitative research provides a source of rich, more personal data. It would be particularly important in addressing such issues as role shifts during the experience, the positive experiences handling of crisis situations, and the daughters' relationships with her family and friends during their mothers' diagnosis and treatment.

Additional research is also needed to "flesh out" the findings that have been reported in quantitative studies. In addition, gathering the stories and personal experiences of mothers and daughters together would provide a new way of exploring systems within the family as they deal with personally challenging events. This qualitative study was undertaken to explore the daughters' experiences from their own perspectives. The aim of the study was to also allow daughters to tell their own stories about their own experiences of their mother's breast cancer. This is only one part of understanding the mother-daughter experience, but it is a first step in filling in an identified gap in the research discussed thus far.

The following chapter will include a description of the method of inquiry that was carried out in this study. It will detail the qualitative approach as well as the methodological details used to address the key research question.

CHAPTER III

Method

When undertaking a research project the research method is selected by considering the research question and the expected outcomes of the research. The objective of this study was to explore the lived experience of daughters of women with breast cancer through the daughter's perspective. It is evident after reviewing the literature in the previous chapter that more insight is needed on the everyday experience of daughters of women with breast cancer. Therefore a qualitative descriptive process using phenomenological principles was chosen for this study.

This chapter will include a description of the methodology. The selection of qualitative approach will be addressed as well as the research design, issues of rigor, and finally the ethical considerations.

THE QUALITATIVE APPROACH

This study utilizes a qualitative approach in order to study daughters' experiences of their mother's breast cancer. There are many different qualitative approaches. A descriptive, interpretive approach utilizing phenomenological principles has been selected.

Phenomenology is grounded in the writings of philosophers like Heidegger (1962), Merleau-Ponty (1962), Husserl (1970), Ricoeur (1981), and Gadamer (1975). Phenomenology is a radical style of philosophizing that emphasizes describing a phenomena or attempting to get to the truth of matter in the way at which it appears and manifests itself to the experiencer (Moran, 2000). Phenomenology seeks to gain a deeper understanding of the nature or meaning of the everyday experience (Van Manen, 1997) and seeks to describe things as they appear to consciousness (Moran, 2000). This qualitative approach is designed to allow a researcher to look at some part of life in a way that surpasses all the expectations and assumptions one has about a particular phenomenon.

The Descriptive, Interpretive Phenomenological Approach

The current study was guided by a question that was suited to a phenomenological approach. As such it was a question that sought to detail and richly describe the lived experience of daughters who had a mother diagnosed with breast cancer. Because of the very nature of what phenomenology seeks to attain, there is essentially no such thing as one phenomenological method (Colazzai, 1978; Omery, 1983; Van Manen, 1997). According to Moran (2000), phenomenology is a "radical way of doing philosophy, a practice rather than a system" (p. 4). According to Colazzi (1978), there is no single procedure or method but rather methods and procedures of description. Each particular phenomenon is studied considering the researchers' particular aims and objectives.

Not every qualitative researcher who uses phenomenological principles and assumptions applies them to a research question in the same manner. For example, Husserl's phenomenology is a descriptive method that endeavors to describe how the world is consciously experienced (Husserl, 1970). On the other hand, Heidegger's phenomenology is not just descriptive but is focused more on an interpretive phenomenology (Spiegelberg, 1975; Van Manen, 1997). Heidegger believed that all description involves interpretation whereas Husserl believed in phenomenology as pure description (Moran, 2000). To Heidegger, phenomenology and hermeneutics are not two but rather one (Speigelberg, 1975).

The specific phenomenological approach that was chosen in this study is a descriptive, interpretive phenomenological approach. My goal was to begin my research with a naïve description of the experience" (Omery, 1983, p. 57) and to suspend my preconceived judgments and misconstruction on what the phenomena should or could be. My focus was to describe the phenomena as it appeared to consciousness or to "let things speak for themselves" (Heidegger, 1962). In this study the hermeneutics aspect of phenomenology took on a more distant role whereas the descriptive method was more predominant.

Van Manen (1997, p.30) describes hermeneutic phenomenological research as a dynamic interplay of six research activities: 1) choosing a phenomena which interests the researcher; 2) researching the experience as it is lived rather than how it is conceptualized; 3) reflecting upon the themes of the phenomena; 4) describing the phenomena through writing and rewriting; 5) maintaining a strong, oriented relation to the question; and 6) maintaining a balance between considering both parts and whole. These six activities provide the framework to detail how the principles of phenomenology were applied in my own research. I have used the above framework to investigate the phenomenon of the experiences of daughters of their mothers' breast cancer.

Choosing a Subject of Interest

As a woman and a daughter, breast cancer is definitely a subject of interest to me. Breast cancer, because of its incidence and impact on women's lives and the public discussion that is currently in the media, is both a woman's issue and a significant 21st century health issue. When I initially was deciding upon my area of research, I knew I wanted to study women, as I had always been interested in women and their experiences. The public discussion of breast cancer and my experiences with other researchers who were working with women with breast cancer led me to focus on the special topic.

A woman does not need to have breast cancer in her own family in order to be aware of the threat and possibility of the disease. There is no breast cancer in my family nor have any of my own friends had the disease. But for *any* woman, I believe it is always a possibility. Having breast cancer does not just impact the patient. It impacts many different relationships, particularly those within the family. As a student of family relations, I am particularly sensitive to the systemic impact of events in a family. I was reminded of this possibility as I heard women in breast cancer support groups tell about the impact of the disease on their partners and children. Many of them talked about how family members were involved in treatment decisions, of the strain that was placed on these people, how they often tried to shield these family members from further strain, and of the incredible assistance that family members gave them as they handled the disease and its treatment.

As I considered the family impact, I came to focus more on women in the family, in particular daughters of women with breast cancer. This was because they might be or feel particularly vulnerable. In addition, my initial review of the literature did not provide me with much information about the experiences of daughters. Both my personal reading and experience with women with breast cancer led me to be convinced that studying the experiences of daughters of women with breast cancer would be a topic that has potential interest not only for me but also for all women.

Breast cancer is a subject that is loaded with emotion. As I took on a qualitative exploration of daughter's experiences of breast cancer it was important to be in touch with my own feelings and beliefs. Because I had not experienced the situation, I tried to put myself in the place of a daughter whose mother had breast cancer and to identify my own personal views about that situation. To imagine having a mother with breast cancer forced me to acknowledge my own fears. Breast cancer seemed particularly bleak, yet I had little understanding of what the real situation might be for my mother and myself. My selection of this topic was guided by a strong desire to understand a daughter's experience and to increase my understanding about daughters and mothers.

The Lived Experience of Daughters

A second principle of a phenomenological approach according to Van manen (1997, p. 32) is that phenomenological research requires the researcher to "stand in the fullness of life, in the midst of the world of living relations and shared situations." And yet on the other hand, it requires the researcher to actively "explore the category of lived experience in all its modalities and aspects" (p. 32). With this in mind, I sought to become immersed in the experience of daughters of women with breast cancer. This required that I attempt to abandon my expectations and assumptions that I previously had regarding daughters and their experiences.

Applying the descriptive, interpretive phenomenological approach to this research involved conducting in-depth interviews from an emic perspective. This elicited the experience or perception from the participants' point of view rather than the researcher's perspective. The goal as a researcher was to identify the daughters' beliefs and values that were the basis of the phenomena without imposing my own beliefs and personal perspectives. An interpretive thematic analysis was conducted on each of the participant's "stories." Meanings were explored in order to understand and interpret the daughters' outlook and perspective. Thematic analysis will be discussed further in the data analysis section of this chapter.

Schwandt and Thomas (2000) proposed that in order to understand the meaning of human action it requires an empathic identification with the participant. It is the act of getting inside another's head in order to better understand what she is experiencing and feeling in terms of beliefs, desires and thoughts. I believe that I possessed an understanding as an interviewer. I believe this was evident in the openness and depth that the women chose to share their experiences with me as an interviewer. Within minutes of beginning the interviews, the daughters opened their hearts and lives to me and I began to share their unique lived experience.

Reflecting on Themes

According to Ryan and Bernard (2000, p. 780) "themes are abstract (and often fuzzy) constructs that investigators identify before, during and after data collection". This research process involved many different ways of reflecting on the themes. Analysis of the data began with a line-by-line analysis of the transcripts or email printouts to search for words, phrases or concepts that might provide insight about the daughters and their experiences. A process of reflection was used to gain insight into the essence of the daughters' experiences. I continually asked myself: Is this what the daughter was feeling and experiencing? As a qualitative researcher, reflection is a daily activity. The daughters' thoughts and feelings were continually mulling in my mind. I was challenged as to whether what one daughter shared was common to all daughters or was it simply just one daughter's experience. Initially one daughter's thoughts could seem isolated yet as I continued pondering, other daughters' thoughts seemed to overlap and be similar in their meanings.

I also had the opportunity to share the themes emerging from the study as means of an oral presentation. One of the participants in the study was in attendance at the presentation. At first, I felt a sense of concern about her attendance as I wondered if I had actually had captured the "essence" of daughters' experiences.

In a subsequent discussion, the participant concurred that the themes I presented were valid for her. She shared with me how it was difficult to reflect about her life in such a telling way. She shared how the process of viewing the themes representing such a powerful event in her life was frightening because the reality of her experience seemed to jump out at her. This illustrates how the process of reflecting on themes is continuous for the researcher as well as the participants as they participate in different parts of the research process.

Write and Re-writing

Writing and rewriting is an essential element of a descriptive, interpretive phenomenological approach. As I wrote each daughter's individual story, I was challenged to maintain the dynamism, emotion and integrity of the stories that were shared by the women. The stories were not those of the researcher but those of the daughters as perceived by the researcher. I was mindful of not simply stating the obvious but to search for deeper thoughts and meanings. In order to be true to the women's experiences, these stories as re-written by the researcher were presented to two participants for their insight regarding accuracy and detail. When writing and rewriting the findings, there was a constant questioning as to whether what I was writing encapsulated the women's experiences.

As much as I endeavored to bracket my thoughts and beliefs regarding the phenomenon, it still was difficult to separate the two. I was constantly reminding myself to write from the daughters' perspective rather than from my own. Even so, it was obvious that the daughters' experiences were written through my eyes and ears as a researcher and writer. The literature on breast cancer that I had read would often come to mind as themes surfaced. This was encouraging, as it became a part of the larger research process and search for understanding, and it suggested that some new thought and ideas had surfaced in the participant's stories that had not been discussed in the research to date.

Maintaining a Strong and Oriented Relation to the Question

Van Manen (1997) suggested previously that the researcher must maintain a strong and oriented relation to the research question. This is a "tall order" for a researcher. This quest has required that I be immersed in the phenomena of daughters and their experience while still maintaining some objectivity. I was mindful of not becoming sidetracked into accepting preconceived ideas and opinions about the phenomenon under study rather than "entering into the world" of the daughter of a woman with breast cancer. It was a continual journey of shedding myself of my preconceived ideas of the experience and discovering what the experience truly was for daughters living with it on a day-to-day basis. I was continually asking myself, "is this the daughter's experience or is this what I think she experienced?"

Balancing Both Parts and Whole

All qualitative researchers have to be sensitive to both the parts of the process and the whole experience. One challenge for me in this project was to allow myself to become immersed in the experience yet not get lost in the process. The very richness of the data and its volume made it both wonderful and frightening. One can become so immersed in the stories that the researcher does not know where to proceed. I felt this confusion many times in this project. Often I had to make efforts to step back from the data and take a fresh look or to discuss the data with colleagues to help me refocus and tackle the task again. Such techniques helped me remain immersed yet clear-minded in the research. The continual challenge was a balancing of the two: both the parts of the story and the whole story knowing that there was no absolute solution about how that was best accomplished.

RESEARCH DESIGN

The research design section will include a description of the respondents, methods of data collection, and techniques of data analysis.

The Participants

Purposive Sampling

According to Morse (1991) a good research participant is one who possesses knowledge of the topic, the ability to reflect and provide information regarding the phenomena, and the willingness to share her experience. A wide range of experiences of daughters was desired. Thus the following selection criteria for the participants in this study included:

- Daughters who were from age 20-55 years of age,
- Daughters who were Caucasian,
- Daughters who had not had breast cancer,
- Daughters whose mothers had either a lumpectomy or mastectomy,
- Daughters whose mothers were currently living, and
- Daughters who were interested in telling their "stories."

The second criterion, limiting participants to Caucasian participants, was necessary because previous research had indicated that there were cultural differences about health matters that might influence particular experiences. Also, persons from different cultures may view body image in a different light. The third criterion (women having no experience with personal breast cancer) was necessary so that the study did not focus on a daughter's illness but rather on her mother's experience of breast cancer. The delimiter of interviewing only daughters whose mothers were currently living was included so that the focus could be on their experiences with breast cancer rather than a focus on experiences associated with grieving due to loss of a mother.

Number of Respondents

Small numbers of respondents are utilized in qualitative research in order to keep the data manageable (Field & Morse, 1996; Sandelowski, 1986). The determination of the appropriate number of respondents for a phenomenological qualitative study depends upon the quality of the data shared by the participants. The researcher originally estimated that between 4 and 6 respondents would be recruited but that the final number would be determined by the nature of the data that were obtained. The researcher concluded after 6 women had been interviewed that the data were rich and that this number of interviews provided a detailed description that reflected the experience of daughters of women with breast cancer.

Recruitment of Respondents

Finding appropriate respondents was much more difficult than I anticipated. My initial goal was to gather participants by word of mouth and from responses to advertisements in both local and community newspapers. I placed advertisements in various newspapers and community newsletters in a large metropolitan Canadian city (See Appendix A). The few responses (total of three) I did receive were from women who did not meet the study criteria. For example, two women who responded to the advertisement had mothers who were deceased. This was discouraging to have women respond that did not meet the interviewing criteria. Using the word of mouth contact method did not immediately obtain eligible respondents. However it was this method that eventually allowed me to identify the respondents. Respondents were primarily recruited from contacts within work groups and community contacts. The researcher was not acquainted with any of the respondents prior to the interviewing process.

One issue emerged as respondents were recruited. While it was assumed that all the respondents would live in close proximity to the researcher, one respondent lived in another province in Canada. In order to allow the participation of this respondent a different method other than in person interviewing had to be utilized. In this case, e-mail interviewing was selected as the alternative approach. This will be described in detail in a latter section.

Characteristics of the Respondents

The six daughters who participated in the study ranged in age from 22 to 36 years of age. The average age was 29. Four of the participants were single and two were married. Three of the participants had children.

The age of the daughters at the time of their mothers' diagnosis ranged from 13 to 35 while their mothers' age ranged from 38 to 79. Two of the daughters were in their early teens when their mother was diagnosed with breast cancer and the other four were adults. In terms of treatment, two of the mothers had mastectomies and four had lumpectomies. The daughters all lived in Canada: five in Alberta and one in a neighboring province.

DATA COLLECTION

Interview Process

My goal in seeking participants for this study was to find women who wanted to share their experiences, who were "in touch" with their feelings, and who found the study relevant. I wanted to gather a wide range of stories and experiences, each having similarities and differences. I expected that their stories might vary depending upon such things as the severity of the mother's breast cancer, the various ages of the daughters, their relationships with their mothers at the time of diagnosis, the mother's experience with diagnosis and treatment, and the amount of depth the daughter was able and willing to share.

All of the six daughters were pleased to share their stories. Most women expressed a sense of satisfaction or relief in telling their stories. As one daughter shared:

> "No one has really asked me the questions that you have today. It seems like people ask how my mom is doing but nobody really asks about me and my experience." (Erin, 22 years)

Prior to any interviewing the respondents were provided with detailed information so that they could make an informed decision and give their informed consent to participate in the study. The researcher discussed the purpose of the study and the nature and time for each woman's involvement. It was stated at the onset of the interview that there were no right or wrong answers when telling their stories. Confidentiality was also assured at the beginning of the interview. Each woman was provided with consent forms that they both read and signed (Appendix C). Women who were out of town faxed the consent forms back to the researcher. Because recalling experiences around the diagnosis of breast cancer had the potential for strong emotional responses, the interviewer spoke with all of the women regarding possible distressing thoughts and feelings that might arise as a result of the sharing process. The participants were offered the names of therapists or counselors should counseling be required. Each participant stated that they had access to therapeutic help if the need arose. All of the women were responsive to the possibility of follow-up calls.

According to Van Manen, (1998, p.98) the art of hermeneutic interviewing is to "keep the question (of the meaning of the phenomenon) "open," and to keep the interviewer and the interviewee oriented to the substance of the phenomenon. Interviewing was conducted by means of unstructured face-to-face interviews or e-mail interviews.

In Person Interviews

Three women were interviewed in person in a neutral location. All of these women were able to commit to one to two interviews of ninety minutes in duration. The researcher did all interviews personally.

The personal interviews were unstructured with the interview content being directed by the participants' stories. All interviews that were conducted in person were audio-recorded. The researcher alone transcribed each tape-recorded interview. The leading question used in the interview was, "Tell me about the time that you first discovered that your mother had breast cancer." The researcher was careful to not interrupt the participant so that she could best share her own story perspective. There was a tendency for the interviewees to talk about their mother's experiences rather than their own. If this occurred, the interviewer would guide the conversation more towards the daughter's experience of what she herself was feeling. For example, if the woman spoke about her mother's experience, the interviewer would ask the interviewee how she felt about that particular experience.

E-Mail Interviewing

Three daughters were interviewed via e-mail conversations. E-mail interviewing is a relatively new technique that capitalizes upon new technology. Research indicates that e-mail is a viable method for obtaining reflective data from participants (Heflich & Rice, 1999; Kieren, 2002; Persichitte, Young & Tharp, 1997). According to Persichitte et al. (1997) the advantages of email interviewing are: 1) the researchers are unable to interrupt the interviewee or to give them nonverbal evaluative responses, 2) time is available for both the researcher and the interviewee to be thoughtful and careful, and 3) both parties do not have to deal with scheduling problems and each could correspond on their own timing. All of these advantages were found to be applicable in this interview study.

The e-mail interviewing process was similar to a face-to-face interview in that there were key questions, and a conversation that involved sending and receiving messages. Even so, there were differences in the approach. Each person could reply at her convenience. Each respondent was able to write her feelings without the interruption or guidance of the interviewer. I also think that think that the women who were involved in email interviews had more opportunity to reflect between receiving and answering the questions.

I initially wondered if I would have difficulties establishing rapport with the respondents and whether the data would have the depth that my study required. I was happily surprised in our ability to "connect" and in the richness of the first interview. The first time I read an e-mail print out, I was moved to tears while reading the participant's experience. After the success of the first e-mail interview, it was offered to prospective participants as an alternative to in person interviewing.

One of the advantages of e-mail interviewing is that there is no requirement for transcription. In addition, it is an efficient way of checking out the accuracy of data and analysis. It was essential however for the researcher to remove any identifiers from an e-mail print out, such as e-mail addresses etc.

In the cases where e-mail interviews occurred, the researcher sent several open-ended questions to the participants and invited them to reply at their convenience. Their replies took approximately 1-2 weeks. Within four days of the receipt of an e-mail response, the researcher sent back clarifying questions regarding the woman's first e-mail. If further clarification was needed e-mailing occurred a third and fourth time. For the three respondents who were interviewed by e-mail, two to three interactions occurred.

During both the personal and e-mail interviews, I was able to clarify my understanding of their experiences with the daughters as well as pursue other topics relevant to the subject. Each of the women, whether interviewed in person or by e-mail, were given several opportunities to express their thoughts and feelings regarding their experience. Two women occasionally needed extra prompts to reflect on their feelings regarding a particular situation. Although focused and dealing with a difficult topic, I found the interviews to be relaxed. I felt that I had established rapport with the daughters almost immediately because of our common commitment to the topic and experience. To ensure the anonymity of the participants, all interview data was only identified by the use of pseudonyms and any specific identifying data was removed from examples.

Each woman provided key demographic information either at the time of the interview or later by e-mail. Demographic information included the ages of daughters and mothers at time of study, daughters' marital status and occupation, ages of daughters and mothers at diagnosis, as well as the mothers' type of operation (mastectomy or lumpectomy).

DATA ANALYSIS

The researcher was guided by Giorgi's data analysis process. Giorgi (1975 & 1979) devised a procedure for data analysis in the following five steps:

1. The entire description of the experience is read to get a sense of the whole,
2. The description is slowly read a second time and identifies units in the experience, called constituents. These units together make up the whole meaning of the experience,
3. All redundancies in the units are eliminated in order to elaborate the meaning of the remaining units by relating them to one another and to the whole,

4. A reflection and interpretation is conducted on the given constituents or units, and
5. The researcher then synthesizes and integrates the insights into a descriptive structure of the meaning of the particular experience.

Initially each daughter's story was read and re-read until the researcher could write a descriptive story that summarized her personal experiences as a daughter of a woman with breast cancer. As the researcher wrote the participants' stories she read and re-read the transcripts and searched for the highlights and particular aspects and meanings that pointed to a greater depth of the experience. The researcher was careful to reiterate the women's stories as stated.

Themes

In order to identify common elements across all six participants' experiences a thematic analysis of constituents was conducted. The interviews were read and re-read with the idea of identifying common experiences that might be established as themes. Analysis of the data began with a line-by-line analysis of the transcripts or email print outs to search for words, phrases or concepts that might provide insight about the daughters and their experiences.

In order to isolate key experience statements, the researcher took the selective reading approach which is where she read the text several times and asked, What does this sentence have to say about the experience of being a daughter of a woman with breast cancer? The researcher searched for phrases that stood out and selected sentences or part-sentences that pointed to an idea or concept regarding the experience of daughters of women with breast cancer.

These phrases or statements were either underlined or highlighted. The researcher continued to ask herself, "What was going on for the person and what was she experiencing?"

A large number of concepts and ideas emerged from this line-by-line analysis. Then the researcher attempted to link identified concepts, phrases, ideas together into themes and to identify what might be the overarching essence of the daughters' experience. One goal of phenomenology is to capture the essence of a phenomenon. Essence is described as that which makes a thing what it is and discovers the inherent essences of appearance of anything of which one is conscious (Husserl, 1982; Stewart & Mickunas, 1990). Although the researcher endeavored to capture the essence of the daughters' experiences, it is her personal opinion that one may never be able to capture the true essence of an experience, in particular, second hand. One can strive to reach some of the essence of the phenomena but certainly I cannot personally say that I have attained this feat.

The themes were named by looking at the commonality of the words that the participant used. A theme was chosen which best-encompassed all of the words or phrases regarding this experience. A label was attached to the particular experience that a woman described. Labels were given that were strongly personal rather than abstract (e.g. Fear Permeates My Life rather than Fear). The transcripts were read and re-read and sorted several times to find the best fit for the data until a category could be named and described with confidence. Initial identified words and phrases were clustered according to observed similarities and differences of content and experience.

As the data collection and analysis continued categories were compared and it was apparent how they clustered and related to one another. Incidents were compared from one person to the other for commonalties and differences. Common questions that I asked myself were as follows. "What does this statement mean? Does it mean the same thing for this woman that it does for the other? How is it different?" or, "How do I best label this theme so that that it encompasses the participant's thoughts and feelings and puts into words for the reader the reality of the experience?

Reviewing all the identified themes together helped the researcher formulate an overall theme, or what some phenomenologists tend to label the overall essence of the daughter's experience. This overall theme was found to be what encompassed the daughters' experiences. This is extracted from the texts by searching for what the participants' underlying expressions of what their experience encompassed for themselves.

ADDRESSING ISSUES OF RIGOR

All research must attempt to reach standards that provide a sense of rigor. These standards vary for qualitative rather than quantitative research approaches. The criteria used for the assessment of methodological rigor in this study included: credibility, fittingness, auditability, and confirmability (Sandelowski, 1986). The rigor of this qualitative study was assessed using the above criteria rather than usual notions of reliability and validity that are more likely used in quantitative studies.

Credibility & Fittingness

Credibility is defined by Guba and Lincoln (1981), as the truth-value by which a qualitative research study is evaluated. Credibility is established when individuals who have had the experience are able to recognize the experience from the descriptions or interpretations of the data as their own (Sandelowski, 1986). Showing the women their stories and the analysis of them and allowing them to verify the descriptions established credibility. The findings were shared with two women who confirmed the themes to be fitting to their experience. Three of the other women were contacted but were unavailable due to personal reasons. One woman in particular shared that many emotions surfaced for her as she read her personal story as well as the findings of the study. This confirmed the power of reading an analysis of ones life experience. Also, this indicated to myself as a researcher that their stories were written with a sense of truth-value.

Field and Morse (1996) maintain that a greater sense of intimacy between research and the participants contributes to the accuracy of the researchers' ability in interpreting the situation. The rapport that was established is one method of ensuring that the respondents were free to tell their experiences and might contribute to the credibility. Also the researcher allowed the interview to continue as long as the participants wished. The researcher believes that her willingness to actively listen to the participants' experiences enhanced a safety whereby the women could comfortably share their stories. The researcher's interest in the topic along with her ability to openly listen with compassion and empathy also created a sense of intimacy.

Fittingness is the interaction between the researcher and the participants in a particular setting resulting in the data reflecting the experiences of the participants involved in the study (Sandelowski, 1986). Also the evaluation of the sample is necessary in order to achieve applicability of the findings in contexts outside the study itself (Sandelowski, 1986).

In order to achieve applicability of the findings into contexts outside of the study, the nature of the informants must be evaluated (Sandelowski, 1986*)*. The criterion for determining generalizability differs in qualitative versus quantitative inquiries (Morse, 1999). For quantitative research, a random sample is compared with the study population to ensure demographic characteristics. The researcher assumes that if the demographic variables are similar to the research participants then they may be generalized to the general population (Morse, 1999).

Qualitative research, on the other hand, purposefully selects participants for the contribution they make with a focus on meaning (Groger, Mayberry, & Straker, 1999). The researchers concern themselves with “repetition and qualitative distinctions of intensity” (Morse, 1998, p. 734). Respondents are recruited who have experience in regards to the phenomena explored as well as those who are willing to take the time and energy to intimately share their experiences (Morse, 1998). It is in this careful selection that the exploration of the phenomena is complete and saturated. The information gained from the study can then be generalized to the larger population of daughters in similar settings.

Sample selection has profound effect on the quality of the research therefore, the appropriateness and adequacy for the sample is critical (Morse, 1991). Purposeful sampling was used as a method of sampling which best provided the experiences of women with breast cancer. The informants were selected who had knowledge about having a mother with breast cancer and who wanted to tell their "stories." Daughters whose mothers were deceased were not included in this study. All women selected for the study were able to express their thoughts and feelings. The daughters interviewed shared a variety of thoughts and experiences that were vast and yet conducive to previous literature.

Auditability & Confirmability

Auditability is defined as the ability of another researcher to follow the "decision trail" used by the researcher of a study (Sandelowski, 1986). Audiotaping and verbatim transcription of the interviews were maintained to ensure for auditability. Also an audit trail was devised in the form of the procedures used in my decisions regarding sampling, data collection, data analysis, and the writing of the findings.

"Confirmability is achieved when auditability, truth value, and applicability are established" (Sandelowski, 1986, p. 33). As a researcher, I journaled and dialoged with my thesis supervisor. I also shared findings and reflections with participants individually. An oral presentation also offered an opportunity to test this aspect of rigor. Further confirmability will be established when the meaningfulness of the findings of the study is found to be of value to others.

ETHICAL CONSIDERATIONS

Various strategies were used to ensure that the study was conducted in an ethical manner. Ethical approval was obtained for this study by the appropriate ethics committee at the institution where I am a graduate student. All participants were informed of the purpose, objectives and time commitments involved in the study. A written consent was given to each participant and signed at the beginning of the interviewing process (See Appendix C). Participants were informed of their ability to withdraw from the study at any given time. None of the women involved chose to withdraw from the study.

Many efforts were made to protect the identities of the participants. E-mail addresses were immediately removed from e-mail interviews. A number and pseudonym were assigned to each individual's data and used throughout the analysis and reporting. Any information that was deemed to be significant enough to identify a particular respondent was altered or deleted in any report to ensure confidentiality. Consent forms for the interviewees were kept separately from the interview data.

Audiotapes were erased after transcription and transcripts of the interviews will be kept for 3 years and then will be destroyed. Informants were advised in the informed consent information that transcripts or excerpts from them might be used for publication or for analysis in future studies.

The women were aware that there were no direct benefits for participating in the study. Several informants expressed that they had experienced value and benefit in participating in the study. This was evidenced in their satisfaction and relief in telling their "stories" that had to this point been left untold. Care was taken in reporting a woman's story. This was conducted in both the writing of the findings as well as in the oral presentation. I was sensitive that the women's stories should not be recognizable to other readers. Defining details were eliminated that could possibly identify a participant.

The Themes

The following chapter will include a description of the findings that emerged from the analysis of the experiences of daughters of women with breast cancer that has evolved from this research study. It has been researcher's goal to capture the essence of daughters' lived experiences with this challenging situation.

CHAPTER IV

FINDINGS

> *"With dread, I had been waiting for this, knowing that one day it would be my turn. I feared its mystery much the way many fear the shadow of death that will one day take us all into the darkness or light. Obsession had me in its grip as I passed every day of my life for five years, touching my breast, pressing my breast, three, four times a day-in the shower, while reading a book or simply while sitting at the computer waiting for inspiration.* Patricia Jones Bacchus, (1997, p. 90)

Waiting, fearing, acting with love and courage, these are all part of the stories of daughters of mothers with breast cancer. In this chapter the stories of the six daughters will be shared. These are the stories of fears mingled with incredible courage and connection. The story telling will begin with short narratives of each daughter's experience. Then, identifying an overall theme and several sub-themes that help describe the commonalties of their stories will highlight these rich and strong narratives. I invite you to listen and learn with these thoughtful women.

Natalie's Story

Natalie is 38 years of age and one of eight children. She is divorced and a single parent. Three years ago, Natalie's mother was diagnosed with breast cancer at 79 years of age. She had a mastectomy a month later. Natalie had always counted on her mother's support. Her mother supported her during her pregnancy, her daughter's birth, and through her divorce.

Natalie's career background was beneficial in handling her mother's breast cancer but placed her in a difficult situation. She had read her mother's chart before her wire-biopsy and knew from the way it was worded that it was suspected to be malignant. Although she was not a doctor, Natalie *knew* the bad news well before her parents or siblings. Although she felt guilty, Natalie felt it was not her place to inform her parents what she suspected until the actual diagnosis had been given.

Knowing this information was one of the most difficult times of Natalie's life. Because Natalie's mother did not want to worry the other siblings, she asked Natalie to keep the operation a secret until after the biopsy. Natalie painfully held the information inside. Her mother was determined that there was no cancer and Natalie felt that there was. Natalie felt alone. She also felt a sense of betrayal towards her siblings and her mother. She worried that something would happen to her mother during the biopsy and how she would explain the secrecy to her siblings.

Once her siblings were told, Natalie still carried major responsibility to support her mother. She also felt somewhat resentful towards her other brothers and sisters as they lived in other cities and were somewhat detached from her parents and her day-to-day situation. She often would go to sleep at night crying in sheer exhaustion. She was a single parent working full-time, supporting her mother and father, and she alone was helping her mother deal with breast cancer.

Not all of the times were bad. The night after her mother's surgery was one of the most rewarding times of Natalie's life. She slept in a cot beside her mother in the hospital and they "talked the night away". Natalie told her mother how proud she was of her and how she had gone through the surgery with such strength and faith. She told her mother that she was a remarkable person and how much she deeply admired her. She felt that her mother exuded such strength in the midst of a life-threatening disease. Her mother had never once complained or looked for pity. She was always positive and believed that God would take care of her.

That night was a most intimate time of sharing for Natalie and her mother. Prior to this, in their sharing, her mother had never revealed when things were personally distressing. But that time her mother shared her feelings of vulnerability. Her mother was no longer just strong; she also could be weak. She shared her concerns and worries with Natalie. The mother-daughter relationship became equal. Natalie's experience was two human beings sharing heart to heart. Their former roles as mother and daughter were not as prominent in the ways that they previously had been. They had a common bond.

Since the diagnosis and mastectomy, the possibility of breast cancer continues to be real. Its danger and fear is never too far away. Natalie checks her breasts each week. She personally has had two needle biopsies to check for possible malignancy. Luckily both were benign but the fear was and is real for Natalie. She explained that no matter how positive a person is and no matter how healthy you live, breast cancer can frighten you like nothing else. Natalie views breast cancer as something that can come without warning and can totally change one's life. She said that no one believes it can happen to her and yet it can overnight. She said that in her mind: "it is the fear of the unknown".

Natalie's mother has been cancer free for 2½ years and in her mother's view and on most days in Natalie's view, she is cancer free. Natalie believes that a positive attitude is what makes the difference for her. She tries not to dwell on breast cancer but subconsciously it is always there. Still, her motto was, "life needs to be lived."

Ashley's Story

Ashley is 22 years old, a single parent and works as youth support worker. She is the younger of two children. Cancer is an especially sensitive subject to Ashley as breast cancer has a history in her family. Her mother was diagnosed with breast cancer for the first time 6 years ago. Not only has her mother had breast cancer but also her grandmother, her great-grandmother, and three of her aunts have experienced the disease. Ashley's mother has had breast cancer three times along with cancer of the uterus.

At 15, Ashley was a normal teenager. Her peers were central to her life and she had little interest in being around her parents. Six years later, Ashley shudders when she thinks back to the difficult time she went through when she discovered that her mother had breast cancer. Her mother suddenly needed her help. She was expected to do more around the house and drive her mother back and forth to chemotherapy appointments. All Ashley wanted to do was get away from her mother.

It was a scary time in Ashley's life. She was petrified that her mother was going to die. She worried about who would do all the things her mother did. Who would do the laundry and the cooking? Who would take Ashley to parent-teacher interviews? Although Ashley was forced to take on more of her mother's roles, she internally chose to disassociate herself from her mother and her breast cancer.

She chose to go out more, never wanted to be around her mother and could not handle seeing her upset. She lived at home, completed her duties but was not emotionally present.

Ashley was overwhelmed with the sudden turn of their lives. Anger was a common emotion Ashley used to keep her mother at a distance. She could not understand the vast changes in their family. She resented her mother for getting breast cancer. It seemed she was always mad at her mother. She angrily shouted at her mom to "get it together and quit feeling sorry for yourself." Each time her mother got emotional was a reminder to Ashley of just how many things had changed. She avoided her mother as it was otherwise too painful.

Ashley feared for her future. She was terrified of cancer overtaking her life. She wondered whether her mother would be alive when she meets someone special and gets married. She was terrified that her mother will not watch her granddaughter grow up. Breast cancer has affected Ashley's relationships. It affected her relationship with her parents, her daughter, and her relationship with herself, and with God. For Ashley, it was scary to be a woman.

Erin's Story

Erin is single, 22 years old, and has two younger brothers. She had led a busy and exciting life as a dancer and has danced in various countries in the world. Erin's close relationship with her mother deepened with the diagnosis of breast cancer. This past summer, both Erin's mother and her mother's sister had exploratory tests for breast cancer. The sister's diagnosis was benign whereas Erin's mother tested positive. Erin's mother had a lumpectomy at 51 years of age.

At the time of the interview, Erin's mother was in the midst of chemotherapy and had had two treatments. Erin explained how even her mother's recent loss of hair was handled with a sense of grace. Her mother one day just flipped off her wig and smiled at Erin saying, "ta, da!" Erin's mother seemed to have the ability to have fun even when life became difficult.

The day of her mother's surgery was a difficult day for Erin. Her mother's lumpectomy was booked for 2 o'clock and she did not go in until 6 o'clock. They spent the afternoon anxiously waiting for her mother's surgery. Time seemed to go by so very slowly. Erin was scared. She worried that the surgery would be worse than anticipated.

Erin felt that the family needed to spend their waiting time almost in a sense of reverence. She wanted the family to focus entirely on her mother. She felt they needed to sit and wait, that they should not go on as if life was normal. Unfortunately, Erin's father and brother did not want to talk about feelings. Erin recalled her father wanting to distract the family whereas Erin just wanted to talk with her mother and discuss their feelings regarding their crisis. Erin felt that they were in the midst of a crisis and it was nothing to be brushed off. She wanted so badly for them to talk in depth. Most of all, Erin wanted everything to be okay.

Although breast cancer was a new experience for Erin, she already felt it was something to be feared. Thoughts rushed to Erin's mind of what may happen to her mother in the future. Erin prayed that if she ever gets breast cancer that she would be as lucky as her mother. Still, she felt that breast cancer was something that all women should be afraid of. The possibilities of breast cancer "pelt at her mind". What if things take a turn for the worse? What if her mom suffers continuously? What if Erin gets breast cancer?

Amber's Story

It has been 2 years since Amber's mother was diagnosed with breast cancer. Amber is 34 years old, married and has two children. She is the younger of two daughters. Her mother had a mastectomy at 67 years of age.

Amber got the call that her mother had breast cancer while she was at work. As she hung up the telephone she felt her body shake. She was terrified of what this would mean for her mother. Her first and foremost thoughts were to be with her mother. She drove the 20 minutes to her parent's home and thought of nothing else but her mother. She just had to get to her mother and get as much information as she could.

Amber sometimes considered what life would be like without her mother. She found this to be a most unnerving thought. Although Amber is an adult, she still felt she needed her mother. She depended on her mother to do all of the mothering things that she had always done. She never wanted that to change. She needed her mother to call her kids, to make them cookies, she just needed her mother to continue being a mother. According to Amber, she was not ready to lose her mother, not for a very long time.

Amber felt an association with breast cancer that she did not like. As a daughter, she belonged to a breast cancer group of which she would rather not be a part. For Amber, her mother's breast cancer was a personal matter yet she felt that people were constantly making it a public matter. It seemed when her mother was diagnosed that people continually asked Amber for details of her mother's breast cancer. They often asked more questions than Amber wanted to answer. She simply wanted to go on with her life and leave the breast cancer issue alone.

Today, her mother is doing well and their lives have gone on. They do not really talk about breast cancer much as a family. Amber sometimes has felt that people regard her as if she is next in line for breast cancer in their family. She felt that others imagined her children without a mother. This was not Amber's experience. She simply wanted to get on with her life.

Mandy's Story

At the time of our interview, Mandy was single and 22 years old. She had no children and worked as a preschool teacher. It had been 9 years since her mother was diagnosed with breast cancer. Her mother was 36 years old when she had lumpectomy. Mandy was just 13 years old and the eldest of four children. At that time there was little public discussion of breast cancer and Mandy did not understand the seriousness of breast cancer.

Mandy learned at a young age that life is something not to be taken for granted. On what started as an average day, Mandy learned that her mother had breast cancer. Her mother shared her fears to Mandy. She was afraid that she was going to die. Mandy searched the recesses of her mind on what this all meant. Her mother was going to die? When? Why? How could this happen to them? She felt too young to deal with this issue. Yet, the seriousness in her mother's voice could not be denied. Mandy's life was taking a most uncertain turn. It was a most disconcerting feeling.

It seemed after that afternoon that Mandy grew up fast. She became strong for her mother. Mandy wanted so much to comfort and help her mother. Yet, would everything be all right? She felt she was dreaming because everything felt so wrong, so unnatural. She desperately wanted to have the whole experience go away. She felt that she needed to be strong for her mother and father, for her brothers and sisters and of course, for herself. She was petrified of the fact that she needed to comfort her mom and be strong for her. How was she to do that at 13 years old?

Mandy felt that the day she learned her mother had breast cancer changed her life. She expressed her desire to never take for granted those people who were in her life whether they were family or friends. She discovered that cancer was something to be feared. Cancer could rob their family of their mother. She cringed at the thought of not having her mother. How would they survive? Who would take care of them?

Mandy is a dancer and found her dancing to be a positive outlet during the difficult times when her mother had breast cancer. She recalled the year her mother went through radiation treatment and how hard it was for Mandy. Interestingly, that was the year that Mandy's dancing became more personal than ever before. She danced to escape reality. It was a place to release her fears and emotions from her mother's battle with cancer. For a few brief moments, dancing distracted Mandy from the realties of breast cancer.

Thankfully, for Mandy and her family, her mother was alive and doing well. Mandy enjoyed a close relationship with her mother. She breathed a sigh of relief when she reminded herself that the family's pillar of strength was still strong.

Elaine's Story

Elaine is 36 years old and married with no children. She is the younger of two children. Her mother has had breast cancer twice: once at 60 years and the other at 65. Elaine was 27 when she first discovered that her mother had breast cancer. Her mother's exploratory tests were well under way when Elaine was given the news that her mother had breast cancer. Elaine was not immediately informed of her mother's illness as her mother did not want to worry her or add to her stress in planning her wedding. Elaine regretted that she had not initially been told of her mother's diagnosis. She felt guilty that she was so wrapped up in her own life that she had not known that her mother was dealing with the diagnosis of breast cancer.

Her mother's diagnosis of breast cancer started Elaine on a journey that she wished she had never begun. She learned that her grandmother who had died only months before had actually died of breast cancer. This was a harsh reality for Elaine to face. The thoughts of what this all meant slowly sank into Elaine's heart. If both her grandmother and mother had had breast cancer was not it only a matter of time for cancer to strike Elaine?

Elaine was faced with a third blow five years later when her mother found another lump in the other breast. Elaine was stunned by this second diagnosis. What did this mean for Elaine? Was she next? She was petrified! What if her mother died? What if Elaine got breast cancer?

It seemed that due to her family history, Elaine has almost reconciled herself to developing breast cancer. She did not want to accept the possibility of breast cancer and constantly fought with negative thinking. Her grandmother died of breast cancer. Her mother has had breast cancer twice. As quickly as she pushed the frightening thoughts away they returned with a vengeance. Elaine wished that she had "safe" breasts.

THEMATIC ANALYSIS

Once the narrative sections were written, a thematic analysis of all interview material was completed. As the narratives were read and re-read, an overall theme comprising the essence of their experience emerged. This was the overwhelming quality of fear – for self and for their mothers. This overall theme was described as, *The fear that never goes away.* The theme of *Fear: Living in terror* and *More fear: The second diagnosis* will be discussed next. The sub-themes will include: *Keeping it together for mom, Experiencing vulnerability: What if it happens to me?, Breast exams: The terror of finding something, Feelings of terror: Mom might die,* and *Changing of roles: It feels so backward.* The final two themes reflect the daughters' experience from a more positive perspective. This was represented by the themes*: Moments of Intimacy: Mom and me,* and finally, *Admiring Mom: How can she be so strong?* The theme and sub-themes will be illustrated by quotes from the women's personal stories.

The Fear That Never Goes Away

> *"My life has been high-jacked by the fear of breast cancer. I think about it almost every day, and often become terrified."*
> Miranda Eve Weingarten Worthen, (1997, p. 45)

Daughters discovered as early as the diagnosis of their mothers' cancer that life offers no guarantees. The daughters who shared their stories gave many examples of fear being a common emotion that surfaced on an ongoing basis. For example, they described being filled with the fear that their mother might die, that other female family members might develop breast cancer, and that they themselves could get breast cancer and could die. The overall essence of fear permeated their minds and affected their personal lives.

Although their fears initially related to concern and care for their mothers it seemed that they eventually related such fears back to themselves as well. There seemed to be a deep cry from within that asked, "how will this affect me?" or "what will happen to me?" This would be illustrated in the daughters' descriptions of possible fear of their losses. They feared loss of their mother's companionship, loss of a normal life, and more than anything, fear of the unknown. Fear robbed their lives of a sure, safe future. As much as they wanted to stay positive, they still were weighted down with feelings of vulnerability to breast cancer and its uncertainties.

Ashley described her fear of cancer as a something that never went away. She did not want to have what happened to her mother happen to her. From her point of view, if a person had cancer once it could easily happen again. Ashley feared that her sister and her daughter might develop breast cancer. She was even worried that the teens with which she worked might develop cancer. She described herself as a "secret advocate" for breast cancer awareness and prevention, always reminding others to do everything they could to take care of their bodies. She was not only afraid of breast cancer, she was afraid of cancer in general. For example, she was fearful of tanning and used only the highest SPF. She was obsessive in keeping active and eating right. She explained further:

> "I think that every woman goes into that phase, of searching who you are, what you're like and just exploring yourself. Mine was out of fear; "I'm going to lose my mom. I'm going to be stuck helpless and then that I might get it and if I'm not together what am I going to do?" It's just utterly, really scary."

Natalie found that having a family member with breast cancer was overwhelming because it was "foreign territory." She described how a person thinks she knows how she would react but reality isn't the same when she suddenly becomes faced with breast cancer in her own family. She expressed it as the fear of the unknown. She described breast cancer to be her greatest fear,

> "I began to think that there's a real possibility that I could have cancer. It wasn't. It was benign. The scare was and still is real. No matter how positive you are as a person, no matter how healthy you live, it can frighten you like nothing else."

Mandy was unprepared to face the fear of breast cancer. Mandy's mother and father returned home from an outing only to tell Mandy that her mother had breast cancer. There were no prior warnings of medical appointments for Mandy to prepare for such a shock. In the span of a few hours Mandy was told her mother had breast cancer and that she could possibly die. Her mother shared her own fear of dying and leaving behind her four children. Mandy took in this information as best she could and then went off to school. Needless to say, for the rest of the day, Mandy's mind was not on her schoolwork. She shared:

> "I was so in the dark about what this cancer was all about. I think to have heard my mom's fears that afternoon scared the hell out of me."

To this day, Mandy cringes when she thinks just how fragile people are. Practically a day never goes by that she is not reminded of how blessed she is to have a mother who is still healthy. She believed that the day she discovered her mother's breast cancer changed her perspective on life. She gained an appreciation for family and friends like never before. Mandy never wants to take them for granted again.

More Fear: The Second Diagnosis

> *"This evening one of those fears overtook me again. I was sitting in one of our comfortable living room chairs talking about health issues when the veil came toward me. I wanted to run out of the room, to say something totally non sequitur, anything to avoid talking about cancer. I didn't though. If anything I perpetuated the conversation more by relating my own view and asking questions. In the midst of people who I feel know me the best and nurture me the most, I felt alone and scared."* Miranda Eve Weingarten Worthen, (1997, p. 45)

Fear wasn't just a part of the present situation but permeated consideration of the future. Daughters expressed an ongoing fear of having their mother's breast cancer return. They struggled with unwanted thoughts about this possibility, many on a daily basis. A second diagnosis seemed to bring the possibility of their mother dying even more to the forefront. Their lives took on a new state of uncertainty. Even when their mothers' physicals and follow-up tests would come back normal, still, the daughters knew that any day that could change.

Whenever Natalie's mother had a cold or a cough or her bones ached, Natalie's first thought was that her mother had a recurrence or that it had spread somewhere else. She explained:

> "I know that in the back of my mind, the thought of having a mom have cancer and being a female scares me."

Erin also dealt with the ongoing threat of her mother's breast cancer returning. She worried that her mother's platelets would become low. She described her fear,

> "I'm scared, scared to see cancer take all of the things she loves to do away from her even if it will be for a short amount of time."

When Ashley's mother got breast cancer the second time it completely devastated her. She was petrified of being motherless:

> "I can't believe this is happening. This isn't supposed to happen. I'm 15 years old. I can't be without a mother. This can't happen to my family, there's so many things we haven't done. I haven't graduated yet."

Elaine's mother had two scares with breast cancer. She recalled the terror when she discovered that her mother had a lump in her other breast four years after the first diagnosis. Her mother's mammogram came back with an unusual result that needed to be followed up. She didn't remember any panic on her mother's part but there was on Elaine's. The doctor thought that the lump was small and it had been caught early. Still, thoughts bombarded her mind, another positive test! Her stomach hit rock bottom. She cringed at what it might mean. To this day, when Elaine recalls that day she feels sick to her stomach.

Mandy described how they just do not know when things might change for her mother regarding a reoccurrence. Years after Mandy's mother's first diagnosis another scare presented itself to their family. Her mother had been complaining about headaches and they immediately tested her for any sign of lumps, possibly cancer of the brain. Mandy shared her concerns for her mother and what the extensive testing may find. For Mandy and her mother, life was no longer normal:

> "One thing that is extremely difficult for my mom now is that she is no longer normal. Any average pain or ailment isn't average to her. They are always testing her for various things."

Because of Mandy's mother's previous diagnosis, her physicians leaned more on the side of caution. Although the tests were negative, it still was an emotionally draining time for Mandy and her mother. Waiting for results was difficult especially since she had already once had a diagnosis of breast cancer.

As the daughters continually fought with unwanted day-to-day fears that always seemed to be close at hand they were challenged with subsequent diagnoses. Each woman endeavored to find a place for the unwanted intrusion of fear.

Keeping It Together For Mom

> *"For you soon learn that there are some things that simply should not be discussed with the loved one... I think most of my generation believes that "honesty is the best policy" and that spouses should discuss every single thing that bothers them with the other spouse. Bad plan. Openness is important and helpful, but only so far. At some point, openness can become a weapon, a spiteful way to hurt someone- "But I was only telling the truth." I have had much anger and resentment at the situation that Treya's cancer has put us both in, but beyond a point, it does no good for me to constantly dump this on Treya. She hates the situation as much as I do; in any event it's not her fault. But still I am angry and hateful and resentful. So you don't "share that with your loved one, you don't dump that on them. You pay a therapist, and you dump the hell all over them."*
> Ken Wilbur, (2000, p. 359)

The sub-theme of keeping it together for mom related to both the daughters personally and also to their relationship. It reflected a tension between wanting to take charge and yet still feeling dependent on the mother for strength. Their mothers were not available to them during diagnosis and treatment. The daughters no longer experienced a mother in charge. This was both confusing and disheartening for the daughters. Although all the daughters supported their mothers during their illnesses, they wanted their mothers to remain strong for them. It seemed backward compared to how things should have been. The assurance that their mothers would always be there for them in their troubles was no longer available.

It was a difficult time for the daughters because they viewed their mothers as vulnerable and often physically weak. Strength increased in the daughters as their mothers' strength decreased. They did express some ambivalence however while they had the desire to give back to their mother what she had given them, this was often clouded with intense emotions regarding coping with the uncertainties of having a mother with breast cancer. The daughters met the challenge, but inside, they were afraid and earnestly needed their mothers to make everything better. After all, providing assurance and support had always been their mother's role.

Ashley needed her mother's strength but unfortunately it was not available. This was difficult, as she was so young. She did not want to burden her mother with her problems during the difficult times of illness. Ashley knew it was not a time to lean on her mother or to burden her. Ashley was overwhelmed but knew that she had to keep holding it together for her mother. Her deepest desire was for her mother to take charge:

> "What I wanted from my mom was for her to get rid of the cancer and just thinking that it was her responsibility to do that, placing that on her not realizing like how it works, you don't have a choice, it's not like you

> could of … so I treated cancer as if it was preventable and mom was not preventing it."
>
> "You solved everything else. You grounded me when I didn't come home, you can make me feel better, you can handle this but you can't do this. Like what's the big deal?"

There was a feeling for Ashley of knowing that her mother had always solved things in their lives and now she was unable to do so. Ashley was confused and angry. She had previously experienced her mother as strong and capable and suddenly she was not. For Ashley, her mother had let her down. She was not doing what was expected.

Elaine experienced a deep need of her mother's care when her mother was diagnosed a second time. She called her parents to find out the results of the tests. Both parents were on the telephone as her father told her that the news was not good. There was a lump in the other breast this time. Elaine's stomach sank as a blanket of fear surrounded her. Her dad got off the phone and Elaine and her mother continued small talk. Finally, "beside herself" with emotion, Elaine blurted out; "will you be okay?" Her mother responded, "well I hope so!" and they both burst into tears. Elaine tried her hardest to keep it together but her emotions were too volatile and raw. She shared:

> "I felt awful for making her cry when I should have been cheerful and positive but it really was a case of a child needing a parent, a mother's assurance."

At that moment Elaine knew that her mother needed her. She also needed her mother. She did not want to lose control but wanted to be strong for herself as well as her mother. Her mother had always been there for her and Elaine desperately wanted to be the "together one."

> "For the most part I feel like my mom needing me then and now feels like fair. She looked after me all these years, now it is my turn to care for her. Mostly I don't mind that at all but there are some days when I miss that mom who seemed to have all the answers and could make most things better."

Elaine recalled in the next two quotes what she had needed from her mother.

> "I wanted my mom to be completely reassuring and confident that she would be fine and that this was not such a big deal. And of course, I wanted this all to not be true then I would be able to feel relief instead of the horrible sick feeling I had that I could, in the end, lose her to breast cancer. I think if she had responded, "strong" I would have allowed myself to believe that it almost wasn't happening, which is not a good thing, denial."
>
> "I really wanted her to just make things better. This is what I have always relied on her for and the cancer situation was no different. I wanted her to be strong and confident, which you know she has been but she couldn't just make the cancer go. In a childlike way, I wanted her to just somehow make it not so."

In these incidents the adult child wanted her mother to make everything better, to wipe away her pain and confusion. The mother was unable to fulfill this wish but rather needed her daughter to step in.

Mandy was also faced with the need to be strong at a time when she desperately needed her mother. While her mother shared her fears of not surviving cancer and her concern that her children wouldn't remember her, Mandy assured her that she would never let that happen. In this incident, Mandy acted as the parent, assuring her mother that she would take care of things. It was one of the hardest moments of Mandy's life yet she knew she had to be strong for her mother and her siblings. She described her mother as follows:

> "The pillar of strength of her family was weak. Not only was she weak there was a possibility she wouldn't come out alive or be strong for us all again.... When you see two people who hold a family together become so

> fragile and upset at a time like this, it is confusing. It is terrifying! When they are weak and upset not only do you know it's serious you know that life won't be the same for a little while or a lifetime."

Although Mandy felt the pressure of responsibilities on one hand, she felt inadequate. Mandy discovered at an early age that life was not easy. She experienced life as having many questions and not many answers.

When taking the lead role, Natalie was the strong, "hands on," person for both her mother and herself. Suddenly, Natalie felt her mother needed her. She shared in her story how she owed her mother so much for always being there for her throughout her life and the least she could do was to be strong for her during this difficult time in her life. It was not just a feeling of having to be there, she wanted to be there. She viewed it as privilege and an honor to be that intimate with her mother and to be needed by her. Natalie was pleased to give something back to her mother after the years of receiving from her.

Amber expressed her need for her mother to continue with the role that she had always fulfilled. Amber worked full time and experienced much support from her mother in regards to her children. They were a close-knit family with her mother playing a primary supportive role. Amber relied heavily on her mother and she feared that breast cancer would rob her mother from her.

Although Amber was afraid of losing her mother and the role that she maintained, she was pleased for a change in that her mother got more attention. She shared her enjoyment in seeing her mother in the center of attention:

> "For the first time in my life my mom is focused on instead of her kids and everybody else. For the first time she can't do something because she's tired and everybody can't believe that because it has never happened in the history of our lives."

Finally, conversation and attention was on Amber's mother. This seemed right for a change. Even though she was upset about her circumstance, Amber enjoyed her mother getting the attention. Her mother was no longer taken for granted.

Experiencing Vulnerability: What If It Happens To Me?

> *"A black cloak was hovering over my head about to pounce on me and envelope me in terrifying darkness. Not the beautiful darkness of a starless night, but that darkness that exists when all feeling is taken away and all that exists is the void. I wanted to cry, I was so scared of this impending shroud, but I couldn't. I was anxious that crying would stop the conversation and I would never hear what I wanted to hear, but knew would be harmful for me to hear. It was like a gruesome accident on the highway; you don't want to look, but you can't take your eyes off it."*
> Miranda Even Weingarten Worthen (1997, p. 45)

Another of the sub-themes that related to the daughter most personally was *Experiencing vulnerability: What if it happens me?* All of the women shared their feelings of vulnerability to breast cancer. Breast cancer was a constant concern. This was evident in the daughters' incessant worrying and feelings of loss regarding their daily lives. This also affected their future plans. As the daughters witnessed their mothers' experiences, breast cancer took on new meaning. It often seemed like it was overtaking their lives. Also, now that their mother had cancer, these daughters became identified with a larger group of women, that being daughters of women with breast cancer. This family association with breast cancer included them within a new group of women who had an increased vulnerability to breast cancer.

Ashley looked cancer straight in the face at an early age. It was not a reality that she wanted to consider. It seemed like cancer was all around Ashley – her grandmother, her great grandmother, and three aunts had experienced breast cancer. She remembered taking her mother to chemotherapy appointments and the results her mother experienced for example, getting sick and her hair falling out. Inside, she felt like these experiences tore her apart. She explained her vulnerability:

> "It doesn't even seem like the cancer, it's the stuff that comes after, like the sickness, having to take the pill, the constantly having to go back to the doctor. Every time I hear a doctor in my house, I think, "oh, my God," I'll have these little panic attacks at night, like, "oh, my God," I'm going to die of this."

Worry plagued Ashley. She worried about her daughter, she worried about her mother and she worried about herself. It seemed that everything in Ashley's life seemed to relate to cancer. She often felt as if there was a huge weight upon her shoulders. She tried her best to keep things together and to do everything in her power from developing cancer. She described her concern:

> "It's like what if I do find out one day, what will I do? What if I lose breasts before I have all of my children and what if… it's just really, really scary"

> "It's like, oh my God, I'm going to get skin cancer. I'm going to get lung cancer. I quit smoking when I had my daughter. You know, it's like really scary all of the time that this cancer is going to overtake my life"

Ashley described breast cancer as a huge force that seemed to overtake her life. She said it was something that pulled her family together yet tore them apart. The constant worry and rallying around her mother and the fear of her dying pulled them together. Yet, because of her fear of losing her mother, she distanced herself from her family. Her acting out behaviors caused conflict in the home and often tore them apart. The two forces were contradictory: there was so much conflict; yet there was closeness in the midst of it all. Although Ashley pushed away, she loved her family very much. She felt love and hate at the same time. She hated her mother for getting cancer and not being able to take care of herself. Yet she loved her mother so much and was petrified that she would lose her.

Ashley was also afraid of change. Prior to her mother's illnesses, Ashley loved change. Now it became something to be feared. Change started to represent bad times. It seemed to her that anytime things changed in their house that it was for the worse. For example, her grandfather got sick and things changed, her mother got sick and things changed. To Ashley, change meant sickness and in particular, cancer.

Natalie felt that breast cancer can come with no warning and can change one's life. Recently her physician recently found a lump in Natalie's breast. She underwent a mammogram, ultrasound and finally a needle biopsy. Her results came back negative and it was thought to be a ridge of muscle tissue. Considering her mother's history, the physician was extra careful. Natalie felt even more vulnerable to cancer because her mother had breast cancer. Her mother lived a healthy lifestyle and she still developed cancer. Natalie reasoned that because her mother got breast cancer anyone could. She said that it frightened her like nothing else. She described breast cancer as foreign:

> "No one believes that it will happen to them and it can overnight. It is the fear of the unknown."

Natalie explained that whenever a family member is diagnosed with cancer it is difficult. Yet, when it is the mother who has breast cancer, the daughter feels particularly threatened. She explained how women find it difficult enough feeling comfortable in their bodies let alone when they have a family history of breast cancer. Natalie's mother's experience made her consider the importance of her breasts. She described that being female is a closeness that only women share. For Natalie, simply being female was a threat. It seemed that her vulnerability was often close at hand:

> "The fact that I am a daughter presents a different feeling. Being a female I understand what a breast means to be a female and now with breast cancer in my family, the significance is even more in that I too could possibly go through this experience someday."

Erin also shared her vulnerability to breast cancer:

> "I was just thinking... I'm a daughter of a mother with breast cancer. You know, it's like it's nothing you never really think would ever happen to you... it's just the stats sit right in front of your face when you're actually experiencing it."

Because of her vulnerability to breast cancer, Erin became much more aware of what she put into her body as far as food and caffeine. She also felt that people tended to minimize breast cancer and its affects. She believed that because breast cancer received so much exposure that people often tended to minimize or glibly assume everything will be okay for Erin and her family. She often wanted to talk about breast cancer but felt others' discomfort with the subject:

> "Like I'm not supposed to cry about it and I'm not supposed to worry about my mom, I'm not supposed to really talk about it. It's so great to have people in my life but I just felt like it's something that people don't want to talk about."

Amber, on the other hand, felt that her life became more public when her mother was diagnosed. She felt identified with breast cancer but it was an identification she did not appreciate. She described how she suddenly felt she was a part of a club, one that was well researched and talked about whether in advertisements, television, or medical pamphlets, but certainly was not prestigious:

> "You all of the sudden have this membership to a group of women and you have a membership to this building where they treat cancer that you kinda drive by and you hope you never are there. So then you go through the doors all of the time … and it's not such a scary place anymore and it's not this ominous place and it's just like going anywhere. So it's like you have this membership."

She did not like the connection she felt to others as a result of breast cancer. Amber felt that people were thinking that her children would lose her to breast cancer. She felt that even once you've worked through the diagnosis and treatment period and you had been given a clean bill of health it seemed like no one really lets you forget that you are a daughter of a woman with breast cancer. She felt labeled. She appreciated the concern and care from others but just did not like being linked to *that* particular group. Being a daughter of a woman with breast cancer gave Amber a feeling of people knowing too much about her personal life.

When asked what she thought that people did not understand about being a daughter of a woman with breast cancer. Amber replied:

> "What is it I want people to understand? I guess although it is a public experience you want to handle it as privately as you can…. Don't dote over me, I'll be fine…don't sign me up for the cancer clinic quite yet… yeah like don't sign me up next. I'll be fine and don't dote over me. It's not helpful at all."

Elaine's research and experience with her mother's breast cancer made her very concerned about breast cancer and her health in general. She still to this day is "freaked out" by the risk factors, particularly because she has all of them:

family history (e.g. she had a grandmother and mother who have had breast cancer), early menstruation (e.g. she menstruated by age 10), having no children (she does not have children). Elaine was scared because statistically her own chances of developing breast cancer were high.

One of Elaine's greatest disappointments to date had been that she still did not have children. This was particularly disconcerting, as she wanted so much for her mother to enjoy grandchildren. Elaine and her husband had often talked about having a family but it didn't quite seem to be the right time. She had witnessed the wonderful relationship that her nieces and nephews had with their grandparents and she wanted that for her own children. She wanted her future children to know her mother well and remember her while she was healthy and active. Her mother's experience of breast cancer seemed to make having children more of a priority.

Breast Exams: The Terror Of Finding Something

> *"Mastectomy. This is what I had decided by the time I called Derek to give him the news. I'm not attached to this breast in any significant way, I told him, near hysteria. As far as I was concerned, it had served its purpose in nurturing and feeding Alexandra. It certainly doesn't define me as a sexual being or as a woman. And, as for its sexual sensitivity, Derek could caress my pinkie and get the same response-take it off! I don't need it, don't want it. If it could quite possibly be the vehicle by which I died, take it off!"*
> Patricia Jones Bacchus (1997, p. 91)

Another personal fear was represented by the sub-theme, *Breast exams: The terror of finding something.* The women's experiences included their fears surrounding breast examination practices. This sub-theme was related closely to their feelings of increased vulnerability. There seemed to be a fear of performing breast examinations for fear of what might be found. That was demonstrated by opposing reaction by being either over vigilant or by avoidance. The importance of breast examinations seemed to take on a different meaning for daughters when they discovered their mother had breast cancer.

Each woman faced the reality of finding a lump in her breasts and the looming possibility that it could be breast cancer. What if they too got breast cancer? Although each woman was aware that self-exams could save their lives, they experienced fear of what outcome that exercise may provide. Even performing regular breast exams did not alleviate their fears because the possible outcome could in fact become a reality.

Natalie shared how having a family history affected her chances of developing breast cancer. She had always believed in breast exams prior to her mother's diagnosis, but she now checked her breasts every week. Ashley became over vigilant in performing breast examinations. She constantly checked her breasts, almost each night. Although she knew it did not make sense, Ashley felt compelled to continue this process. She needed to check and re-check her breasts just in case there was something.

According to Erin, everyone should be afraid of cancer. She felt fortunate in some ways to have had her experience, as she believed it would cause her to be aware for the rest of her life. She suggested that she would never let a lump or bump escape her thoughts. She said that she would always get it checked. Erin checked her breasts every seventh day of her period.

Elaine on the other hand, had a real problem doing self-exams. She explained:

> "How difficult is that? Here I have a high risk for breast cancer and I can't even do a simple monthly exam. I can't explain why… I am afraid that I will find something. My husband gets very impatient with me about this because of course it is better to find anything that might be there early so it can be treated. I know that but I can't seem to get past it… I am essentially taking the "doomsville" approach and almost reconciling myself to getting breast cancer at some point in my life."

Elaine shared her fears with her doctor who responded that she needed to get over her anxiety and persist in performing regular breast exams. Elaine made attempts every so often. She knew that to expect cancer as the inevitable was not healthy and described it as "insane" to just give up and accept that it will probably happen to her one day. She said that she didn't know if she would ever accept the possibility of breast cancer for her, but still, the fear was real. She also worried that her glum attitude might in some way, actually cause her to get cancer, such as a self-fulfilling-prophecy. Still, she resented that she even had to reconcile with the disease of breast cancer.

Feelings Of Terror: Mom Might Die

> *"I curl up on the couch, pulling my blanket tighter around me. All is quiet, very still. How many other women, I wonder, have also awakened in the middle of this same night with the same stark knowledge? How many awakened last night, how many will awaken nights to come? How many women have heard this word CANCER pounding like an endless drumbeat inside their heads, relentless, unforgiving. CANCER. CANCER. CANCER. This cannot be undone, this cannot be erased. CANCER. A cloud of voices, images, ideas, fears, stories, photographs, advertisements, articles, movies, television shows arises around me, vague, shapeless, but dense, ominous. These are the stories my culture has collected around this thing, "the big C." These voices and stories and images around me are full of fear and pain and helplessness. This big C is not a good thing. Most die from it, the stories tell me, their deaths often protracted and painful, terrible indeed. I don't know the details. I know very little about cancer, really, but these stories tell me it is terrible and painful and uncontrollable and mysterious and powerful, especially in its mystery. No one understands it, this growth gone out of control. No way to stop it or direct it or ultimately to contain it. A wild, blind growth that ultimately destroys itself and its host with its voraciousness. Blind, self-destructive,*

> *malevolent. No one understands it, not how it begins or how to stop it."*
> Treya Wilbur (2000, p. 40)

Another fear was represented by a sub-theme that is related specifically to the possible death of a mother. This was labeled, *Feelings of terror: Mom might die.* Although the possibility of death is a reality for each of us, daughters of women with breast cancer become in touch with this reality on an ongoing basis. Both adult and teenage daughters frequently spoke of the possibility of their mothers dying. Although they continually fought their negativity, their stories illustrated the real fear of losing their mothers. They expressed their innate need for their mothers to be there for them and to continue on with the roles that they always had provided. The thoughts of death often bombarded their minds.

Natalie knew things could change over night. She worried that her mother's cancer might return and that she could possibly die. If it could happen to her mother one time, it could happen to her a second. Or, it also could happen to someone else in the family or even to Natalie. She tried to stay focused in the present and not to dwell on the "what ifs" but it was not easy. It seemed that the possibility of a reoccurrence was often lingering in her mind:

> "Breast cancer can come to someone without much warning and can totally change ones life. Here was a woman who lived a healthy lifestyle and still got cancer. Does this not mean that anyone can get it for any reason or better yet no reason at all? With the diagnosis of cancer always comes the thought of death, loss, and grief, all of which my mom and probably all of us went through. Death of her beauty in the way that she knew it, loss of an important part of her body and the grief that accompanies all loss."

Fifteen-year-old Ashley was petrified of losing her mother. She felt panic every time she spotted a letter or they received a call from the cancer clinic. Her grandmother got breast cancer in her later years just like her mother and aunt. She dreaded getting old herself and developing breast cancer.

Ashley imagined what she would do if she did not have a mother. She made plans in her mind about how she would act. She imagined all the things that a mother did: the laundry, the cooking, etc. She imagined parent teacher interviews without her mother. She could not believe that her mother actually might die. Ashley described her mother's breast cancer as something that was not supposed to happen. She said that it was something that should not happen to their family. She felt like there were so many things they had not done. She pondered life without her mother.

> "I'm going to get married and what if my mom dies? It's important that she be there. It's important that he meets her and she's a part of my life. So that's really scary."

Amber considered from time to time the possible death of her mother and how it would affect her. She described her anxiety of not being ready to face the possibility that her mother might die:

> "I need her because I have 2 small kids at home... she'll bring over cookies or she'll phone them during the day. I rely on that relationship a lot. And I say, no, no you can't go, you can't die yet. I'm still young for you to die. I still need you as my mom."

Elaine came to realize the frightening possibility of losing her mother when she discovered that her mother had cancer a second time. Her thoughts rushed into remembering her grandmother who had actually died of breast cancer. Hearing the news that her mother had breast cancer a second time was devastating:

> "This time it hit me like a truck. The reality that this was now a second round with the same cancer. What would that mean? I cried because I couldn't imagine not having my mom and because it seemed so unfair that she should have to go through this again.... Everything seemed very bad. I couldn't believe it was happening again and I was scared too about what it meant for me."

She can remember looking to her mother for assurance when her mother had been diagnosed with cancer. She wanted so much for her mother to make things better and yet she was unable to give guarantees.

Mandy was a young teenager when she faced the possibility of her mother dying. She described her experience:

> "I was scared that we had to pull it together for her. I was scared I wouldn't be able to help her. I was scared that she would slip away and I would never get to be with her as I was at that moment."

For these women death became a harsh reality that they wished would go away. Not only were they faced with the reality that their mother had breast cancer, they also faced the possibility of losing their mothers. They witnessed their mother's illness, which was a powerful reminder of what that might personally mean for them. For these women their fears never seemed to subside for long.

Changing Of Roles: It Feels So Backward!

> *"But something has changed this time. Both of us are exhausted. Both of us are starting to fray at the seams. It is as if we both carried a huge and heavy load up a steep mountain, carried it up quite well and set it down quite carefully only then to completely collapse. Although the strain had been building slowly in both of us, particularly over the seven months of chemotherapy, we both came unraveled rather abruptly, as abruptly as I have introduced it in this narrative. It just seemed that one day we were fine, and then the next day life came apart at the seams like a cheap suit. It happened so suddenly, it caught us both off guard. I do not intend to dwell on this period in our lives, but neither will I gloss over it. It was, for the both of us, hell."* Ken Wilbur (2000, p. 140)

Another sub-theme for the daughters related to the typical mother and daughter interplay and how breast cancer had turned their roles around. This was illustrated by the phrase, "our roles were reversed." Over our life cycle there are certain role expectations related to mothers and daughters. Generally, it is the mother who takes the lead role and the daughter follows. Breast cancer disturbed this expected relationship for all six women. Where in the past the mothers took the lead for their daughters' health care, now they were expected to take lead roles in regards to their mothers. The daughters experienced a role reversal in many areas during their mothers' diagnosis and treatment, but particularly in the medical interactions.

One way that the daughters took lead roles were in asking medical questions and gathering information. Natalie had a list of questions ready for the surgeon. These were related to the size of the tumor, the grade, and of course, options. Natalie had anticipated both negative and positive options when they consulted a surgeon. Her mother was confident they wouldn't need the questions, as she believed she didn't have breast cancer.

As reported in her narrative description, Natalie felt the weight of knowing her mother's outcome well before her mother had. In this case, rather than the mother having initial information, it was the daughter. Natalie felt helpless, as she desperately wanted to save her mother from any bad news but knew that there was nothing she could do. Natalie was concerned and began taking care of her mother well before her mother was aware that she needed help:

> "I right away put on the social work hat and explained to mom what a wire-biopsy entailed. I also explained to her that if the surgeon felt it was probably nothing then that was what she should go with for now. Inside, I remember feeling very nervous as how many times had I heard this before. Mom had never smoked, she has always lived a healthy life-style, is not a drinker and had no familial history. Yes, the surgeon must be right!"

Natalie spent the next two weeks educating her mother about types of surgery and treatments. She made arrangements for her mother to talk to a woman who had had a mastectomy. She took her to the prosthesis shop, the cancer clinic, and gave her written information regarding pros and cons of each type of surgery. She provided information about issues such as the meaning of "estrogen positive." Although it was difficult for Natalie to be the strong one, she felt she had no choice. Her action in taking charge was simply automatic, she had to take the lead role.

At the time of the interview Erin's mother had been diagnosed 3 months previously. Erin was involved in making decisions about her mother's surgery and supporting her during her two chemotherapy treatments. At that point, it still did not feel that her mother was dependent on her. In many ways, Erin felt that her mother was more of a strength to her rather than vice versa. She shared:

> "I wish I could be more for my mother. I wish I could be way more. It's just that she has it all together."

For Erin, her mother seemed to find her own strength as well, during diagnosis.

Amber recalls giving herself little pep talks such as, "Be strong, be strong, you know you're there because you're supposed to help her out." Amber was very involved with her mother during the decision making process. Her mother wanted her to be present for all of the appointments. She knew that Amber could talk with the doctors and ask all of the hard questions. Amber asked the things that her mother did not understand at the time or that she thought her dad would not have considered. Amber and her sister were involved with their mother in the final decision making process such as whether her mother should have a lumpectomy or mastectomy. She expressed her feelings regarding being able to take the lead role for her mother:

> "You finally feel like after all of those years that you can finally give back in some way, in some very little way. Like you can reciprocate."

Ashley was care giving well before most women her age. She experienced a role reversal while she was a young teenager. Instead of her mother taking her to appointments, Ashley took her mother to the cancer clinic. She often watched with horror as her mother was in the treatment process. Her teenage life was thrown out of order. Her life was wrapped around keeping things together. Ashley had to redirect her life activities around her mother rather the other way around. She shared her experience of driving her mother to chemotherapy appointments:

> "You know, it just tears a person apart, like I wouldn't go to school, like I'd have to take her in the morning. I got excused from classes because I had to take my mom. Dad had to work, my sister couldn't drive and my grandparents didn't drive and we wanted someone real close and all the other family members were far away so I had to take her. And I remember, I think part of the time I didn't even have my license. But I had to wait there. You know, she'd come out and she'd be sick and pale and yucky and she'd get sick after and I'd have to stop the car on the ride home so she could puke. And here I'm taking the mother role, taking care of my mother like that, at that age, was really, really tough. So I started to hate breast cancer."

Elaine rushed to the hospital the day her mother had surgery for the removal a second lump. She so badly wanted to be there for her mother but could not get away from work until after the surgery. Elaine felt that no one would do as well as herself in caring for her mother. It was very important to Elaine that she was able to care for her mother. She was willing to do anything to help her. She dressed her wound and cleaned her after she had been sick. She had no resentment in taking on this "mothering" role. Elaine just wanted to be there and nurture her mother. She felt a sense of relief to have finally taken care of her mother:

> "She was groggy and needed me! … I remember staying until past visiting hours. I had a hard time pulling myself away. I helped her when she had to throw up and go to the washroom – a total role reversal."

During her mother's illness Mandy became responsible for day-to-day duties around the house. It seemed that Mandy always had more responsibility than her friends, some due to looking after younger siblings and others due to her mother's illness. She felt the weight of her family in a most unsettling situation. Her role as a daughter was now different. Since Mandy was the eldest child, the responsibility around home fell on her shoulders. She felt a need to be strong for their family and somehow kept things as normal as possible. It was very traumatic and emotionally draining for Mandy but it made her mature quickly:

> "There were nights I felt I was missing out. Every weekend I wanted to hang out with my friends and I knew I had to baby-sit.… I always felt like I was missing out on my socializing yet I felt that I was being responsible."

Mandy went with her mother to her radiation sessions. She remembered seeing the radiation burns that looked like sunburn.

Not all of the personal responses involved fears. Daughters also described the experience of their mother's breast cancer as having positive elements. For the daughters in this study, breast cancer affected their relationships with their mothers as they reached a new level of intimacy due to its affects. This is represented by the sub-themes, *Moments of intimacy: Mom and me,* and *Admiring Mom: How can she be so strong?*

Moments Of Intimacy: Mom And Me

> *"All that I am or hope to be I owe to my angel mother".*
> Abraham Lincoln

Not all of the personal responses involved fears. Daughters also described the experience of their mother's breast cancer as having positive elements. This is represented by the sub-theme, *Moments of intimacy: Mom and me.* Mothers are often typically viewed as strong for their families. Other issues often shadow their fears, concerns and worries. It is often in moments where life does not make sense that families experience mothers in a different light. The daughters in this study had the opportunity to experience their mothers in a deeper, more meaningful way. They experienced a side of their mothers like they never had before.

Natalie's friendship with her mother took on new meaning the evening of her operation. Her mother explained to her that although she was positive and believed strongly that God would take care of her still, she was frightened. That night at the hospital, Natalie's mother revealed her vulnerability to her daughter. Natalie referred to the experience as " the most intimate time of my mom's life and I was a part of it." Prior to her breast cancer, Natalie's mother had never shared her fears with her. At that moment, her mother became a human being on equal terms with her daughter. In the safety of that moment, Natalie's mother shared her deepest fears with her daughter. The closeness and intimacy that the two shared at that time was their most meaningful moment to date.

Erin and her mother had always been close. When Erin was a young child, her mother had shared her past with Erin. Erin had always respected her mother for this disclosure and also told her mother everything. They would laugh together, went for drinks together, and had “giggly stupid times” together.

The week before her diagnosis, Erin and her mother had gone to a Janet Jackson concert. Erin was surprised to see her mother totally “let loose” at the concert. Her mother secretly knew that her lump might be cancerous and the concert was a release for her. Erin did not understand the reason for her mother’s freedom but was thrilled to witness her mom acting so ridiculous and silly. All of her friends admired her mother and wished their mothers could be as much fun. Erin was happy to experience her mother as fun loving, even to the point of silliness. Erin felt that although their relationship had changed since her mother’s illness in some ways, they still were close. She shared her deep feelings of love for her mother:

> “ I guess it’s just, I don’t know if I’ve totally expressed to my mom how much I respect her.”

Amber had also been close to her mother both prior and after breast cancer. Although Amber and her mother shared a lot of their life experiences with one another, her mother had never talked personally about her relationship with her dad. After her diagnosis, she began to share openly and intimately. Their relationship was more of an equal sharing between two friends. Amber felt that since her mother’s diagnosis her mother leans on her like she never had before.

She shared:

> "She talks more about her relationship with my dad more….She never shared that about their relationship. Their relationship was something I didn't really know about. So she talks about my dad, their relationship now and that's been interesting, as she never really revealed that part before."

Mandy and her mother have always had a close relationship, more like a friendship than most other mothers and daughters. They talked and fought like friends. When Mandy arrived home after school she found her mother laying on her side facing the window away from her. Mandy did not know what to say. Her mother started talking about her life and Mandy began to feel scared. Her mother talked about how she was worried that her youngest three year-old son would not remember her. At first Mandy did not quite understand. Mandy then realized that her mom was talking about a situation where she might die. Would her children remember her? Mandy climbed on her mother's bed and snuggling in with her as they both cried and cried. As Mandy shared, "it was our moment." Mandy believed that her mother's illness contributed to their special bond.

Since her mother's diagnosis with breast cancer, Elaine felt that she needed to talk to her mother every day. Outside of their daily telephone conversations, Elaine tried to spend as much time with her parents as she could. She believed that she had a closer relationship with both of them because of their scare with breast cancer. She shared:

> "For now I try to spend as much time as I can with my parents and I think I have a much closer relationship with them both because of the breast cancer. I guess that is one positive!"

Admiring Mom: How Can She Be So Strong?

"The influence you exert is through your own life and what you become yourself".
Eleanor Roosevelt

Sometimes good things happen in the midst of some of the darkest moments in ones life. Relationships although they endure strain, often become stronger in the face of adversity. The daughters of the study shared their deep admiration for their mothers as a result of their breast cancer. They admired the strength their mothers exuded in the midst of their illnesses. Although the idea of developing breast cancer was not in their plans, daughters hoped if they ever had breast cancer that they could be as brave as their mothers. Their respect and admiration for their mothers reached a new level.

Natalie expressed the positive impact of observing her mother face a life threatening illness:

> "I think the greatest impact on me of my mom having breast cancer was being able to see and share in the strength that she had developed when faced with a life threatening illness. The admiration for my mom and what she went through and continues to live with every day is a true testament to her faith and desire to remain positive. I believe that if I end up with cancer at some point, going through my mom's experience with her, will only encourage me and keep me strong as a person."

Erin also admired her mother's strength when she was first diagnosed with breast cancer. On the Friday that her mother was diagnosed they had plans to go to their family cabin. Her mother found out the diagnosis and three hours later was packed and ready to go camping. Rather than changing plans, her mother insisted on going camping especially since all of the family would be there. Erin described her mother's attitude as amazing. Erin admired how her mother loved her family and the way she'd been there for everyone. She was constantly doing new things for her family. She also admired her mother's ability to push ahead even in the face of adversity:

> "If I were to go through exactly what she's gone through I wouldn't want to change a simple thing. Like she's done everything so incredibly well with such grace. She's never asked for sympathy. She's never ever even hinted that she wants someone to shed a tear for her. That's pretty amazing."

Erin described her mother as an amazing woman who went through her diagnosis with such grace:

> "A couple of days after chemo she was a bit drowsy and I think she just flipped her wig off, like "ta da!" My father had shaved it. The plan was for us all to do it, but the timing didn't work. I thought she looked beautiful when she showed me. She has a well-shaped head. She's fortunate. I think she pulls it off with a lot of grace."

Elaine was also amazed at her mother's positive attitude during her cancer diagnosis and treatment. She could not remember her mother ever breaking down. This positive attitude helped Elaine to believe that they would beat cancer. Elaine too shared her admiration for her mother:

> "Through it all my mom's attitude has been so good. She is a positive, busy, active, happy and healthy so far! I look at her and hope that I could be the same if I ever go through what she has."

Mandy described her mother as the most wonderful and strong mother of four children at the weakest time of her life. Over the passing years Mandy watched her mother inspire many of her friends who faced similar personal difficulties. She shared her deep admiration:

> "My admiration for her has grown so much and the shock that made me confront how fragile life really is has also made me see every day as a blessing. Every day with my life and every moment with my mom and family are precious. My most important fan is my mother…At 22 , my mom is absolutely the most important person in my life and I know I still don't tell her that enough."

Conclusion

The daughters experienced overwhelming fears both for themselves as well as their mothers. Although difficult to handle, breast cancer provided an opportunity for a greater sense of intimacy and a celebration of their mother's strength. Human responses are not unitary. Our fears reside along with our joys and celebrations. Our experience in dealing with the unknown, the unspeakable, and the most frightening have the potential to generate hope, new aspects of current relationships, and a new discovery of self. Living with fear is a most daunting experience that triggers many thoughts and emotions. Still, in the midst of a most difficult situation we may experience new closeness and love for others in ways not experienced previously. As one woman from my practicum at a large cancer center in a metropolitan city shared, "I would not trade the experience of breast cancer because of what I have experienced within myself." This statement, in my opinion reflects the reality of a positive deeper experience in one's life in the midst of a most frightening hell.

It is difficult to comprehend how good may come out of a most difficult, frightening experience. Thus our experiences may be two-fold: the experience of a most frightening, most difficult time in one's life along with a most intimate and deeper experience with another individual. It is said that one cannot experience the mountaintop until one has experienced the valley. Daughters of women with breast cancer experience both ranges of emotion. They are a living testament of courage, strength and commitment in the midst of most uncertain difficulties.

CHAPTER V

DISCUSSION

> *"What is more difficult for the support person, however, and more insidious, is the inner turmoil that starts to build on the emotional and psychological levels. This turmoil has two sides, one private and one public. On the private side, you start to realize that, no matter how many problems you personally might have, they all pale in comparison to the loved one who has cancer or some other life-threatening disease. So for weeks and months you simply stop talking about your problems. You sit on them. You don't want to upset the loved one; you don't want to make it worse for them; and besides, in your own mind you keep saying, "Well, at least I don't have cancer; my own problems can't be so bad."*
> Ken Wilbur (2000, p. 357)

The purpose of this study was to explore the experiences of daughters of women with breast cancer. The key findings of this study, in particular, fear issues, relationship issues, and normalization will be discussed in relation to current research. Following this discussion the implications of this study will be considered and finally, the strengths and limitations of the study will be identified.

The Key Findings in a Research Context

Fear Issues

Wellisch and Lindberg (2001) described having a mother with breast cancer as constituting a traumatic event that triggers extreme fear and a feeling of helplessness. Fear represented the essence of the experiences of all of the daughters in this study. Fear surfaced in many different ways such as the daughters' expression of vulnerabilities and uncertainty and also in their reported feelings of having their lives altered as a result of breast cancer. According to Lewis (1986), uncertainty on the part of family members related to the patient's prognosis, the outcomes of the disease's treatment or recurrence, future vulnerability, and family members' inability to predict the future disease course. The daughters in this study experienced some of the same uncertainties. For the daughters, what was once stable and somewhat secure in their lives was no longer so. There was a constant fearful concern for their mothers. Fear permeated their minds towards their mothers and also for themselves.

Fear was something that never went away. For the women in this study, the reality of breast cancer was always in the back of their minds. The thought of breast cancer was always there, waiting to attack at a most seemingly inopportune moment. Breast cancer was constantly hovering at a distance, similar to a nagging headache that persisted as the daughter carried out her day-to-day business.

The findings of this study were similar with respect to fear associated with uncertainties to those found in a study by Wellisch and colleagues (1992). The researchers studied 60 daughters whose mothers had breast cancer. They deduced that the daughters perceived that their mothers' breast cancer had altered their long-range life plans. Hilton (1993) also studied family members who had mothers with breast cancer and found that the daughters' worlds were no longer predictable. This type of unpredictability was also one element of fear expressed by daughters in the current study. Their futures were no longer viewed as safe and predictable. This view created fearful uncertainties. For example, some daughters were uncertain that they would not have children before their mothers could possibly die. Other younger daughters feared their mothers would not be around for events such as parent teacher interviews. Thus, the daughters felt that their life long plans could possibly be altered by their mothers' breast cancer. But there was no way of being sure just how. They were plagued with the possibility of that their mothers' lives would be cut short and the very thought of losing their mothers' interaction with them and their families was unthinkable.

While there was strong evidence of such unpredictable events generating fear the daughters in the current study also expressed views that things would be okay. This finding may be somewhat conflicting with the results in Gilbar & Borovik (1998) where the daughters in the study had a greater sense that things would not work out in their futures. Although the daughters in the current study were not confident that their mothers would live to see grandchildren for example, there still seemed to be a belief that things would work out. It was as though sharing their mothers' experiences with cancer and their courage and perseverance under duress that they viewed the future in a more positive light. This was evident when the daughters shared their admiration for their mothers and what they had gone through. Although fear was present for the daughters, there was a consistent belief that things would work out. For example, it seemed that as their fears surfaced in the possibility that breast cancer could happen to them, there was a igniting of hope and belief in themselves based on the example of their mothers' coping and survival. They reported that if they got breast cancer that they could also push through it. Although the daughters' futures were uncertain, they had a strong belief in themselves and their outcomes.

The increased fear of getting cancer for close female relatives has been well documented. Lerman and others (1995) studied 200 women who had a family history of breast cancer. After three months of individualized breast cancer risk counseling they found that two thirds of women continued to overestimate their risk of breast cancer. Gagnon and colleagues (1996) discovered that 76% of high-risk women actually doubled their actual risk of developing breast cancer. This is also similar to other findings of other researchers (Black, Nease, & Tosteson, 1995; Esplen et al., 2000; Lerman et al., 1995; Wellisch et al., 1991; Wellisch & Hoffman, 1998; Wellisch & Lindberg, 2001). Although the daughters in the current research did not directly state an overestimation of risks, they expressed their concerns about their family histories and how this might affect their futures. The daughters' constant battling of their day-to-day fears may also be an example of an overestimation of the possibility of breast cancer in their lives. The daughters realistically wondered whether they in fact would possibly get breast cancer. All of the daughters spoke of the possibility of this unwelcome reality.

The participants often expressed having intrusive thoughts about breast cancer. These are reported as uncontrolled thoughts and feelings. Many other researchers have described the presence of intrusive thoughts on the part of family members of cancer patients. For example, Lerman et al. (1993) accounted a substantial proportion of the daughters of women with breast cancer reported experiencing intrusive or uncontrolled thoughts and feelings. Baider and colleagues (1999) in their study of psychological distress in daughters also found they had higher amounts of intrusive thoughts than daughters without a family history of breast cancer. Women in this current study reported experiencing fears that haunted them in their everyday lives. This was experienced as disruptions to the daughters' daily functioning whether at work or at home. This was also evidenced in the daughters' repeated comments about having a mother with breast cancer. The intrusive thoughts focused on the possibility of getting breast cancer themselves along with the reality that their mother could die. The daughters in this study were continually reminded that their lives were no longer as normal as they once appeared to be.

The daughters who participated in this study also experienced fear in the form of an increased vulnerability in being a female. The very characteristics associated with being female became an enemy. Their breasts were no longer viewed as simply physical and sexual entities. Their breasts became something to be feared and were no longer safe and prized body parts. They constantly wondered whether they had "safe breasts." Their mothers' diagnosis of breast cancer robbed them of this comfort with their body. Their breasts were now viewed as being vulnerable to a very unwelcoming disease such as breast cancer. The daughters experienced what Holland (1989) described as "cancer-phobia", in that they had ongoing thoughts about the possibility of cancer that never seemed to move too far away.

For women, breast cancer as compared to other types of cancer and even other serious diseases such as heart disease, is often viewed more negatively. Statistics may play a small part in generating this fear. There is certainly some substance to the anxieties generated by the increased possibility of first generation relatives of breast cancer patients contracting cancer. For example, women with a sister or mother are 2-3 times more likely to develop breast cancer. Also when a woman has both an affected mother and sister, she is 14 times more likely to develop breast cancer (Canadian Cancer Statistics, 2001). But are there other reasons why breast cancer generates so much fear? These powerful fears relate to the daughters' beliefs in regards to the meaning of breasts to a woman, to her partner, and to those she relates with. Do individuals see women who have lost a breast differently as compared to women who have lost a limb? It seems that they do. It seems that breasts in our society hold many associations and attachments. Breasts are perceived as a central feature of female identity and womanhood. In our society breasts are very important, often too important. A woman's belief and the meaning that she and others attach to breasts has significance in understanding the fear of contracting breast cancer and losing a breast.

Relationship Issues

The second area of discussion of these findings relates to the issue of the impact of breast cancer on the mother-daughter relationship. There seems to be a connection that goes deep with mothers and daughters. Mothers may be a daughter's view to their future experiences. Daughters tend to relate to their mothers with respect to who they are as well as to whom they may become. Often the connections between mother and daughter are tighter than many daughters choose to admit.

When a mother has breast cancer, the fears that surface for the daughter relate directly to the mother, to the daughter, and to their relationship. Relationships can change in many ways given a crisis situation. They can become better, worse, or stay the same. The literature tends to differ as to whether and how the mother-daughter relationship changes when a mother has breast cancer. Wellisch et al. (1979) and Wellisch et al. (1991) reported negative changes in the mother-daughter relationship as a result of a mother having breast cancer. Role expectations and responsibilities had an affect on the mother-daughter relationship. Role overload and role reversals added strain to the mother-daughter relationship. Often daughters were expected to carry out more of a mother role and the mother played a childlike role.

Yet, Lichtman et al. (1984) in their research found that one half of the women interviewed reported no change in their relationship with their mothers. For most relationships that changed, there was more of an improvement rather than deterioration in their relationship. This was evidenced in greater understanding and closeness between the daughters and mothers and also in the admiration daughters felt towards their mothers.

For the daughters in this current study, they gave consistent evidence that the mother-daughter relationships inevitably changed. One important area was in the nature of the roles between mother and daughter. Role reversal was common during the experience. Depending on their perceptions, the daughters reported that this role reversal was either positive or negative. For some daughters, the role reversal was a positive change and seemed overdue given all the things their mothers had done for them. They talked about appreciating the fact that their mother was getting more attention, even though they did not appreciate that it was due to illness. For other daughters, the role reversal was viewed as an upheaval and was experienced as unfair.

Age seemed to make a difference as younger daughters perceived the role reversals as more negative changes. Here the important fact was whether the role reversal was stage/age appropriate rather than untimely. For younger daughters, taking on a mother like role as an adolescent was backwards. This was also true of daughters who were in their twenties when their mothers were diagnosed. There were contradictory feelings of taking on a more adult role toward their mother. There was a contradiction in that the daughters were needed by their mothers to act as a strong adult at the same time that they needed their mother to address their "child like" needs in a crisis situation.

The findings of this study revealed the daughters' strong need of their mothers' nurturance and reassurance in the midst of the demand for them to be a strong adult person for their mothers. This was one element of the study that I had not anticipated: adult daughters seemingly resorting to a childlike need in the eye of crisis. It was as if the daughters needed their mothers to help them through their own fears and not vise versa. This is generally the role that mothers play: to help their children through their concerns and fears. For the daughters in this study, there seemed to be a tension that surfaced inside where they knew they needed to take care of their mothers. Yet, they still wanted their mothers to be there to take care of them. The mothers who had always handled life's challenges in the past now were unable to carry this out. Again, fear permeated into the mother-daughter relationship. It seemed that daughters were fearful of the losses represented by the role reversal that breast cancer demanded of them. The losses daughters feared went far beyond losing their mother's physical presence. They feared the upheaval of the role that their mothers had always fulfilled.

The literature to date has revealed similar findings (Lichtman et al., 1985; & Wellisch et al., 1979; 1992; & 1998). This study reveals the angst of daughters at a most frightening time of their lives. While daughters took charge of their mother's needs a new dimension of the relationship surfaced in the midst of a role reversal. Still, they felt the raw need for their mothers' care. It was painful for the daughters to watch the key figure in their home become sick, weak, and at times fall apart. The daughters learned to change their expectations of their mothers and to shape what their usual role had been. They saw a new side of their mother's character and her role as a patient. Although this was not a welcomed change it was a reality that the daughters faced. It seemed that the daughters were ambivalent about this new role that demanded them to be mature. In their words, the mother-daughter relationship was significantly altered.

Although the daughters reported their mother's breast cancer being a difficult, if not the most difficult time in their lives, many daughters still reported a deepening of their relationship with their mothers. The experience of breast cancer seemed to move the mother-daughter relationship to a more equal partnership. Their interaction was more adult-adult rather than adult-child. During treatment and diagnosis, the daughters experienced their mothers' vulnerability and dependency like never before. This offered mothers an opportunity to share their feelings more deeply and intimately than in the past.

This deeper sharing may be due in part to the depth of their feelings and to a newly discovered vulnerability and dependence. The daughters experienced this increased intimacy in the midst of turbulent times. As a result, the mother-daughter relationship took on new depth and meaning due to their experiences with breast cancer. This was one of the few benefits daughters mentioned about going through the "depths of hell" with their mothers. They experienced an intimate closeness that possibly would never have been experienced had things remained the same. These findings of changes to the mother-daughter relationship are more similar to those of Lichtman and colleagues (1984) than to other researchers in that overall, the mother-daughter relationship took on a new depth and meaning

Fear as a Normal Response Given the Situation

One question that could be asked about the findings of this study with respect to daughters' experiences of their mother's breast cancer is: are the reported responses "normal" given the circumstances? Rolland (1993) has defined a normal response as one that is expected given the nature of the situation. He has analyzed a whole range of chronic illnesses and charted different characteristics of the illness and its course that help us understand the possible responses of family members. The family crisis literature has also helped us gain some understanding of "normal" responses to extraordinary illness situations.

What is a normal response to breast cancer for daughters given the maternal, personal, and interpersonal implications of this illness is fear an expected response? This question needs further development in regard to daughters' coping with their mothers' breast cancer. These daughters' responses in regards to their mothers' breast cancer appear normal when compared to the literature relating to family members' responses to chronic and life threatening illnesses. The literature has indicated that cancer is an interpersonal crisis for patients and for those who love them (Biegel, Sales, Schultz, 1991; Hilton, 1994; Hilton, Crawford, & Tarko, 2000; Hough, Lewis, & Woods, 1991: Sales, Schulz, Biegel, 1992) and also that cancer poses enormous physical and psychological challenges for family members (Hilton, 1994; Northouse, 1992). For daughters of breast cancer patients there is an overlaying genetic link to the increased possibilities of personal risk. With this in mind, it is important that the experiences of daughters of women with breast cancer be considered within the context of the situation. For some, this would be viewed as normalizing the responses to the experience.

Rolland (1993) maintained that all families and family members are challenged by adversity. The number, type and responses to these situations may vary however. He suggested that for those family members who viewed problems as normal had an advantage in dealing with the situation in that they were more likely to be able to access help and maintain a positive identity in the midst of a life-threatening chronic illness. It was not unusual for families in these circumstances to want the situation to be different and for life to return to the way it had been. Family members were fearful and often ambivalent about what to do. The daughters in this current study were no different. They initially wanted things to be normal and to return to the way it had been. Eventually however they faced dealing with a situation they could not change.

Hilton (1996) found that daughters of women with breast cancer identified normalization as a major family coping strategy in dealing with breast cancer. This involved the daughters in getting things back to normal which was viewed in seeking a stable, safe life free of health problems. The daughters in this current study expressed their desire for their mothers to be like they once were as far as comfort and their caregiver roles. They struggled with wanting things to be the way they had been before and how they perceived they should be. It would be helpful to assist daughters in further realizing that many of their experiences and responses are expected and therefore normal given the situation. While fear may be an expected response to a new and frightening illness and as such may initiate action to handle the situation, it can also become debilitating. This is why it is so important to distinguish expected and normal responses to crises from those that might lead to a breakdown in functioning. There are no easy formulas that distinguish these two differing responses.

Hilton's (1996) findings suggest that having a positive attitude is important in maintaining a sense of normalcy and reducing stress for family members. The daughters in this current study certainly displayed a sense of positiveness. This was evidenced in their relating their experiences in a positive manner as well as their incredible sense of positiveness when considering the possibility of breast cancer for themselves. The daughters demonstrated strength of character when dealing with their mother's breast cancer. Most daughters had never faced a situation like this one. They had no idea what was a normal response given their personal situation and that of their mother. Some even felt guilt as they focused upon their own fears and anxieties when it was their mother who was most affected. The role changes that were described by the daughters gave evidence that they were able to make changes in their behavior and relationships in order to handle the situation as it evolved. The daughters' day-to-day struggle to stay positive was commendable. Their experiences were a personal journey that included challenges, growth, and change.

Implications

The purpose of this study was to understand daughters' experiences in having a mother with breast cancer. It was important to hear from daughters first hand and to gain further information regarding their experiences from their own perspectives. These daughters shared their experiences in a very personal manner. The essence of this sharing was represented by the phrase living with fear. As I considered this description I was aware of the fact that fear is often viewed as a negative and debilitating emotion, particularly when associated with a crisis situation. The stories that are included in this study however, provide illustration of the energizing and change producing elements of fear.

When a person lives with fear, she is able to identify the uncertainties, begin to see the ambiguities of life, and chart some possible actions. Not all the actions will work and fear may continue to rear its disruptive head again but life does go on. Decisions are made, actions are taken, thoughts and emotions are shared, plans are made for the future and lives are celebrated. That is what is meant by living with fear. Fear is acknowledged as an expected and even normal response to crisis situations such as breast cancer. These situations are uncertain, have ongoing implications for self and others, and have a societal view that creates a negativity that is not helpful.

The findings of this study have implications for health professionals and for educators as well as for those who are in charge of promoting a less negative view of cancer. For health professionals, the findings need to be added to the growing body of information about the importance of considering the family and family members as an important element of the medical treatment team. Daughters have a significant role in the treatment process for their mothers. These findings note that daughter's needs and contributions should be considered when developing a treatment plan for a mother.

Daughters have a significant care-taking role in families and the findings bear this out. Thus special attention may need to be taken with respect to handling this care-taking role particularly when it involves a significant role reversal. In addition, educational programs that deal with expected and normal responses to family crises involving a parent would be particularly useful. Handling intrusive thoughts, dealing with role reversals, balancing family and patient needs are subjects that might be included in such an educational program. Counseling for daughters as well as other family members when needed should be provided as well.

The societal negativity that surrounds cancer provides a context that continues to isolate daughters of women with breast cancer. Educators and media experts need to address this isolation and balance it with sensitivity to the privacy that daughters and their mothers often desire when undergoing treatment.

Development of Programs

There is a need for practitioners and health professionals to develop programs, support groups, and pamphlets that address daughters' concerns at a time when it is most needed. As part of my master's practicum, I researched available supports for family members of persons with cancer. Although there were many resources for the persons with cancer this was not the case for family members, specifically for daughters. Visuals such as videotapes would be helpful for daughters and their concerns that could be available during their mothers' diagnosis and treatment. Short stories of daughters' experiences during their mothers' diagnosis and treatment would be a great source of strength for daughters. This would be beneficial when daughters are in a most critical time of their mother's breast cancer. Health practitioners could also act as facilitators to connect daughters in order to share and support one another, in particular during the difficult time during diagnosis and treatment.

As health practitioners seek to aid daughters during their mother's diagnosis and treatment of breast cancer it is important to be aware of their conscious and unconscious needs. The first step in helping daughters is to normalize their experience and offer assurance that they will survive the crisis. Practitioners can assist daughters in developing strategies around talking with others and areas around self-care. Also, daughters need to be assisted in exploring and discussing their feelings of fear and uncertainty. Discussions of breast examinations should also to be addressed. Daughters need the opportunity to openly discussion their feelings around conducting breast examinations. Often when a person's feelings are normalized there is a tendency for individuals to feels validated and a sense of normality. Again all of this may be of great assistance as the daughters learn that they are not alone in their array of feelings. Conversations around care giving albeit earlier than expected would also be beneficial. Discussions with daughters around their moving into a caregiver role earlier than expected can be helpful as well as encouraging daughters that care giving of parents is an inevitable transition even when they face this role earlier than others. Normalizing care giving for daughters of women with breast cancer is a key topic for a support program.

It is important for daughters to identify their own needs in the midst of the crisis of their mother's breast cancer. Practitioners may assist daughters in acknowledging that they still have needs and concerns even though they themselves do not have cancer. Conversations around not denying their needs during this difficult time may be helpful. When I went through my personal care-giving experience with my partner I felt alone and that little was asked of just how difficult this whole process was for myself. Daughters need the constant reassurance that their feelings and concerns are valid. One daughter earlier described her isolation and the fact that no one really asked how she was doing. These needs could be a topic of education for those in contact with caregivers. Considering the daughter's cry for help in the expression, "what about me", is crucial.

Strengths and Limitations

Every study has both strengths and limitations. This study is no different. I had difficulty recruiting the respondents through newsletters and posters as well as breast cancer groups. I had chosen not to use recruitment through a cancer clinic or hospital. I was most successful when I used a personal contact method. Given the sensitivity of the topic, in future it would be most useful to develop personal contact procedures that allowed the respondents to develop trust with the researcher.

The participants in this study were strong resources. Their stories were rich and detailed and they provided a range of experiences. The women in this study represented a homogenous group in that all of the participants were Caucasian, from middle-class backgrounds and were educated with some post-secondary education. Even so, they provided diversity of experience. The women were diverse in terms of age when their mother was diagnosed, stages of mothers' diagnosis, marital status, and whether they had children. One limitation to the study was that the women who participated were either adolescents or young adults when their mothers were diagnosed. I cannot therefore speak to the experiences of middle-aged or older women who have a mother with breast cancer. Given the differences of experiences of adolescent and young adult women, it would also be useful to study these groups in more depth.

The nature of this research process allowed a rich sharing of experience from the daughters' perspective. This provided the women with the freedom to share their stories in terms of what they deemed important or significant. I believe that as a researcher I was able to provide a comfortable and relaxed environment for the daughters to share their personal stories. This was evidenced in their willing openness to share their hearts to virtually a stranger. Also the daughters were able to share their experiences in the context of what they deemed as important.

The use of email interviewing in this study proved to be very useful. While some researchers have questioned the method in that it may not be able to provide as much detail as telephone or personal interviews that did not prove to be the case for these respondents. Email interviews were as detailed as the personal interviews. This technique however needs to be tested in many other qualitative contexts to determine its strengths as well as its limitations.

A limitation of this study is that it only captures the experiences of women who wanted to share their stories. There are many breast cancer patients and their family members who choose not to seek out educational experiences, counseling and research studies to describe their experiences. The experiences of the daughters in this study may or may not be similar to those who would choose to internalize their experiences and not want to share with others.

My objective in selecting participants for this study was to ensure that the women would be representative of a variety of personal experiences. I believe I was able to capture similarities across the span of their different experiences that provided insight into daughters' experiences. With the exception of one, the women shared their perspectives after their mothers' diagnosis and treatment. For the daughter whose mother had not yet completed all of her chemotherapy treatments she appeared to be more positive and had less trauma to report as compared to women whose mothers had a second diagnosis.

This research illustrates the continuing need for subsequent research on daughters and their experiences. Further research comparing those daughters who were at the beginning of diagnosis and treatment as compared to those after the fact would be both of interest and importance. A longitudinal study would also be beneficial to compare women at various stages of their mother's breast cancer.

Research conducted around the experiences of daughters who not only had a mother with breast cancer but also had the disease themselves would shed further light on women's experiences. Studies regarding daughters whose mothers had died from the disease would also be of importance in understanding women's experiences.

In this chapter, the findings of this research have been discussed in relation to the current literature available regarding women's experiences of having a mother with breast cancer. The implications for further research are addressed, as well as the strengths and limitations of the study. It is hoped that this research conceptualizes the daughters' experiences of having a mother with breast cancer and will provide the impetus for further research. It is also hoped that this study will assist health practitioners in providing care and insight for daughters whose mothers have had breast cancer.

There is a popular slogan that says: "Cancer can be beaten." While it probably refers to a medical treatment or cure, the message relates as well to the power of the human spirit in beating illness and its effects. The following poem by an unknown author captures the messages that these daughters have shared about living with fear. These women lived with the fears associated with a mother's breast cancer. The fears did not destroy them. The daughters took on roles and responsibilities to handle the fears and live productively given the situation. Yes, cancer can be beaten!

WHAT CANCER CANNOT DO

Cancer is so limited...
It cannot cripple love,
It cannot shatter hope,
It cannot corrode faith,
It cannot destroy peace,
It cannot kill friendship,
It cannot suppress memories,
It cannot silence courage,
It cannot invade the soul,
It cannot steal eternal life,
It cannot conquer the Spirit.
Author unknown

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APPENDIX A

ARE YOU A DAUGHTER OF A WOMAN WITH BREAST CANCER?

Volunteer research participants are required for a
University of Alberta interview study
of the experiences of daughters with women with breast cancer.

If :

- You are 20-55 years of age,
- You are Caucasian,
- You have not had breast cancer yourself,
- Your mother has had a lumpectomy or a mastectomy,
- Your mother is currently living,
- You are interested in sharing your "story".
- Please Call: Debra @

APPENDIX B

INFORMATION SHEET

Daughters of Women With Breast Cancer:
Living in Fear

Purpose:
This research seeks to gain insight into the everyday experience of daughters of women with breast cancer.

Methods:
You are invited to share your everyday experience of what it is like to be a daughter of a woman with breast cancer. Although your experience may have similarities to other daughters, it is your own. There are no right or wrong answers to the interview. The researcher will ask you to share in your own words your experience of having a mother with breast cancer. You will meet with the researcher for sixty to ninety minutes for one or two times. The researcher's questions will be limited, except for clarification or for further understanding.

Confidentiality:
The interview will be audiotaped. The researcher and one other person will transcribe the tape. The participants' names will not be recorded on the tape. You will be assigned a number or pseudo name that will be used on the tape. The person with this knowledge will be the researcher. All information with the participants' names will be kept secure.

Interviews will be done at the International Institute for Qualitative Methodology. There is a possibility that individuals from the research center will recognize the participants as part of research but they will not be informed of the interview information.

Benefits:
This study gives you the opportunity to share your everyday experience as a daughter of a mother with breast cancer. Implications of this study will assist in further education and knowledge for both educators and counselors in helping daughters of women with breast cancer.

Risks:
There is no anticipation that this research will bring harm to you. There may be a possibility that through telling your everyday experience that various feelings may arise that could possibly cause strain. The researcher will listen and assist you in finding help if the situation arises for a further need in discussing your feelings.

Withdrawal from the Study:
You may withdraw from the study at any time that you desire with no explanation to the researcher. If you choose you may decide to participate in only one interview. You may request that any information you shared will not be used. The researcher will not use your story if you so choose.

Use of your Information:
This research is conducted for a Master's thesis. This study is not being paid for by the International Institute for Qualitative Methodology or by the government. The researcher is a student at the University of Alberta. Data from your experience along with other daughters will be compiled and themes will be identified. The research may be used in presentations and published in scholarly journals. You will receive a summary of findings if you desire.

APPENDIX C

CONSENT FORM

Title of Research Project:
Daughters of Women With Breast Cancer: Living In Fear

Investigator:
Debra Walsh
Master of Science Candidate
Department of Human Ecology
University of Alberta
Phone Number:

Consent:
Please circle your answers:

I understand the procedures of this research study.	Yes	No
I have read and received a copy of the attached Information Sheet.	Yes	No
I am aware of the benefits and risks involved in participating in this research study.	Yes	No
All of my questions have been answered to my satisfaction.	Yes	No
I understand that I am involved in this research voluntarily and that I am able to withdraw from this study at any time.	Yes	No
Confidentiality has been explained to me.	Yes	No
I have been assured that personal records relating to this study will be kept confidential.	Yes	No
I am aware that the tapes will be destroyed once the data has been transcribed and checked. I am aware that the data will be kept for up to 3 years or until all articles are published.	Yes	No
I agree to have my interviews audio-taped.	Yes	No

Contact person regarding the research:

Debra Walsh, Master of Science Candidate, University of Alberta, Phone:
Dianne Kieren, Research Supervisor, Phone:

Debra Walsh explained this study to me and I agree to take part in this study.

Signature of Research Participant	Date (dd/mm/yyyy)	Witness
Printed Name		Printed Name

Copy of the Report:

Would you like to receive a short version of the report? Yes No

If you would like a copy, please print your mailing address. Your address will not be used for any other reason than to send you a copy of the report.

Address

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