DISSERTATION

ADULT SIBLINGS OF BREAST CANCER PATIENTS: A QUALITATIVE ANALYSIS

Submitted by

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In partial fulfillment of the requirements

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY LAURIE ANN SCHLEPER ENTITLED ADULT SIBLINGS OF BREAST CANCER PATIENTS: A QUALITATIVE ANALYSIS BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

ADULT SIBLINGS OF BREAST CANCER PATIENTS:

A QUALITATIVE ANALYSIS

This qualitative study explored the stories of thirteen adult sisters of breast cancer patients. Participants engaged in interviews during which the following topics were explored: a) support and assistance provided to siblings during their cancer experience; b) the emotional and psychological toll of witnessing a sister's breast cancer diagnosis and treatment; and, c) impact of a sibling's breast cancer diagnosis on the sibling relationship. In addition, participants completed the Lifespan Sibling Relationship Scale (LSRS) regarding their childhood sibling relationship, pre-cancer adult sibling relationship, and post-cancer adult sibling relationship. Analysis of interview data and questionnaire reports indicated that participants provided a great deal of support and assistance to their siblings, experienced heightened fears regarding their own well-being as well as their siblings', and experienced an increased closeness in their sibling relationships as a result of the cancer experience. Findings from the present study address a void in the literature by specifically addressing the psychosocial needs of sisters of breast cancer patients. Recommendations for mental health and medical professionals working in the field of oncology are provided.

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Introduction

"Terror, rage, sadness, and above all, a feeling of complete and utter helplessness invaded me" (Susan G. Komen Breast Cancer Foundation, n.d.). These are the words used by Nancy Goodman Brinker, founder of the Susan G. Komen Cancer Foundation, to describe her experience of witnessing her sister's breast cancer diagnosis, treatment, and eventual death. Shortly before losing her sister to breast cancer, Nancy made a promise to Susan that she would dedicate her life to fighting breast cancer. This promise, made from one sister to another, has resulted in the Komen Foundation, a leader in the field of breast cancer education, screening and treatment. In this example, the power of sisterhood prevailed despite the devastating impact breast cancer had on the lives of both Goodman sisters. This study is dedicated to the exploration of sisterhood in the face of breast cancer.

Breast cancer has a strong presence in the United States; aside from skin cancer, breast cancer is the most common type of cancer among women, accounting for nearly one-third of the total cancer diagnoses in American women (American Cancer Society, 2003). According to the American Cancer Society (2003), an estimated 212,600 new cases of breast cancer will be diagnosed in the year 2003, and an estimated 40,200 new deaths due to breast cancer will occur within the same year. The vast majority of breast cancer patients are women, with under one percent of expected new diagnoses in 2003 being male and exactly one percent of expected new deaths being male (American Cancer Society, 2003).

The statistics reported above reflect the enormous amount of epidemiological data gathered on the incidence and prevalence of cancer, and have led to a large body of literature exploring the psycho-social impact of the cancer experience on patients and their families. As stated by Nezu, Nezu, Friedman, Faddis, and Houts (1998), "Like most wars, the 'war on cancer' leaves casualties, scars, and lives in need of healing in its wake" (p. 3). Given the growing number of individuals affected by cancer, it has become increasingly important for both medical and mental health professionals to understand the psychological impact of cancer diagnoses and treatment. For women diagnosed with breast cancer, there is a great need for enhanced understanding of their experiences, their support systems, and the impact of their illness on loved ones. The psycho-oncology literature includes studies focused on breast cancer patients' experiences and psychosocial needs (Baider & Kaplan De-Nour, 1984; Barraclough, 1994; Buick et al., 2000; Crossland, 2000; King, Kenny, Shiell, Hall, & Boyages, 2000; Maguire, Faulkner & Regnar, 1993; Massie, Holland & Brietbart, 1989; Rinehart-Ayres, 1997; Shapiro et al., 2001; Spiegel, 2000; Watson, 1994), appropriate psychosocial interventions for breast cancer patients (Badger, Braden, Longman, & Mishel, 1999; Boyers, 2001; Hosaka, Sugiyama, Tokuda & Okuyama, 2000; MacCormack et al., 2001; Maguire & Sellwood, 1988; McGregor, 2001; Spiegel, 2000; Watson, 1991), and, to a lesser extent, the reaction of patients' spouses and children (Baider & Kaplan De-Nour, 1984; Croog & Fitzgerald, 1978; Dhooper, 1983; Fengler & Goodrich, 1979; Harpham, 1997; Keitel, Cramer, & Zevon, 1990; Oberst & James, 1985; Vasta, Haith, & Miller, 1999). However, to date, there is no mention of the impact breast cancer diagnosis and treatment has on relatives in

the family of origin, nor on the impact of cancer diagnosis and treatment on relations within the family of origin.

Sibling research in general, and particularly as pertains to the area of psychosocial oncology, has focused on childhood sibling relations. In addition to research on the psychosocial consequences of cancer for pediatric patients (Butler, Rizzie & Bandilla, 1999; Crouch, 1999; Hoffman-Crabtree, 1998; Katz, Dolgin & Varni, 1990; Ritchie, 2001; Varni & Katz, 1997), effective interventions to enhance pediatric patients' coping (Cunningham, Betsa & Gross, 1981; Evans, Stevens, Cushway, & Houghton, 1992; Greenly, Maher, McGrowan, & Meyers, 1986; Kinrade, 1985; Sahler & Carpenter, 1989), and attention to the needs of parents faced with cancer in their children (Boyer & Barakat, 1996; Fisher, 1987; Hoekstra-Weekbers, Jaspers, Kamps, & Klip, 1998; Libov, 1997; Ogg, 1998), extensive research has been conducted on the reactions of child siblings to their sister or brother's cancer diagnosis and treatment (Adams-Greenly, Shiminski-Maher, McGowan, & Meyers, 1986; Cairns, Clark, Smith, & Lansky, 1979; Cohen, 1985; Dolgin, Somer, Zaidel & Zaizov, 1997; Hamama, Ronen & Feigin, 2000; Havermans & Eiser, 1994; Heffernan & Zanelli, 1997; Iles, 1979; Johnson, 1997; Koch-Hattem, 1986; Kramer, 1984; Murray, 2000a, 2000b; Rollins, 1990; Sahler & Carpenter, 1989; Sargent et al., 1995; Sloper & While, 1996; Sourkes, 1980; Spinetta, 1981; Sullivan, 1990; Walker, 1988), as well as intervention programs designed to effectively address the psychological needs of child siblings of cancer patients (Adams-Greenly et al., 1986; Carpenter & Levant, 1994; Dolgin et al., 1997; Heiney, Goon-Johnson, Ettinger & Ettinger, 1990; Johnson, 1997; Martinson, Colaizzo, Freeman, & Bossert, 1990; Sahler & Carpenter, 1989). The strain pediatric cancer diagnosis and treatment has on sibling

relationships has also been acknowledged in the literature (Adams-Greenly et al., 1986; Cairns et al., 1979; Havermans & Eiser, 1994; Iles, 1979; Kagen-Goodheart, 1977; Koch-Hattem, 1986; Kramer, 1984; Minuchin, 1989).

While sibling interactions in adulthood were considered insignificant in the past, more recently sibling relations throughout the life span have been recognized as worthy of recognition and exploration in the psychological literature (Cicirelli, 1995). Due to minimal attention given to adult sibling relations, little is known at this point in time about sibling relationships in the support networks of adults (Scott, 1983). Based upon the model provided by pediatric oncology research, the present investigation explored the following areas for adults: (a) impact of cancer on the adult sibling relationship; (b) psychosocial needs of breast cancer patients with an emphasis on the role siblings can potentially play in meeting these needs; and, (c) impact of cancer on the adult patient's sibling (i.e., psychosocial needs of the sibling).

Adult Sibling Relationships

Studies have found that 75 to 93 percent of adults have at least one living sibling (variation in percentage is largely attributable to mean age of research participants), indicating that the majority of people have a sibling available to them throughout most of their lives (Avioli, 1989; Cicirelli, 1980b, 1982, 1995; Connidis, 1989). Recent recognition of the importance of adult sibling relationships has largely stemmed from adaptation of adult attachment theory (Cicirelli, 1989, 1991, 1995). Life span attachment theory maintains that a child's early attachments to the primary caregiver and to other family members persist through the adult years and provide the foundation for an adult's continued relationship and helping interactions with family members (Bowlby, 1979,

1980). The sibling bond is maintained despite prolonged separations in space and time due to alternate means of satisfying needs for closeness and contact. More specifically, an individual may continue to experience the bond with an absent sibling by using "symbolic representation" (i.e., maintaining memories of early closeness and internalizing shared values, goals, and interests) (Bank & Kahn, 1982a, 1982b; Cicirelli, 1989; Dunn, 1984; Ross & Milgram, 1982). Symbolic contact is supplemented with more direct contact in the form of occasional visits and telephone calls (Cicirelli, 1989).

According to the life span attachment theory, helping behaviors among siblings in adulthood are rooted in the desire to protect and preserve the existence of the attachment figure (Cicirelli, 1989), thereby preserving the survival of the shared emotional bond. Cicirelli found support for this contention by identifying a relationship between sibling psychological support and strength of the attachment bond, with a strong relationship when attachment to a sister is involved.

Avioli (1989) described the motivation for sibling support provided later in adulthood as a combination of attachment and the social norm of family obligation. Avioli further stated that the actual provision of help is a function of multiple factors, including proximity, health and functional status, developmental stage, gender composition of the siblings, and ethnicity. According to Cicirelli (1995), in situations where a close attachment between siblings exists, the provision of help is likely to go above and beyond the level dictated by the norms of family obligation. If, however, sibling attachment is weak or "disturbed," the minimal amount of help during times of need will be provided in accordance with norms of reciprocity and family obligation.

Beyond the influences of attachment and family obligation, Bank and Kahn (1982b) outline a number of "cultural transformations" that have taken place over the last century and may have resulted in increased importance of the sibling relationship. According to these authors, diminishing family size, longer life spans, increasing geographic mobility, increasing divorce and remarriage rates, and declining effectiveness and presence of parents during youth may contribute to increased reliance on siblings for support throughout the life span. Many of the trends outlined above speak to the increasing brevity and unreliability of various personal connections; the "constancy and permanence" of a sibling relationship may be viewed as one of the few remaining reliable relationships an individual experiences in his or her lifetime.

As mentioned above, one of the unique qualities of the sibling relationship is the length of its duration. Beginning at the time of the younger sibling's birth and ending at the death of one sibling, sibling relationships are often the longest in duration of all relationships an individual has in a lifetime (Cicirelli, 1982, 1991). Additional qualities that characterize sibling relationships include the following: sibling relationships are generally egalitarian in nature and exist between similar-aged peers, siblinghood is an ascribed (as opposed to earned) social role, siblings share early childhood experiences, and siblings share common genetics (Cicirelli, 1980a, 1982, 1991). Additionally, sibling relationships are often regarded as friendships in later life; as Cicirelli (1995) mentions, friends are often regarded as "like a brother" or "like a sister," implying a large degree of similarity between these types of relationships.

A vast amount of literature does indeed support the contention that many siblings are regarded as desired friends and close companions in adulthood. While it is important

to recognize that all sibling relationships can be characterized on a continuum ranging from intimacy to estrangement (Hoyt & Babchuk, 1983), a considerable number of sibling dyads identify their relationship as being "close." Through qualitative analysis, Gold (1989) identified five types of sibling relationships: intimate, congenial, loyal, apathetic, and hostile. According to Gold and others (Bank & Kahn, 1982b; Cicirelli, 1985; Matthews, Delaney & Adamek, 1989; Scott, 1990), the majority of sibling relations are close as opposed to indifferent or estranged. Adams (1968) asked young to middle-aged adults to report their ratings of "closeness" to the sibling most similar in age; 48 percent reported a high degree of closeness to their sibling, although sisters reported considerably higher ratings of closeness (60 percent of sister pairs reported a high degree of closeness). Similarly, Cicirelli (1980a) reported that college women, on average, feel very close to their siblings. Cicirelli further elaborated that the women in his study felt very friendly and relaxed, very much understood, and felt they held very similar views to their closest sibling.

Feelings of closeness toward siblings have been found to persist into older adulthood as well. Studies investigating elderly sibling relations have reported high degrees of closeness. Cicirelli (1979) reported that 53 percent of his sample of elderly individuals (over 60 years of age) described themselves as feeling "extremely close" to one sibling and an additional 30 percent reported feeling "close." Similarly, Connidis (1989) found 77 percent of 294 older adults considered at least one sibling to be a close friend. Cumming and Schneider (1961) found sibling solidarity to be second in strength only to that between parent and child. Further, Cumming and Schneider found the sibling relationship to be more emphasized, especially among sisters, than the spousal bond in

middle and old age. Closeness in sibling relations is especially true for elderly who are female, widowed, divorced, childless, or never married (Adams, 1968; Cicirelli, 1982; Connidis, 1989; Connidis & Davies, 1992; Gold, Woodbury & George, 1990; Kendig, Coles, Pittelkow, & Wilson, 1988).

Many authors have observed that siblings draw closer to each other in old age (Allan, 1977; Cicirelli, 1981, 1982, 1994; Laverty, 1962; Leigh, 1982). Explanations for increasing closeness in older age have typically been rooted in two areas: decreased sibling rivalry and developmental tasks of older adulthood. Allan (1977) asserted that the reduced frequency of interaction, as compared to earlier years, and the changed nature of sibling interactions allowed siblings to avoid "rivalrous conflict." Allan's argument that sibling rivalry likely diffuses in later years has been supported by subsequent research. Cicirelli (1981) found that only two percent of his sample reported feelings of competition with their siblings frequently or often, whereas 93 percent reported rarely or never experiencing feelings of competition with their siblings. Cicirelli (1994) and Leigh (1982) have also posited that negative sibling interactions peak in adolescence and steadily decline to very low levels later in life.

From a developmental perspective, the timing of decreased and subsequent increased closeness in sibling relations fits well within developmental tasks of adulthood. As compared to earlier developmental theorists who conceptualized development only through adolescence, Erikson (1963) proposed the "Eight Ages of Man" in a developmental theory covering the entire lifespan. Erikson outlined the following developmental tasks for each stage of life following childhood: (a) Adolecence – focus is on transitioning from childhood to adulthood and developing a sense of identity; (b)

Early Adulthood – emphasis is on establishing intimate bonds with others; (c) Middle Age – concentrated work toward fulfilling life goals involving family, career, and bettering society at large; (d) Later Years – this period of time is spent reflecting on one's life and accepting its meaning. Goetting (1986) has hypothesized that sibling contact in early and middle adulthood is limited to low levels of involvement and assistance, with help exchanged only as necessary (for instance, in the case of a sibling needing help due to illness or financial strain). In line with the developmental task of re-evaluating one's life, Goetting proposed that older adult siblings are valuable in the role of helping to validate and clarify life events. This process of reflection is likely a source of comfort in older years; it appears that siblings are uniquely qualified for participation and assistance in this reflection process. In addition to reflection on previous years, older siblings also provide assistance with illness, financial support, decision-making, business dealings, homemaking, home repairs, transportation, and shopping (Goetting, 1986; Kivett, 1985; Scott, 1983).

As described above, one important aspect of the sibling relationship appears to be the help and support siblings provide for one another in times of need (Cicirelli, 1982). Although societal norms generally dictate that helping behaviors flow between parents and children (Cicirelli, 1982) or between spouses (Wilson, Calsyn & Orlofsky, 1994), research indicates that siblings often serve as additional sources of support within family networks, particularly in later adulthood. For adults who are divorced, widowed, never married, or childless, sibling assistance may be the primary source of help during times of hardship (Connidis, 1994; Cicirelli, Coward & Dwyer 1992; Scott, 1983). Considering the increasing rates of women who do not marry (Fields & Casper, 2001), the increasing

rates of married couples choosing not to have children (Fields & Casper, 2001), climbing divorce rates (Fields & Casper, 2001), and the longer life expectancy of women as opposed to men (Hetzel & Smith, 2001), it is conceivable that sibling support will become increasingly important in the years to come.

Aside from direct assistance provided by siblings during times of need, additional benefits are posited in the literature simply by virtue of siblings' existence. For example, Cicirelli (1980a) found a greater sense of control in life (as displayed through internal locus-of-control orientation) in older adults who experience more frequent interactions with siblings. In a later study, Cicirelli (1989) also found greater well-being in older adults who perceived themselves as having a close bond to a sister. In addition, McGhee (1985) found frequency of contact ratings to be unrelated to the well-being of older adults; a relationship was identified, however, between life satisfaction and availability of a sister. It appears that in older adulthood, the perception of sibling support enhances well-being (Blieszner, 1986; Cicirelli, 1977, 1989; McGhee, 1985; Scott, 1983; White & Riedmann, 1992b).

Thus far, various aspects of sibling relationships in adulthood have been outlined (i.e., development of attachment between siblings, characteristics of sibling relationships, closeness of sibling relationships, helping behaviors in sibling relationships, and benefits of sibling relations). It is important to note at this point that not all sibling relationships are alike; several authors have noted the uniquely close bond often developed between sisters as being quite different from sibling relations observed in sister-brother or brother-brother pairs (Adams, 1968; Cicirelli, 1979, 1989; Connidis, 1989; Finch, 1989; Flaherty & Richman, 1989; Gold et al., 1990; Hoyt & Babchuk, 1983; McGhee, 1985; Troll, 1971;

White & Riedmann, 1992a; Wilson et al., 1994). Particularly in the areas of perceived closeness and observed benefits of sibling relations, sister-sister relations appear to offer many additional advantages in adulthood.

Studies on adult sibling relations have indicated sister-sister relationships are the closest and most satisfying, followed by sister-brother, and lastly by brother-brother (Cicirelli, 1979; Hoyt & Babchuk, 1983; Wilson et al., 1994). Cicirelli (1989) found that perceptions of close relations with a sister (for men and women) is positively correlated with well-being for older adults, whereas perceptions of close relations with a brother does not appear to be correlated with well-being. Beyond mere perceptions of available assistance from siblings, Connidis (1994) found that individuals are more likely to receive sibling support during an illness if their sibling is a sister. Clearly, sisterhood in adulthood plays an important role in the well-being of many individuals, particularly during illness or other times of misfortune. The consequences of sibling assistance for the sibling relationship, however, have not been explored in the existing literature.

Impact of Breast Cancer on the Adult Patient

The psychological and emotional impact of cancer, as well as the psychosocial needs of cancer patients, have been well-documented in the literature. A cancer diagnosis elicits powerful emotions in the patient, including sadness, depression, anxiety, shock, confusion, and anger. It is highly likely that the patient will experience diagnosable psychiatric conditions ranging from mild adjustment disorders to chronic major depression (Baider & Kaplan De-Nour, 1984; Barraclough, 1994; Maguire et al., 1993; Massie et al., 1989; Northouse, 1988, 1992). Indeed, researchers have estimated depression to be four times more common among cancer patients than in the population

at large (Barraclough, 1994). In addition to depression, individuals with cancer frequently report higher levels of anxiety compared to individuals without cancer. These feelings of anxiety generally take the form of ruminative worry concerning the impact of the disease on one's ability to continue living a normal life (Watson, 1994). Despite substantial heterogeneity in psychological symptoms, the empirical literature portrays the average cancer patient as an individual with depressed mood, tearfulness, agitation, irritability, unremitting worries, and feelings of hopelessness and despair (Barraclough, 1994; Cody, 1990; Haig, 1992; Maguire et al., 1993; Massie et al., 1989; Mermelstein & Lesko, 1992; Spiegel, 1996; Walsh-Burke, 1992; Watson, 1994).

Frequently the diagnosis of cancer is accompanied by shock as well as feelings of confusion and loss of control (Watson, 1994). Once the shock subsides and staging and treatment begin, cancer patients often report intense feelings of anger, injustice, and betrayal (Walsh-Burke, 1992; Watson, 1994). Patients often ask, "Why me?" and having no palatable response, become despondent and, at times, immobilized (Watson, 1994).

In addition to ruminating over the seeming senselessness of why they have cancer, patients report other intrusive thoughts throughout the cancer experience. First and foremost are thoughts about death and dying (Watson, 1994). A cancer diagnosis serves as an immediate reminder that life is finite, and concerns regarding quality and length of life, fears of dying, and worry about those who may be left behind are perseverant. Patients are plagued with concern not only for themselves, but also for friends and family. Guilt and self-blame for the suffering experienced by others and the burden one's health care places on family members are frequently reported by patients (Barraclough, 1994).

Thus far, the cancer patient has been described as an individual faced with any combination of the following: depression, anxiety, shock, confusion, anger, guilt, and fear. For many, the multitude of symptoms experienced due to cancer warrant the provision of increased social support. Unfortunately, a common tendency of cancer patients is to withdraw socially, thus decreasing the potential positive impact of the emotional and instrumental (e.g., transportation, child care, cleaning) support available from others (Barraclough, 1994; Spiegel, 1996).

In addition to impacting their own lives, cancer and the patient's cognitive/emotional reaction to the disease also impact the experiences of spouses. Fengler and Goodrich (1979) asserted that spouses of patients undergoing medical care are also experiencing emotional consequences of the illness and should thus be identified as "hidden patients." This is clearly the case with spouses of many cancer patients, as mounting evidence suggests that spouses who are faced with the stress of their partner's chronic illness also experience declines in mental health (Croog & Fitzgerald, 1978; Dhooper, 1983; Keitel et al., 1990). Research has indicated that it is not unusual for spouses to experience even greater distress than patients during the time when patients are undergoing medical treatment and/or surgery, especially in cases where wives are the patients (Baider & Kaplan De-Nour, 1984; Keitel et al., 1990; Keller, Henrich, Sellschopp & Beutel, 1996).

Cancer, with its multiple demands, frequently produced depressive mood and/or distress in both the diagnosed patient and his or her partner (Baider & Kaplan De-Nour, 1984; Northouse, 1988, 1992; Northouse & Swain, 1987; Zahlis & Shands, 1993). Although the medical illness resides within the patient, the negative feelings experienced

in response to the patient's illness are shared by both marital partners (Gritz, Wellisch, Siau & Want, 1990). The majority of research on spouses of cancer patients indicates that they frequently feel overwhelmed by their emotions, including feelings of depression, loneliness, and helplessness (Kalayjian, 1989).

Although some couples experience a strengthened relationship during the cancer experience (Rait et al., 1989), heightened marital tension, as a result of spousal cancer, is well-documented in the literature (Barraclough, 1994; Gritz et al., 1990; Lewis, Hammond & Woods, 1993; Lewis, Woods, Hough & Bensley, 1989; Molumphy & Sprokowski, 1984; Skerret, 1998; Walsh-Burke, 1992). Walsh-Burke (1992) explored couples' communication regarding cancer and discovered some wives reportedly discuss information related to cancer with their husbands, but do not discuss their feelings related to cancer with husbands. Thus, needs for increased support from individuals outside the marriage may be expected for adult cancer patients.

Impact of Breast Cancer on the Adult Sibling

Adult siblings of cancer patients are conceived, in this study, as both potential sources of support for the cancer patient and as potential sources of needed support. It seems reasonable to conclude that a sister's cancer diagnosis and treatment will elicit emotional arousal in the sibling as well, although to date no empirical research has directly examined this hypothesis. In addition to coping with the emotional hardship of witnessing a loved one's struggle with cancer diagnosis and treatment, siblings are additionally burdened by potentially increased fears regarding their own mortality and cancer risk. The risk of developing breast cancer is significantly higher for women who have a family history of breast cancer (i.e., breast cancer in a mother, sister, or daughter)

(American Cancer Society, 2003; National Cancer Institute, 2000; Pharoah, Day, Duffy, Easton, & Ponder, 1997).

Researchers have identified genetic mutations linked to inherited tendency toward developing breast cancer; it has been estimated that approximately one in every 300 women carries an inherited mutation of breast cancer susceptibility genes (U.S. Dept. of Health & Human Services, n.d.). Women who have abnormal BRCA1 or BRCA2 genes are considered to be at very high risk for developing breast cancer; women with abnormal BRCA1 genes are also considered to be at high risk for developing ovarian cancer (Weiss & Weiss, 1998). Normal BRCA1 and BRCA2 genes are "suppressor genes," meaning their role is to manufacture proteins to suppress uncontrolled cell growth (particularly in the breasts) (U.S. Dept. of Health & Human Services, n.d.). Without normal BRCA1 and BRCA2 suppressor genes, breast cells can grow uncontrollably and develop into breast cancer tumors (Weiss & Weiss, 1998).

Researchers have expended extensive effort to increase a woman's likelihood of preventing and detecting breast cancer; in addition to those available for the general public, specific methods have been developed for women considered to be high-risk for developing breast or ovarian cancer due to family history. Oftentimes, women with heightened risk for developing cancer are provided with a wide range of options for prevention of the disease, although very little direction or assistance is provided by medical professionals in regard to the best course of action. Options available to women in the past have ranged from the "wait-and-see" approach to surgical removal of both breasts; current technology is making significant advancements, however, in the effort to assist women in making informed decisions regarding their health (Pozniak, 2001).

One option available to women with heightened risk for breast cancer is genetic testing. Genetic tests have been designed to identify whether a woman carries a disease-related gene mutation. Genetic testing offers the potential to greatly inform women as to appropriate measures to take with their health (U.S. Dept. of Health & Human Services, n.d.). For example, women who test positive for the BRCA1 breast cancer susceptibility gene have an 80 percent chance of developing breast cancer by the time they are 65 years of age (U.S. Dept. of Health & Human Services, n.d.); a woman who has undergone testing and is aware of her heightened risk of developing breast cancer may then choose to take measures toward protecting her health.

One option that recently became available to women considered high-risk for developing breast cancer is the drug tamoxifen. Tamoxifen is typically used to prevent the return of breast cancer in women who have tumors that test positive for estrogen receptors (Shaw, 2001). Recently, however, it has been shown that tamoxifen effectively reduces the incidence of first cancers in women with the BRCA2 mutation. Tamoxifen reportedly reduces the incidence of breast cancer by 62 percent in healthy women who test positive for the BRCA2 genetic mutation (Shaw, 2001). Unfortunately, tamoxifen does not prevent the development of breast cancer in women with the BRCA1 genetic mutation (Shaw, 2001). This line of research presents strong evidence that women considered high-risk for breast cancer can be helped by early screening for genetic mutations, while simultaneously being helped to avoid unnecessary and/or unhelpful medical intervention.

An additional option for women considered high-risk for developing breast cancer recently described in the literature is ductal lavage. Ductal lavage is an outpatient

procedure shown to effectively detect the earliest stage of cancer within the breast ducts by extracting ductal cell fluid and testing it for abnormal cells (Pozniak, 2001). Given that 99 percent of all breast cancers originate in either the ductal system or the lobular system, advancements in the early detection of abnormal cells within the ductal system could lead to early detection and treatment of breast cancer (Pozniak, 2001). One study of 507 women at high-risk for breast cancer underwent ductal lavage; abnormal cells were detected in 24 percent of the women (all of whom had normal mammograms and clinical breast examinations within the previous year) (Pozniak, 2001). Women considered high-risk for breast cancer are currently faced with more options for detection, prevention, and early treatment of breast cancer than ever before.

Despite the many health advantages inherent in early awareness of breast cancer risk (i.e., awareness may lead to increased utilization of detection and prevention methods), there are negative psychological consequences that can potentially result from the knowledge of one's own susceptibility to developing breast cancer. For this reason, specific considerations for the psychological needs of high-risk women considering genetic testing and/or prophylactic mastectomy have been proposed. Issues faced by high-risk women include: confronting the significance of one's own risk status, including fear of harm, disfigurement, pain, and death; feelings of guilt for possibly passing on genetic mutations to children and/or feeling as though one has not done enough to care for loved ones; stress and worry management, particularly as pertains to intrusive thoughts and cancer-related worries; problem-solving and decision-making; and, need for effective coping skills (National Cancer Institute, 2002).

Goals of the Present Research

The purpose of the present research is to investigate the impact a woman's breast cancer diagnosis and treatment has on the sibling relationship, the sibling's psychological well-being, and the degree of support provided by the well sibling to the patient. It is hoped that such knowledge will inform professionals working in oncology settings as to a potential source of support for patients, as well as a potentially untapped population (i.e., well siblings) in need of intervention and attention following a sibling's cancer diagnosis. Given the paucity of information available on this topic, a qualitative approach is taken in order to allow participants to fully describe their experiences in their own words. In addition to open-ended interview questions, participants will also be asked to complete the Lifespan Sibling Relationship Scale (Riggio, 2000) to assess participants' overall attitudes toward the adult sibling relationship pre- and post-cancer diagnosis in the sibling.

Methodology

The Phenomenological Method

The phenomenological method is an approach to qualitative research which focuses on understanding the lived experience of individuals who have encountered a particular phenomenon (Creswell, 1998). Jones (1985) summarized the intent behind qualitative analysis in the following manner:

> To understand other persons' constructions of reality we would do well to ask them (rather than assume we can know merely by observing their overt behavior) and to ask them in such a way that they can tell us in their terms (rather than those imposed rigidly and 'a priori' by ourselves) and in a depth which addresses the rich context that is the substance of their meanings (rather than through isolated fragments squeezed onto a few lines of paper). (p. 46)

The phenomenological method is chosen to facilitate a comprehensive exploration of the cancer experience for siblings of breast cancer patients. Given the exploratory nature of the present study, the phenomenological method was deemed most appropriate because it allows for rich descriptions of individual experiences with the topic of interest (Miles & Huberman, 1994). Participants in this study were asked open-ended questions regarding their experience, encouraged to describe the experience in their own words, and allowed the freedom of describing the experience in depth.

Researcher's Perspective

In conducting a qualitative analysis of any phenomenon, it is imperative that the investigator be aware of biases, preconceptions, and personal experiences that may contaminate the research process. While the presence of such complicating factors is

inevitable, awareness of them is the first step toward decreasing risk of confounded research results.

My interest in the topic of this study is rooted within personal experiences, although my personal experiences are only tangentially, and not directly, related to the topic of inquiry. I have witnessed the sudden decline of a sister's health in adulthood, and personally experienced much of what is posited in the literature about adult sibling relationships. My sister and I experienced much sibling rivalry in our childhood; I am the younger sibling and was never completely forgiven for interfering with the attention my sister received from our parents. Distance through different stages of life and different geographic locations resulted in decreased rivalry and a much more "loyal" relationship. We wrote letters, talked on the telephone occasionally, and enjoyed one another's company on holidays. We no longer lived together, our arguments diminished a great deal in frequency and intensity, and we each continued to value our sisterhood despite limited contact.

I was 23 years old when my sister (at age 27) had a stroke. Her sudden illness, her diminished physical and mental capacity, and the sudden overwhelming awareness that I could have lost her resulted overnight in a major shift in our relationship. I no longer maintained my own schooling and personal goals as top priority. Countless hours were spent in the hospital, followed by my moving in with my sister for a short period of time following her release from the hospital. I do not recall having ever assisted my sister with daily living tasks prior to this event; still, I suddenly found myself in the roles of chauffeur, cook, and confidante to my sister. My sister's illness profoundly altered our relationship and brought us closer than we had ever been before; her illness also imposed

immense psychological hardship on each of us as she struggled to cope with the physical, cognitive and emotional ramifications of her stroke and I struggled to cope with feeling helpless and scared while watching her do so. In addition, I became aware of my own genetic propensity toward the same disorder that caused my sister's stroke; as a result, my own fears of mortality and illness became heightened. Thankfully, my sister fully recovered from the stroke and our relationship has now calmed to a still close, yet less intense, bond.

In addition to my personal experience described above, I also witnessed the importance of the sibling bond while working in a private oncology clinic. Many of my most memorable experiences from working in this setting include witnessing the close bond between sisters, oftentimes involving sisters who flew across the country to provide support to a patient or who took over custody of an incapacitated sibling's children. On many occasions I watched in awe as the strength of sisterhood combated the illness, through shared fear, shared hope, and shared fortitude.

The phenomenological term "epoche" refers to the process by which researchers contain their own perceptions and experiences with the phenomenon of interest so as to not influence responses provided in the interviews nor the analysis that follows (Creswell, 1998). Although the method of collecting data through interviews necessitates dialogue between two individuals and taps into the life experiences of each, significant attempts were made to separate the interviewer's perceptions and experience from the interview process. To minimize risk of influencing the responses provided, interview questions were phrased in an open-ended manner and participants were asked to describe their experiences in a way that did not impose expectation of certain responses. In

addition, responses were summarized and fed back to the participants during interviews to allow for clarification and correction of the interviewer's understanding of participant responses.

Lifespan Sibling Relationship Scale

As was previously mentioned, all sibling relationships fall at some point on an intimacy-estrangement continuum (Hoyt & Babchuk, 1983); it was expected that pre-cancer sibling relationships would be an important factor to consider when analyzing sibling relationships following cancer diagnosis and treatment. It is for this reason that all participants were asked to complete the Lifespan Sibling Relationship Scale (LSRS) twice: the first time completing all 48 items regarding the current sibling relationship and childhood sibling relationship, and a second time retrospectively responding to 24 items pertaining to the adult sibling relationship prior to cancer. While the accuracy of retrospective reports has been questioned (Liebert & Liebert, 1995), it is the participants' perceptions of their pre-cancer sibling relations that are considered most important for purposes of the present investigation.

The Lifespan Sibling Relationship Scale (LSRS), developed by Riggio (2000), assesses affective, cognitive, and behavioral components of the sibling relationship. Because sibling relationships generally originate in childhood, retrospective childhood items are included as well as items assessing the current sibling relationship (Riggio, 2000). Initial evaluation has indicated that the LSRS has high internal consistency and reliably demonstrates the ability to differentiate between positive and negative sibling relationships (see Riggio, 2000). Riggio reported coefficient alphas for the six subscales ranged from .84 to .91; the coefficient alpha for the total LSRS was .96. In addition, test-

retest reliability indicates a correlation of .80 or greater for each of the subscales, and a correlation of .91 for the total LSRS. Although the small sample size of this study prohibits statistical examination of significant change in ratings of the sibling relationship, the scores are believed to provide useful descriptive information by creating a context for understanding participants' responses to interview questions.

Participants

Requirements for participation in this study included:

(a) Participants are adult females (18 years or older);

(b) Participants are sisters of women who were diagnosed with breast cancer within the five year period prior to research participation;

(c) Participants were willing to engage in an audio-taped interview for a duration of 60-90 minutes, and were also available for follow-up questioning should clarification or elaboration on responses be requested.

Due to the exploratory nature of this study, inclusion criteria were intentionally broad and allowed for a heterogeneous group of participants. It is believed that parallels found in the experiences of a diverse group of women will be more transferable to the larger population of sisters of breast cancer patients than would a more homogeneous sample. Several commonalities, however, do exist between all participants in the study and are important to keep in mind when reviewing the findings of this study. Commonalities among participants include: 1) All participants actively sought participation in the study after viewing a recruitment advertisement in the newspaper; 2) All participants lived in the same medium-sized city (population: 125,000-130,000); 3) All participants spoke of a full-sister who had been diagnosed with breast cancer; and, 4) All participants denied any

personal history of a breast cancer diagnosis, although several had experienced suspicious mammogram results requiring repeat testing and/or further exploration. Participants varied, however, in ethnicity (ten women identified as Caucasian, three identified as Hispanic), sexual orientation (twelve women identified as heterosexual, one as lesbian), and age (ages ranged from 30 to 57 years). A further description of the unique characteristics and background of each participant is provided in the Findings section.

Sampling

Participants were recruited through local newspaper advertisements. It was initially hoped that a minimum of ten women would participate in the study, with additional participants sought until saturation was obtained. A total of fourteen women were interviewed, although data from one interview was not included in the data analysis. The participant whose interview was removed from analysis met initial inclusion criteria (i.e., she is an adult, she has a sister who was diagnosed with breast cancer within the last five years, and she was willing to participate in the interview process); however, the participant also had several other sisters who had been diagnosed with breast cancer, two of whom had passed away more than ten years prior to the study. Despite the researcher's attempts to focus on the living sibling diagnosed within the last five years, the participant's focus was on describing her emotions regarding the experiences of her deceased sisters. Consequently, the content of the interview conducted truly did not fit inclusion criteria and was eliminated.

Data Collection

Potential participants were encouraged through newspaper advertisements to contact the primary investigator; upon doing so, each received a description of the study

and information regarding tasks involved in study participation. All participants were informed of the voluntary nature of research participation. Interested participants were scheduled for a 60-90 minute interview to take place at the primary investigator's office. Upon arrival, participants were again reminded of the purpose of the study, familiarized with the interview structure and questionnaire, and provided with an informed consent form to review with the researcher and sign. The researcher reiterated to participants that participation was voluntary, interviews could be halted at any time, and participation did not require that they answer any interview questions or questionnaire items with which they were uncomfortable. Once participants signed the consent form, they were provided with the questionnaires to complete. Upon completion of questionnaires, the tape recorder was turned on and the interview began.

The primary investigator, a Ph.D. candidate in Counseling Psychology, conducted all interviews. Each interview began with a request for information concerning the ages of participants and their siblings, date of diagnosis for the patient, patient's treatment regime, and patient's current health status. Following this preliminary information, the interviewer asked questions that were broad, open-ended, and designed to gather information regarding the participant's relationship with her sibling before, during, and after cancer diagnosis and treatment, as well as the psychological impact these experiences had for the sibling. Four questions were asked of each participant and were utilized to guide the interview process; these guiding questions were:

(1) Please describe the relationship you had with your sister prior to her breast cancer diagnosis, including childhood years.

(2) In what ways, if any, did her diagnosis impact your relationship with your sister?

(3) Please describe any assistance (either practical assistance or emotional support) you provided (or continue to provide) to your sister during her cancer experience.

(4) In what ways, if any, has your sister's breast cancer impacted you personally?

The interviewer employed probes, inquiries, and requests for clarification in order to gain a comprehensive understanding of each interviewee's experience. All interviews were transcribed to allow for accurate data analysis; however, names of participants, names of individuals mentioned during the interviews, and other pieces of identifying information were removed from the transcribed text to ensure confidentiality.

Data Analysis

Data analysis progressed through the following stages, as recommended by Creswell (1998), Moustakas (1994), and Patton (1990):

1) The researcher reviewed all transcribed interviews. Data were "bracketed" and studied in pure form; to the extent possible, interview comments not directly related to the topics of interest were eliminated from further analysis.
2) The researcher identified significant statements from each interview (i.e., "horizonalization"), treating all statements with equal value.
3) The significant statements were formulated into meaning clusters.
4) The meaning clusters were combined into themes.
5) The researcher then integrated themes into a narrative description of the experiences of siblings of breast cancer patients. The narrative description

incorporates both "textural" and "structural" descriptions (i.e., what was experienced and how it was experienced). At this level, the text presents a summary of the "essence" of being an adult sister of a breast cancer patient, as described by research participants.

Methods for Enhancing the Quality of the Study

Several procedures were employed to enhance the quality of this study, including reflexivity, triangulation of methods and analysts, member checks, discussion of negative cases, and thorough description of study participants and setting. Patton (1990) described reflexivity as the process by which examiners contemplate their own influence on data collection, analysis, and presentation. The researcher carefully reviewed and compared the progression of all interviews, and concluded that similar format, structure, and wording was used in conducting interviews with each of the participants. In addition, data analysis did not occur on a single occasion; rather, the investigator coded and recoded the data on several occasions in an attempt to uncover inconsistency in coding. The researcher also kept notes regarding her personal process throughout this research project, including reasoning behind decisions made during each stage of the process, struggles faced during the course of the project, and insights gained throughout the study.

Triangulation of methodology, an additional strategy recommended by Patton (1990), was implemented by utilizing two methods to tap a single aspect of the participants' experiences, that of changed sibling relationship. The impact of a sister's breast cancer was assessed through interview-based inquiry as well as ratings of a questionnaire assessing sibling relationships (rated to assess present sibling relationship and again to retrospectively assess the pre-cancer sibling relationship). In addition, an

advanced doctoral student with experience in conducting qualitative research provided support and assistance in data analysis, a strategy referred to as triangulation of analysts (Patton, 1990). The input of both individuals, rather than analysis by only one person, served as a means of increasing the likelihood that conclusions drawn indeed reflect the data rather than the perspective and/or biases of the researcher.

Member checks is a process by which researchers seek feedback from participants regarding the accuracy of findings, thereby enhancing the credibility of the study (Seale, 1999). Initially, the researcher had intended to conduct thorough member checks by supplying each participant with a copy of the manuscript and requesting feedback. Unfortunately, due to unforeseen circumstances, the length of time available for the study to be completed was shortened and this thorough form of member checks could not be completed. As a substitute, the researcher contacted participants by telephone, provided a brief verbal overview of the findings, and requested feedback on participant's perceptions. Although this approach is not considered ideal, as the findings were summarized rather than read in detail and participants' feedback was elicited verbally rather than in writing, it was implemented as a second-best strategy for eliciting feedback from participants on a shortened timeline. Nine of the thirteen participants were successfully reached by telephone, and all nine were willing to listen to a brief summary of the findings and provide verbal feedback to the researcher. Each of the participants contacted concurred that the brief summary captured their experiences; therefore, no revisions to the analysis were made following member checks.

Authenticity of a study is increased by incorporating discussion of negative cases (i.e., those cases which differ from the primary themes identified across qualitative

interviews) into the manuscript (Seale, 1999). In this manner, it is hoped that a "range of realities" is truly captured by the study rather than an overly narrow description of women's experiences with their siblings' breast cancer. Thus, negative cases are discussed within the context of findings from the study.

Finally, a thorough description of participants in the study and the setting of this particular research project is provided to allow the reader to determine his or her own perception regarding transferability of the findings to populations and settings other than those studied (Seale, 1999).

Introduction to Participants

It is valuable to keep in mind the heterogeneity found within participants, for each woman brings to the study her own unique story characterized by the history of her sibling relationship prior to the cancer diagnosis, family history of cancer, and specifics of her sister's diagnosis, treatment, and prognosis. For these reasons, the following pages entail a description of each participant and the unique perspective and background she brings to the study. Please refer to Table 1 for a summary of general facts on all participants (including age of participant, age of participant's sister, marital status of sister, whether sister lives in-state or out-of-state, total number of siblings in family, length of time since diagnosis, diagnosis, and treatment received). Please note that all names utilized in the text are pseudonyms and do not in any way reveal the true identity of research participants involved in this study.

Participant 1: Amy

Background Information: Amy is 53 years old and the oldest of four siblings (one sister, two brothers). Her only sister is three years younger than herself and was diagnosed with breast cancer one year prior to the research interview. Amy's sister is married and lives in the same state as Amy. In describing her childhood relationship with her sister, Amy stated, "I think the thing that's difficult is that she was so much younger, so we didn't spend a lot of time together when she was young." Amy indicated that she did not feel she knew her sister very well during their childhood years, although stated, "we've just gotten closer and closer as the years have gone on." Amy stated that she and her sister

lived in different states for many years, although Amy moved back to the same state as her sister several years prior to the cancer diagnosis. The closer proximity helped to enhance their relationship and they began to experience a much closer relationship than they had at any earlier time in their lives.

Relevant Personal and Family Health History: Amy described cancer as being "very prevalent" in her family. Amy's mother died as a result of breast cancer when Amy was in her early 20s. In addition, Amy's nephew (her sister's son) was diagnosed with non-Hodgkins Lymphoma three years prior to his mother's breast cancer diagnosis. Finally, Amy has a first cousin who has also been diagnosed with breast cancer.

Sister's Diagnosis and Treatment: Amy's sister was diagnosed in 2001 with Stage III breast cancer. Her sister underwent a double mastectomy with reconstruction, followed by chemotherapy. At the time of our interview, her sister had completed chemotherapy and was considered to be in remission.

Reaction to Diagnosis: Upon hearing the news of her sister's breast cancer diagnosis, Amy indicated she felt "shock." She stated that her sister's strength and positive attitude, however, assisted her in coping with the news. Amy indicated that her relationship with her sister initially felt "a little bit distant," as her brother-in-law did not want family present at the hospital during surgery. Amy recognized this was her brother-in-law's method of coping and trying to "protect" her sister, and yet also indicated, "it was difficult to be away." Amy first had contact with her sister two days following surgery, at which time they spent an entire day together. Amy stated, "we had some great talks at that time." Amy indicated that she and her sister spent much time together talking throughout her sister's treatment, and further elaborated, "I'm sure that the cancer drew

us closer together, there's no doubt in my mind about that. We were close before but I don't think we were nearly as close as we are now...."

Participant 2: Barbara

Background Information: Barbara is 47 years old, the youngest of three sisters. Her oldest sister, six years older than herself, was diagnosed with breast cancer two years prior to the interview. Barbara's sister is married and lives within the same state as Barbara. When asked to describe her childhood relationship with her sister, Barbara stated, "We sparred. We sparred quite a bit, because she was perfect and I wasn't. I tried not to be." Barbara stated that her sister married while Barbara was still in junior high school. Although their relationship was filled with rivalries prior to her sister's marriage, Barbara stated that she began to miss her sister once they were no longer living within the same home. At that point, when contact between Barbara and her sister became voluntary, their relationship grew closer. Soon after, however, her sister moved to another state and their contact dissipated. For much of Barbara's early adulthood she and her sister saw one another at large family gatherings, but did not have frequent contact with one another. In middle adulthood, Barbara's sister moved back in-state and their relationship once again grew closer. Barbara stated, "It was after they moved back, oh, we were close. She had two kids at the time and I had mine and we tried to bring them up together as well as we could."

Relevant Personal and Family Health History: Barbara did not report any family history of cancer.

Sister's Diagnosis and Treatment: Barbara's sister was diagnosed in 2000 with Stage III breast cancer. She initially had surgery; at that time it was discovered that 14 out of 25

lymph nodes tested positive for cancer. Her sister underwent chemotherapy and radiation, although a follow-up bone scan indicated suspicious spots on her spine. The diagnosis was then changed to Stage IV breast cancer and her sister underwent a second round of radiation. At the time of the interview, her sister had completed all treatment and her most recent bone scan revealed no suspicious spots.

Reaction to Diagnosis: Barbara stated that her sister's breast cancer diagnosis came as a surprise to the entire family. Barbara's sister had been fatigued for a lengthy period and was involved in a treatment program for sleep disorders, which was believed at the time to be the cause of her fatigue. Barbara had a routine mammogram during the same time period; the mammogram showed several suspicious spots and the cancer diagnosis occurred shortly thereafter. Barbara described her initial disbelief: "She had several tumors and I was figuring, well they're just cysts, we're not going to worry about it until after the surgery. And then that's when it hit, when they gave us the poor prognosis." Barbara described herself as being very focused on having a positive attitude and providing assistance to her sister at that time. "You've got to be strong for her, to keep her spirits up." Barbara has a medical background and immediately became involved in attending medical appointments with her sister, "so I can kind of absorb what the doctor is telling us and translate it to the family."

Participant 3: Carol

Background Information: Carol is 45 years old, the oldest of three sisters. Her youngest sister, three years younger than herself, was diagnosed with breast cancer just over two years prior to the interview. Carol's sister is married and lives in-state. In describing her childhood relationship with her sister, Carol stated, "Me and my sisters are all very

different personalities, but still I think have all generally been pretty close, even though we've been very different." Carol stated that she and her youngest sister oftentimes fought with neighborhood children in their youth. Carol described her sister as being "feisty" and "protective": "She was pretty scrappy, she would not take any crap from anybody. She would actually beat up some of the kids that were picking on me, and then other times I would stand up for her with other kids." As Carol and her sisters grew and matured, each began to develop her own niche and associate more with her own peer group, rather than primarily with her siblings. Carol stated,

> I'd say kind of during college years we started moving apart a little more, didn't see as much of each other because we were off going away, doing summer jobs out of state, that kind of thing. But it was still like, it's your sister, so they're just always there.

Carol moved out of state as an adult; both sisters followed to the same state, although the middle sister has since moved away. Carol and her youngest sister had a somewhat strained relationship in early adulthood. Carol described her sister as being "very angry about a lot of things, she has a temper." Despite this rough period in the relationship between Carol and her youngest sister, two events later in life improved the closeness in their relationship. Carol stated that her sister's marriage, which reportedly "mellowed her," opened the opportunity for the two sisters and their husbands to spend much time together. The second significant event was their mother's diagnosis of breast cancer, and eventual death. Carol stated, "I think my sisters, we all got closer because we realized, 'My God! We got to watch out. We've got to watch out for each other because there's a bully picking on us!'"

Relevant Personal and Family Health History: As mentioned above, Carol's mother was diagnosed with breast cancer. Her mother's initial diagnosis was made 13 years prior to

the interview. Carol stated that her mother's cancer was quite advanced at the time it was discovered; her mother received treatment for five years, but did pass away due to complications of metastasized cancer eight years prior to the interview. Carol stated that of the three sisters, she was most involved in helping her parents during her mother's illness. Feelings of grief and guilt regarding her mother's death continue to plague her thoughts. "I kind of always felt like I didn't do enough because I wasn't there enough." Carol described her mother's side of the family as having an extensive history of breast cancer; in addition to her mother's diagnosis, Carol has a grandmother, aunt, and several cousins who have also been diagnosed with breast cancer.

Sister's Diagnosis and Treatment: Carol's sister was diagnosed in 2000 with Stage II breast cancer. She initially had a lumpectomy to remove one large tumor; surgery was followed with chemotherapy and radiation. At the time of the research interview, Carol's sister had completed treatment and was considered to be in remission.

Reaction to Diagnosis: Carol vividly recalled the day she first heard of her sister's breast cancer diagnosis:

> I remember I got a call from my husband and he said, "You really need to call your sister now, it's really bad." So I called her up and she was just hysterical because she had found a lump in a breast exam. She had found a lump and she had gone in and got a biopsy, and it was breast cancer. So she was freaking out and I was freaking out, because all we knew about breast cancer was you die. Everybody we had seen that had it died.

Carol stated that in addition to her initial reaction of fear, she also immediately made a commitment to become involved in her sister's care:

> And so I decided I'm not going to let the same thing that happened to my mom happen to my sister. I was going to be there more and be more involved and do more research, ask more questions, study more, do whatever it took.

Participant 4: Donna

Background Information: Donna is 34 years old; her only sibling is her older sister who has been diagnosed with breast cancer. Her sister is four years older than herself and was initially diagnosed with breast cancer three years prior to the interview. Donna's sister was married and living in-state at the time of diagnosis; she has since divorced. Donna stated, "When we were kids we weren't close because we have a four year age difference. I was kind of a pest and someone she had to take care of a lot, which I think she found a burden." Donna indicated that her relationship with her sister became even more distant during junior high and high school years, "because we were into totally different things in our lives." Donna stated, "We always cared about each other and loved each other and had fun like on vacations and things, but we weren't real close when we were kids. We didn't do a whole lot together." A significant shift occurred in Donna's relationship with her sister once her sister moved out of the family home and began attending college. "Once she left for college we became good friends and then once I was in college and she was on her own and stuff, we were best friends. From that point on we were best friends."

Relevant Personal and Family Health History: Donna reported no family history of cancer.

Sister's Diagnosis and Treatment: Donna's sister was diagnosed in 2000 with Stage I, borderline Stage II breast cancer. She underwent surgery, chemotherapy, and radiation. Donna's sister had been in remission and feeling healthy for over a year; unfortunately, three months prior to the interview her sister was diagnosed with metastatic breast cancer.

Her sister was undergoing intensive chemotherapy treatment at the time of the research interview.

Reaction to Diagnosis: Donna's sister had shared her suspicion of breast cancer with Donna prior to going to the doctor. Donna stated, "She was suspicious. Of course she told me, we tell each other everything." Donna's sister was hesitant to see a doctor, as she feared the news would not be good. Donna stated, "I kept pushing her to go to the doctor. She didn't want to go because she thought she knew what it was." Donna went with her sister to the initial doctor's appointment and to the follow-up breast biopsy. Donna recalled the following events:

> When they did the biopsy they told her they didn't think it was cancerous from the way that it felt and some other characteristics. And then the next day she was at home in the evening, when she found out she called me. I was at work and I just dropped everything and came out that night. I stayed a week with her at her house because she had surgery the next two days. I took care of the kids. So, I was pretty much with her when I found out and kind of had a suspicion of what was going on.

Donna remembered providing much support to her sister during the first few days following the diagnosis.

> She kind of went into shock and the doctor had prescribed some sedatives to calm her down because he knew she was going to be upset. She had two little babies to take care of, a husband who wasn't altogether supportive, and she went into shock. She kept saying that she didn't want to die and she didn't want to leave the babies. She pretty much cried and was pretty unstable for the first couple days.

Participant 5: Emma

Background Information: Emma is 50 years old, the youngest of three siblings (one brother and one sister). Her sister is four years older than herself and was initially diagnosed with breast cancer five years prior to the interview. Emma's sister is divorced and living in-state; she has a supportive boyfriend, although he lives in another state. In

describing her childhood relationship with her sister, Emma stated, "We shared a bedroom together, which was a big problem. My sister is very territorial and I was the younger sister who never felt that my sister would let me share a room peacefully with her." Although Emma and her sister share many similar interests, she clarified that their similar interests sparked more competition than camaraderie. An additional source of competition between Emma and her sister was their relationship with their mother. Emma stated,

> I was very close to my mom and I still am close to my mom. I think there is some issue with the three of us, my mother, my sister and I. She is not necessarily jealous, but sometimes uncomfortable about the relationship that Mom and I have with each other. There was competition between us, there was competition for affection.

Emma stated that she and her sister have grown closer as they've grown into adulthood, although remnants of the childhood competition continue to impact their relationship. "There still is some disharmony between the three of us, my mom, my sister and I. It's just like oil and water when the three of us are together."

Relevant Personal and Family Health History: Emma is a physician; although she does not currently work with oncology patients, part of her medical training did take place in a cancer treatment center. In addition to working with patients diagnosed with cancer, Emma was intensely involved in her father's care when he was ill. Emma's father died from aggressive lung cancer more than twenty years prior to this research interview; Emma had been involved in his care as a supportive family member, but also as a medical professional who helped coordinate his medical care. Emma reported that her paternal grandmother died of breast cancer long before Emma was born. In addition, she had an uncle who was diagnosed with a rare form of cancer.

Sister's Diagnosis and Treatment: Emma's sister was diagnosed with breast cancer in 1997; although Emma was unsure of the staging, she did recall that her sister had no lymph node involvement (indicating most likely either Stage I or Stage II). Emma's sister underwent a lumpectomy and radiation therapy immediately following her diagnosis. At the time of the interview, her sister had been considered cancer-free for over four years.

Reaction to Diagnosis: Emma recalled her reaction upon learning of her sister's cancer diagnosis, and the immediate fear that ensued.

> I had a layover at the airport and I remember calling my sister-in-law at my brother's house. "I'm just on my way home," and I ask her, "How are things?" And she said, "Well, did you know about [sister]'s breast cancer?" And I said, "Oh my God. What?" I didn't. And I started crying right there in the waiting area of the airport. So, immediately I hear the diagnosis of my sister's breast cancer and part of me becomes the doctor and the other part of me is still the sister. And I think the sister aspect just totally overwhelmed me because I was just, "What can I do?" And my feelings to her, of course, were of total concern and of also just shuddering loss. "What if I lose my sister? How could I tolerate that?"

Participant 6: Fran

Background Information: Fran is 48 years old and has twelve siblings altogether. The oldest sister in the family, six years older than Fran, was diagnosed with breast cancer two months prior to the interview. Fran's sister is married and lives out-of-state. In describing her childhood relationship with her sister, Fran stated, "She was like our second mother, really." Fran described her sister as "quiet and responsible," stating,

> I kind of looked to her for that, but I was nothing like her. I was flighty and just wanted to have fun. She was different because she was so responsible and so much like a mother that that's the kind of relationship we had. I used to think she wasn't really very much fun. She was too serious.

Fran indicated that her respectful, yet somewhat distant, relationship with her sister continued throughout the majority of their lives. Approximately four years prior to the research interview, Fran's sister came to her house for a visit. During this visit, Fran and her sister had a conversation that dramatically altered their relationship. Fran stated that she had always respected her sister for being quiet and responsible; a conversation during her sister's visit revealed to Fran that her sister respected her for being gregarious and outspoken. Fran stated, "I kind of understand a lot more where she's coming from, she understands where I'm coming from, so our relationship definitely has changed. It kind of opened up some doors and we started relating in a different way."

Relevant Personal and Family Health History: Fran stated that her father's side of the family does have an extensive history of cancer; her father and his brothers have all been diagnosed with colon cancer. In addition, one paternal aunt has been diagnosed with breast cancer. Fran additionally has another sister (eleven months younger than her oldest sister) who had a benign, but fast-growing, tumor in her breast approximately one year prior to her oldest sister's breast cancer diagnosis.

Sister's Diagnosis and Treatment: Fran's sister was diagnosed in 2002 with two forms of breast cancer. Fran indicated that at the time of her sister's diagnosis, three tumors were found (two in one breast, one in the other). Fran indicated that doctors were uncertain about the staging of her sister's diagnosis. It was not possible to determine whether cancer had spread from one breast to the other, which is vital to differentiating between Stage III and Stage IV breast cancer. Fran's sister underwent surgery and was undergoing chemotherapy at the time of the research interview. Fran's sister also planned to receive radiation treatment once chemotherapy had been completed.

Reaction to Diagnosis: Fran indicated that the method by which her sister was diagnosed was, perhaps, one of the more traumatic aspects of her sister's breast cancer. Fran's sister is a medical technician who performs mammographies as a profession. Upon noticing several suspicious spots on her own mammogram, Fran's sister consulted with a doctor. She was told that she had nothing to worry about. Feeling unsettled about the physical symptoms she began experiencing, she pursued a repeat mammogram. Fran's sister was again assured that she was perfectly healthy. Still feeling concerned about her health, Fran's sister pursued a sonogram; the first doctor she consulted regarding the sonogram results again assured her she was healthy. Fran's sister obtained a second opinion, and at that point was diagnosed with breast cancer. Fran stated,

> And so by the time they're getting to it, it's so far along! That probably bothered me more than if she had just gone in, they did a mammogram, said "There's something here," and then said, "You have breast cancer." But it's like she had to fight for somebody to pay attention to her, and she works there! So, when I heard the news I was just devastated, especially because of how we found out and how much there was already, how far it had gone. There couldn't be anybody in the world that I would rather not hear that news about then [sister] because she's just so sweet.

Participant 7: Gloria

Background Information: Gloria is 42 years old and has five sisters. The oldest sister in the family, one year older than Gloria, was diagnosed with breast cancer three months prior to the interview. Gloria's sister is single and lives out-of-state. When asked to describe her childhood relationship with her oldest sister, Gloria stated, "We did struggle against each other a lot." Gloria stated that she was outgoing and social, whereas her sister tended to keep to herself. Gloria and her four other sisters oftentimes played together and had similar interests; Gloria's oldest sister was often uninvolved in their games and activities. Gloria stated, "Oftentimes it was the five of us and [sister] would

be off doing her own thing." Beyond different interests and disagreements, Gloria in fact stated that she and her sister simply did not like one another as children. "We really weren't close. There were times when I really didn't like her and the same, I don't think she liked any of us a lot of times." In summarizing her childhood relationship with her sister, Gloria stated, "I never would have chosen her as a friend. Oh Lord, no way. When we were kids, I can't imagine ever, ever wanting to be around this person." Gloria stated that the relationship between herself and her sister did not improve even after they each moved out of their parents' home. Gloria resented the fact that her sister attended the same college and described their early adulthood relationship as "competitive." In 1999, a family visit created significant change in the relationship between Gloria and her sister. Gloria described an argument between herself and her sister in the following manner,

> She came out to visit and we just had a huge argument. It was like, okay, this is it. For once and for all, let's get it out. We said awful things to each other. We were both crying, it was horrible. And I walked away. I thought, "She's going to be gone when we get back. This is it. We really have said enough horrible, hateful things to each other that our relationship will end."

Gloria returned home and found her sister had not left; the two were then able to address their rivalrous past.

> Her comment to me was something about how she felt held in the past by me and I thought, "You know, I think I am doing that to you because I expect that of you every single time I see you and we get back into the old patterns." And I said, you know, I remember turning to her and holding her hand and saying, "[Sister], from this moment on, there is no past as far as you and I are concerned. We're sisters, we're not going to bring up this rivalry stuff. There is no competition. I'm not going to hold you in the past if you promise to not hold me in the past." And, I'll tell you, our relationship at that moment was like night and day. This was about three years ago and now we can talk about anything, it's just truly changed. So, that's kind of the history of how we really kind of had a hateful, horrible, really horrible relationship and it wasn't until we became adults and really, really got into each other's face so honestly. It's the best thing that's ever

> happened to both of us. We just had to chose to either have a relationship or not, and you know, I think we both really knew that we really did love each other despite all the yucky stuff.

Relevant Personal and Family Health History: Gloria reported no family history of cancer.

Sister's Diagnosis and Treatment: Gloria's sister was diagnosed in 2002 with Stage III breast cancer. Immediately following the diagnosis, Gloria's sister underwent a lumpectomy. At the time of the interview Gloria's sister had undergone two rounds of chemotherapy and was scheduled for her third round several days following the interview.

Reaction to Diagnosis: Gloria was initially informed of her sister's breast cancer diagnosis by another sister. She reportedly cried upon hearing the news and immediately felt concern for her sister. Gloria stated that the news was difficult to cope with, as the diagnosis (in terms of staging) was worse than what was initially expected. Gloria initially experienced much fear and anxiety, but indicated that her own emotional response was helped a great deal by how well her sister was coping with her own cancer diagnosis. Her sister's positive attitude and optimistic outlook greatly alleviated Gloria's distress upon first hearing of her sister's diagnosis. In discussing her sister's response to the cancer, Gloria referenced the argument between herself and her sister in the following manner,

> Had she gotten the cancer before we had our little blow up, I just can't even imagine what the experience would have been like. I'm not sure at that age and stage, I'm thinking she might have never gone in [to the doctors] at all. I just think that whole thing just changed everyone. As weird as that sounds, that one fight – we fought a lot over the years, but that one was the first really honest I really care about you, we're willing to put each other out on a limb and say, "I really do love you even though you make me so damned mad!"

Participant 8: Hannah

Background Information: Hannah is 40 years old; she has one older sister and two younger brothers. Her sister, two years older than herself, was diagnosed with breast cancer four months prior to the interview. Hannah's sister was separated from her husband prior to her diagnosis, and was living out-of-state. In describing her childhood relationship with her sister, Hannah stated,

> My sister and I were very close. We really were a pretty insular unit. My sister's older than me and she protected me, very much so. I remember a neighbor girl wanted to beat me up and you know she took care of that for me, like a good big sister.

Hannah's family moved during her high school years, a change that Hannah's sister "never recovered from." Hannah described her sister during their high school years as having low self-esteem and few friends. Hannah's sister lived at home during college, whereas Hannah attended college in another state. This dynamic created problems in their relationship. Hannah stated, "There was a lot of resentment on her part that I went away, that I was so special because I was gone and she was there cleaning the house." Resentment characterized Hannah and her sister's relationship for many years to come:

> I graduated from college. I lived on my own a few hours away. I had traveled, had a large circle of friends, had money to do whatever I wanted to. She didn't have all those things. And so there's always been some resentment toward me in what I had. I think she's had a lot of resentment towards me over the years. So, our relationship has not been that close.

Relevant Personal and Family Health History: Hannah stated that the only other family history of cancer she was aware of was a first cousin who had been diagnosed with breast cancer.

Sister's Diagnosis and Treatment: Hannah's sister was diagnosed in 2002 with Stage II breast cancer. Doctors declared that her sister's cancer was "pretty advanced" and

suspected lymph node involvement. At the time of the interview Hannah's sister had completed six of eight planned rounds of chemotherapy. Her sister planned to have surgery following completion of chemotherapy.

Reaction to Diagnosis: Hannah explained that intermixed with the story of her sister's diagnosis of breast cancer is the story of her own hardship. Hannah's husband had been out of work for approximately one year at the time she learned of her sister's diagnosis. She recalled having been very focused on praying for her and her husband's situation to improve on the same day she learned of her sister's diagnosis, and described an immediate shift in attention and concern upon hearing about her sister having breast cancer. Hannah stated that her prayers immediately turned to her sister's well-being. Hannah learned of her sister's breast cancer diagnosis during a phone call from her parents. She stated that her sister had felt a lump several months prior, but "thought it would go away." Hannah indicated that the diagnosis and beginning of treatment occurred in very quick succession, within days of each other. Hannah went to visit her sister for the first time since her diagnosis the weekend before the interview, to assist her during her sixth round of chemotherapy. Hannah stated, "She actually did, I thought, very well while I was there."

Participant 9: Irene

Background Information: Irene is 57 years old, the younger of two sisters. Her sister, two years older, was initially diagnosed with breast cancer approximately four years prior to the interview. Irene's sister is in a long-term committed relationship and lives out-of-state. When asked to describe her childhood relationship with her sister, Irene stated, "We were extremely close, just super close." Irene shared stories of playing, walking to

school, and attending family functions with her sister. Irene stated that her sister oftentimes took the role of caretaker and looked out for Irene's well-being. Irene's memories of her childhood with her sister were all positive; she stated,

> We weren't allowed to fight or get mad at each other, so if we were ever angry at each other I don't know if we were able to show it. But I never really felt, as a kid, that I had any reason to be angry.

Irene stated that her relationship with her sister grew more distant during college years. "We didn't stay in touch very much. Nobody called each other, like long-distance, back then and we didn't write much. It wasn't for any reason that we wanted to separate and not be together, you just did your own life." Irene stated that she and her sister eventually married and began their own families.

> I would say we didn't really start doing the phone call thing until I had a daughter. I think that really made a difference. Also, my parents died ten and twelve years ago, something like that, and so that brought us together a lot. We just really support each other, we probably talk at least once a week.

Relevant Personal and Family Health History: Irene stated that her father and grandfather both died of cancer. In addition, she had one aunt who was diagnosed with breast cancer.

Sister's Diagnosis and Treatment: Irene's sister was diagnosed with breast cancer in 1998, although Irene was unsure of the exact diagnosis or staging of the cancer. Her sister underwent a lumpectomy, followed by both chemotherapy and radiation. At the time of the interview, Irene's sister had completed treatment and considered herself to be cancer-free.

Reaction to Diagnosis: Irene stated that she heard of her sister's breast cancer diagnosis during a phone call with her sister; she described her initial reaction as "shock":

> I was initially really scared about the whole thing. It was just really a blow because she's always been my idol and I always held her on a pedestal. She's just extremely important to me. Especially with my parents being gone, the idea of having her gone is just really freaky, it really is. It's a terrible thing. I was the one who had all these childhood things like allergies and stuff, and she was always rock solid hard, never got anything wrong with her. She never had any problems with anything, and so for her to get sick was real weird. I felt terrible. It was very upsetting, and I think it also made me start worrying about myself.

Participant 10: Julie

Background Information: Julie is 57 years old and the youngest of three sisters. The next oldest sister is three years older than herself and was diagnosed with breast cancer four years prior to the interview. Julie's sister was married and living out-of-state at the time of her cancer diagnosis and treatment, although had moved to the same state as Julie following completion of her treatment. In describing her childhood relationship with her sister, Julie stated,

> I was the youngest of the three girls and I always felt like my sisters insisted on picking on me. I'm sure this was just sibling rivalry, but they would tease me and tease me and I would cry, and you know, they'd laugh. Just typical sibling rivalry.

Julie described herself as being closer to her oldest sister than to her sister who was later diagnosed with breast cancer, although she recalled several activities she and her sister enjoyed doing together during their adolescent years. Julie spent occasional weekends with her sister during the years when Julie was at home and her sister was in college. In early adulthood, Julie and her sister saw little of one another until they were both married and would celebrate holidays together. Julie stated that her relationship with her sister became a great deal closer once her sister divorced and moved out of the country. Julie and her sister alternated years visiting one another,

> And we really got closer, the closest we'd ever been, when we started traveling together. And I think a lot of it had to do because we always went on family

> vacations in the summer as kids, we traveled so well together. We wanted to do the same things and see the same things. I never found a traveling partner I enjoyed doing things with more than her, and so that's when we became closer.

In more recent years, Julie's sister has remarried and moved back to the United States; Julie stated that she and her sister are supportive of one another, but do not have same kind of closeness experienced during their times of traveling together.

Relevant Personal and Family Health History: Julie stated that her sister's breast cancer diagnosis was a surprise, as her family has a history of ovarian cancer, not breast cancer.

> My grandmother died of ovarian cancer, my mother had it, and then I was not diagnosed with ovarian cancer, but I had what was called precancerous cells and so then they did a hysterectomy to make sure it didn't turn into that. As far as the breast cancer goes, this was not in our family. This was the first one, so it's made all of us a lot more aware.

Sister's Diagnosis and Treatment: Julie's sister was diagnosed with cancer in 1998. Julie was unsure of the exact diagnosis, but believed it was either Stage II or Stage III breast cancer. Her sister underwent a lumpectomy and radiation. At the time of the interview, her sister was taking tamoxifen, but had completed all rigorous cancer treatment and was considered to be cancer-free.

Reaction to Diagnosis: Julie described herself as having been in a state of shock and disbelief upon hearing of her sister's diagnosis. "I don't think I really, truly wanted to believe it. I was in a state of shock." Julie recalled offering to fly to the state where her sister was living to provide assistance, but indicated that her sister discouraged her from coming and assured Julie that she did not need to worry. Julie called nightly, particularly in the beginning, to offer support to her sister. "I kept thinking, 'She's got to be hurting more than she's letting on.' And through the phone, she just sounded like 'I'm tough and don't worry about me. I can deal with this.' And so I didn't go there." Julie expressed

regret over her decision to remain home during her sister's cancer treatment. "She tells me I was very supportive because I was always calling, and I may have been supportive that way, but I feel that I should have gone there. If I had it to do over again, I would go."

Participant 11: Keri

Background Information: Keri is 53 years old and the oldest of five siblings. Her sister, 18 months younger than herself, was diagnosed with breast cancer three years prior to the interview. Keri's sister is married and living in-state. Keri indicated that she and her sister had a "good" relationship during their early childhood years, although described a dramatic shift in their relationship at the ages of 10 and 8. Keri stated,

> My parents had like a second family, so I have a sister that's 13 years younger than I am and 10 years younger. So, my sister and I, we kind of became parents at an early age. So, then our relationship became very strained and wasn't so good.

Keri further elaborated on the strain in her relationship with her sister, "I think we put a lot of blames on each other. You feel like one's getting better treatment than you are and that's just kind of what happened to us. It is sad, but it did happen." Keri described how her relationship with her sister remained strained for many years:

> It remained strained even as we became adults and started our own families. What's really sad about the whole process of it all, because my sister and I talked about this after we finally got together, we always loved each other but it was actually our mother that pulled us apart. And the further it went along, the worse it got. It's like you don't even know why you're upset with each other. That's the sad thing, I didn't really have any grudges or hatred or dislike or anything. I've always loved her, but my mother always kept pulling us apart. We had children, we have sons that are the same age. They really didn't grow up together. So, it's sad that it happens, but it does. It's sad that we lost what we lost. We lost childhood together.

Keri indicated that she and her sister were not outwardly unpleasant to one another, but there was a distance in their relationship that persisted well into adulthood. Keri and her sister did provide support to one another, such as being present when each gave birth to her children and when spouses experienced medical difficulties; however, Keri described even these times of support as hampered by the distance in their relationship. "We always cared, we were there at times of need, it's just that it was strained. For some reason, you stayed in the background." Keri described a dramatic shift in her relationship with her sister following the death of their father.

> My father died and something happened and my sister called me one morning to see if I had heard about something with my mother, and we talked for eight hours. And in those eight hours we talked about things we had never been able to talk about, because we were always afraid of my mother. And so we just talked about things, how we felt, we found out how our mother had lied about us to each other, and so we just started talking and just realized that it had nothing to do with us at all and it really was our mother. We always thought, but you know you just never really want to believe it. It's hard to believe that a mother would not want to see her children love each other. And so it did, it just took eight hours of talking and it was wonderful. And it was from that time on that our lives changed. We have a beautiful relationship, we really do.

Relevant Personal and Family Health History: Keri reported that her paternal grandmother had been diagnosed with breast cancer and had a mastectomy. She knew of no other family history of cancer.

Sister's Diagnosis and Treatment: Keri's sister was diagnosed with breast cancer in 2000. She was unsure of the exact diagnosis, but believed it was likely Stage I or Stage II breast cancer. Her sister underwent a lumpectomy, followed by radiation. At the time of the interview she had completed all treatment and was considered to be cancer-free.

Reaction to Diagnosis: Keri described feeling "devastated" upon hearing of her sister's breast cancer diagnosis. She elaborated by saying,

> You think you finally have a relationship and she's not going to be there, because that's what we thought at first. I didn't tell her that, but I did, I thought, "Oh my gosh. We now have such a terrific and fantastic relationship and we're finally together, our families were happy, and now God's going to take her away from me? He can't do that!" So, that was difficult.

Keri struggled to overcome her initial fear of losing her sister and forced herself to take on a more positive, optimistic outlook. "You have to get into that other mode where you think everything's going to be okay."

Participant 12: Lynne

Background Information: Lynne is 52 years old and the oldest of three siblings (one sister, one brother). Her sister is one year younger than herself, and was diagnosed with breast cancer three years prior to the interview. Lynne's sister was divorced prior to her cancer diagnosis and lives in-state. Lynne stated that she and her sister were not close during their childhood years. She described herself and her sister as being very different, having different interests and different groups of friends. She stated,

> We really weren't close, we didn't share secrets. I'm sure we had some fun, but it wasn't a constant thing. We did fight a lot, scratched a lot – that was our thing. I can't say we were real close, we just weren't.

Lynne and her sister attended the same college, and experienced increased closeness in their relationship during that time. Although each continued to maintain individual interests and groups of friends, Lynne and her sister socialized together and "just got closer and closer all the time." Two additional events brought Lynne and her sister closer in their relationship. The birth of Lynne's daughter strengthened their relationship a great deal. Lynne's sister never had children of her own, but was extremely close to Lynne's daughter. As her daughter grew and matured, Lynne, her sister, and her daughter would often take road trips together. In reference to this time period, Lynne stated that her

relationship with her sister, "it just blossomed as the years went on." Approximately ten years prior to the research interview, Lynne's mother developed significant health problems. Lynne oftentimes provided her father with respite by providing care for her mother. Lynne's sister lived in another city at the time, but offered support to Lynne through daily phone calls. Lynne stated that talking on the telephone drew her and her sister even closer together.

Relevant Personal and Family Health History: Lynne did not report any family history of cancer.

Sister's Diagnosis and Treatment: Lynne's sister was diagnosed with cancer in 2000. Lynne was unsure of the exact diagnosis, but believed it was likely Stage I or Stage II breast cancer. Lynne's sister underwent a lumpectomy, followed by radiation and chemotherapy. At the time of the interview, her sister had completed all treatment and was considered to be cancer-free.

Reaction to Diagnosis: Lynne described the events around her sister's breast cancer diagnosis as occurring extremely fast. Lynne primarily focused on logistics and had difficulty reporting exactly how she felt at the time. She stated that her sister called to tell her she was going in for a biopsy, and was scheduled to have surgery the next day. Upon learning that her sister was having surgery, Lynne made arrangements to take time away from work so she could be with her sister. She stayed with her sister following surgery. Lynne stated,

> I was there for five days, just kind of waiting on her. You know, she had strict instructions not to get up, not to move around, and she was trying to do too much. So, I just kind of was there nagging her.

Participant 13: Mary

Background Information: Mary is 50 years old; she grew up with an older sister and a younger sister. Her older sister, two years older than she, passed away two years prior to the interview due to breast cancer. Her sister had been married and living out-of-state. Mary described her childhood relationship with her sister as being close and described her sister as being protective of her. The relationship between Mary and her sister began to change and become more distant, however, during adolescence. Mary recalled,

> I don't remember having big disagreements with her or anything until probably high school, and then we did fight a lot. I think it was competitiveness, and even then she was really angry at the world about a lot of stuff.

Mary described her sister as an angry and mostly dissatisfied individual. Mary described "moments of closeness" she shared with her sister, particularly during conversations regarding their children or parents. Mary attributed some of the distance in her relationship with her sister to the physical distance between the two, living in different states throughout much of their adult lives. Despite the distance and frequent arguments Mary and her sister experienced in their relationship, she was also able to identify moments of great closeness and support during traumatic events that took place in each of their personal lives.

Relevant Personal and Family Health History: Mary did not report any family history of cancer.

Sister's Diagnosis and Treatment: Mary's sister was diagnosed with Stage IV breast cancer in 1999. She initially had a double mastectomy, followed by chemotherapy and radiation. Mary's sister finished her final round of radiation treatment approximately one month prior to her death.

Reaction to Diagnosis: Mary recalled first learning of her sister's diagnosis during a discussion about her sister's difficulties with her daughter and husband. Mary stated,

> She was having problems with her daughter, just typical rebellious stuff. Then she was still angry with her husband and I was encouraging her, saying, "Maybe you'd be better off if you just left, even if you're on welfare." But then all of a sudden she said, "Well, I have a lump on my breast." I said, "Go to the doctor, today!" So she went to the doctor the next week and it happened really, really quick. They found out it was Stage IV and they did a mastectomy probably within a couple weeks, a double mastectomy. And at that stage it was really hard because everything they came up with was just really horrible. She had her lymph nodes checked. I read up everything I could on the computer and it would say if five or six lymph nodes are cancerous, that's bad. They checked 28 lymph nodes, and 27 were cancerous. So, it was just like every single diagnosis was just the most severe you could get. So, that was a really tough time. We talked on the phone a lot. Even before that, I had a very large phone bill. Once that happened, then it was a daily thing.

Findings

Essence of the Experience

If a single word had to be chosen to capture the essence of research participants' experiences of witnessing their sisters' battles with breast cancer, it would be *fear.* The most prevalent themes that arose from interviews with the thirteen women in this study were fear for their own well-being, fear for their sister's well-being, and a resulting shift, for many, in their relationship with their sister.

Analysis of Themes

The experiences of the thirteen women who participated in this study were unique in many ways; variations in childhood relationships, pre-cancer adult relationships, geographic location, marital status of each sister, and personality factors appeared to shape the particular story told by each woman. Nevertheless, several dominant themes (i.e., themes identified in a minimum of ten out of thirteen interviews) became evident during analysis of the interviews. The themes, to be discussed within the context of the research questions posed, are: an extensive degree of assistance and support provided to sisters, descriptions of sisters' spousal relationships (if applicable), positive attitude, coping strategies, fear for self, sense of the cancer experience "happening to me," fear for sister, increased closeness in the sibling relationship, and descriptions of the unique qualities of a sister-sister relationship.

Support Provided by Siblings

All thirteen participants referenced the marital status of their sisters and, if married, the quality of their sisters' marital relationships. The siblings of seven participants were married, one was in a long-term committed relationship, one was separated from her husband several years prior to her breast cancer diagnosis, one was divorced but dating a man who lived out-of-state, one was married at the time of diagnosis but since divorced, one was divorced several years prior to her diagnosis, and one was single (never married). The relationship status of each patient was described as being a factor that influenced the degree to which participants felt their support was needed and/or desired.

> I just think she already had a lot of support there at home, because if she hadn't had that I probably would have been there. (Irene)

> He was very supportive. I've known of families that this has really torn apart, and it's just the exact opposite here. (Barbara)

Carol's brother-in-law was also supportive to her sister, but in a much different manner:

> My sister's husband is really uncomfortable with all the medical stuff. She said, "I don't want him to be there seeing me being, looking so bad and feeling so bad." She goes, "I want him to treat me like he always has and to make me laugh." And she said, "He does that. He treats me like he always has and he makes me laugh." And so he couldn't be there for the medical, you know, all the gorey, icky stuff, but he was there to bring normality to her life.

Donna had a quite different observation of her brother-in-law and the degree of support he provided to her sister:

> I think, from other people I've met, your husband goes one way and is one hundred percent supportive and is right there for you, or the other way and they just check out. And he decided to check out. He couldn't handle it. He wasn't very mature to begin with and emotionally he just couldn't handle it. Quite honestly, I think I became her support system. He wasn't there to rely on and I was. He chose to go to his little cave and deal with it that way. And she said,

> "You know, I may only have a few more years. I'm not going to spend my life with him."

Julie also observed lack of support in her sister's marital relationship:

> I didn't feel she was getting the support from her husband. He had lost his first wife to cancer as well and he was extremely scared. He thought, "Here we go again." So, I think it strained their marriage a little bit. He just held back a lot. He was protecting himself, he was withdrawn.

The statements about participants' perceptions of the support their siblings had through romantic relationships provide some indication of the degree to which they felt support outside themselves was available. Regardless of the siblings' relationship status, however, each participant in the study described methods by which she provided support to her sister during the cancer experience. Specific methods by which the women provided assistance varied, and each woman described multiple methods by which she helped her sister. The most common strategies for providing assistance are highlighted in the following paragraphs.

Several women found themselves advocating for quality care of their sisters. Women who described themselves as generally quiet, polite, and passive found motivation in their concern for their sisters to approach people, argue with people, and insist upon changing a situation; for many, the experience was both empowering and new. Donna described herself as "passive-aggressive" and "not very outspoken" prior to her sister's diagnosis. Feelings of anger about the care her sister received from insurance personnel drove Donna to advocate for better care:

> I just challenged them on things that I never would have done before. Like, they wanted to kick her out of the hospital after her lumpectomy. She had two little kids and she had drains coming out of her and her one-year-old was going to cling to her. And so they told her that she had to go home, and I called them back and said, "No, you're going to cover it until the next day because she has two kids and that's impossible." And so they changed their tune and we got it covered for another day.

For some, advocating for better treatment of their sister had nothing to do with better medical care. Mary explains, "I'd yell at her husband when I thought he was being a jerk!"

Providing emotional support, simply talking with sisters and listening to descriptions of the emotional impact of cancer diagnosis and treatment, was a very common type of assistance provided to sisters.

> All I can do for her right now is just to give her encouragement, love, and support. (Barbara)

> So, if anything, it made me try to respect her need for talking, confidence, intimacy, silence. (Emma)

> I told her, "You just can't hold it inside. You've got to share it with somebody!" I said, "If you don't share it with me, we can't do this together, and if you want me to do this with you together, you have to share with me what you're feeling! It's like lifting that off your shoulders." A lot of times she holds things inside because she doesn't want you to worry, but I think with me she's gotten over that. So, part of it was me teaching her you can't do that. (Keri)

> We talked. I tried to make her feel free to talk about her innermost feelings to me and what was important if she did only have a short period of time. (Mary)

Many women described increased frequency of telephone contact and increased duration of telephone conversations.

> I suppose my biggest support to her was that we talked every day, just daily on the telephone. Whatever it was, whether it's just to say, "Hello, I'm thinking of you. Anything you want to talk about?" (Keri)

> I think a sister has to call a lot because being the person that your sister talks to, which we share a lot of confidences and things, that's a big support that you can offer. I think it would have really hurt her had I not offered that daily, every other day, kind of contact. (Lynne)

In addition to somber discussions of the harsh reality of experiencing cancer, sisters also provided an escape from negativity through humor and reminders of shared memories. Donna shared many ways in which she strived to lift her sister's spirits:

> I would prepare stuff to entertain her the whole time, just so we could laugh and not deal with what was actually going on. The chemo room's hard to deal with. So, to keep our mind off stuff, I bought all kinds of funny books, you know, things that are just ridiculous. All those fun books, we bought them and we read them. You know, she felt like crap, but we kept laughing and laughter's such a great thing when you feel awful.
>
> We have all these wonderful pictures, so I compiled them and made this huge album just for her. We looked through those a couple times when we went to the chemo room, and just reminisced about all those fun times.

A positive attitude and optimistic outlook was deemed extremely important by each participant, although was reportedly harder for some to maintain than others. The reality of the diagnosis and prognosis for each woman's sister certainly impacted her ability to maintain a positive outlook; however, each woman described an attempt to allow her sister to hear only the positive thoughts.

> You have to be that support system and be strong with her and feel that it will be taken care of, everything will be fine. I think that's the only way you can be, is positive. I wasn't in the beginning, at first I thought it was just horrible and I was sure I was going to lose her. I never, ever told her that though. (Keri)
>
> We had to change a lot of those negative thoughts. We were both like, "It's time to think positive!" Because we were both like 'glass half empty' type of people. But we were like, "No! We have to break that cycle and think positively!" And so we started reworking everything and rethinking everything, so everything is positive. (Donna)

Many of the participants indicated that they played a role of gathering information about breast cancer, treatment options, and reputations of doctors and treatment facilities.

> I went out to this research facility, it's like a health library, and they were really great there as far as providing references, doctors' names, suggestions, giving me information on what type of breast cancer she had, all of that. So I went out and gathered all that information and then we both sat down, and her husband too, and kind of went through it and went, "Okay, here's what we understand, here's what the options are, here's what we have to do." You know, "Where's the best place to go do this?" (Carol)
>
> You know, we got our medical degrees real fast. We always joke about that. We've read every single book and read everything on the internet we could. We

> educated ourselves, and that made us feel a lot better, just knowing more about the disease itself. (Donna)

In addition to gathering information about treatment options and gathering facts about cancer, many participants accompanied their sisters to medical appointments. This type of support seemed to be all or nothing; sisters were either extremely involved in their sister's medical treatment or were quite removed and attended very few, if any, medical appointments. Several participants described quite intensive involvement in their sister's medical care:

> I'm the one that goes with her to her medical appointments. I've got a medical background and I went to all of her chemo appointments. Sometimes I think the doctors are afraid when I come in because I'm the one who asks all the questions. They're very responsive, though, and I think they like the idea of somebody that's so proactive in her treatment. (Barbara)

> My sister is really needle phobic, so the oncologist we went to had a really good set-up where he had like counseling, nutrition, psychological counseling, and then the oncology stuff. We told them she's terrified of needles and asked, "How do we deal with this?" They were really great. They said, "Well, we can teach you some relaxation techniques and we'll teach you how to help [sister] relax." And we did like visualization and that worked like a charm. It was really cool to see how quickly it made a difference. And then the other thing they taught me was how to give her shots to get her red blood cell count up. I gave her the shots because she couldn't do it herself. (Carol)

For sisters who lived in another city or another state, traveling to visit their sister was an additional mode of offering support. Many women described frequent visits to spend time with their sisters and provide practical assistance.

> Well, I called her one weekend and she said, "I'm done. I'm not doing any more chemo. I'm going to call the doctor. I'm finished, I don't want to fight this anymore." I said, "Well, you've got to complete it. You don't want the cancer to come back." She said, "I don't give a crap if it comes back because I'm not going to do this anymore. I'm done." So I'm like, "Oh my God. We've got to do something drastic." So, I scheduled my trip to visit. I hadn't stayed at her house in nine years, but I went out there to be with her and see what I could do. (Hannah)

Much of the support provided to sisters involved practical support. For participants who lived within the same state as their sister, practical support was provided on a frequent basis. For participants who lived in a different state than their sister, an opportunity to provide practical support was often the motivation behind traveling for a visit. Practical support ranged from physical assistance when a sister was ill to housecleaning when a sister was too tired or ill to take care of daily chores to rather monumental expenses.

> I did stuff like I bought gobs of paper plates and cute paper things that were pretty so that she wouldn't have to be doing dishes. And then when I cooked stuff for her, I tried to put things in the freezer. And I called her church and tried to get people to bring meals. (Mary)

> I'd do things like I'd clean her house. (Carol)

> We're going to buy a house for her, my boyfriend and I. It's kind of against her will, but I just want her to have something cute that she'll like. (Donna)

An additional source of both practical and emotional support offered involved providing support to nieces and nephews.

> I've had to babysit because she has appointments or whatever and they're sad a lot because she's away so much. So, I explain things to them, just try to explain what's going on and explain things like the whole hair loss, and do it in a positive fashion. We've changed our diets and all that stuff, so you know we don't do things quite like other kids, like go to McDonald's and things like that. We don't drink a lot of soda pop. So, step-by-step I'm there to explain things to them and to reinforce things I know my sister wants for them when she's not there or when she's too tired to take care of them. (Donna)

> I've talked with that niece a number of times and I can tell she really needs that. She needs to talk to me because they don't really talk about it. I have long chats with her when she answers the phone. I know she feels comfortable, I want her to feel comfortable and be able to say whatever she wants. (Fran)

One role described by multiple participants, that of managing family dynamics from the family of origin, was one many women felt they were uniquely qualified to

fulfill. Patients were often protected, either from experiencing strained family dynamics or from having to address the family dynamics. Several examples follow:

> Well, the first thing I had to deal with was my mother. My mother worries about everything. If she doesn't have anything to worry about, she worries. And so after the diagnosis I had to take her aside, and I said, "Now look, you cannot be mopey around her or else she's not going to want to be around us. So, chin up!" And I think, well, my sister said that's the best thing I could have done for her at that moment, was to take care of my mom. (Barbara)

> We have all these issues with my parents, we've never talked about anything with them and it's been really hard for my sister and I. One thing that I changed, I'm like, I'm not doing this anymore. I can't hide things from them about her. I'm just going to tell them like it is and be a lot more open and communicate with them so that they can help her and be supportive and understand where she's coming from. (Donna)

> I've approached my brother and said, "Do you want to talk to me about it?" Nope. That's not an issue that we discuss, so my sister doesn't know. And I feel very strongly that if it were me, I'd want to know that [family member] is not managing well with one young child, let alone taking on two other children who've just lost their mother. So, I mentioned it to my mom. I said, you know, I really think [brother] is the one that needs to address it with my sister. I followed up with my mom when I was there last week and she said, "Well, I haven't said anything to anyone yet." I mean, it's got to come out! She can't go through this thinking that they could be great parents for her girls! (Hannah)

Several women spoke of their desire to provide more assistance than they were able, or their guilt over having not offered or insisted upon providing more support than they did.

> But then I couldn't be there for her when she was in the hospital. I mean she was in the opposite end of the state and I was teaching in the other end of the state. I couldn't be there all the time, and I really have some heavy-duty guilt feelings about all that that still linger with me. (Amy)

> Looking back on it I think, "Boy, I didn't do very much." It's like, I didn't get very involved and maybe I should have. It probably would have been good to have been more support. Looking back on it I really feel like I should have gone out there. (Irene)

The statements of regret and comments about ways in which participants would like to have responded differently to their sisters' cancer experiences reveal a component of the emotional toll experienced by several of the women interviewed, speaking directly to the second area of research inquiry.

Emotional and Psychological Well-Being of Siblings

Emotional implications of witnessing a sister's breast cancer diagnosis and treatment revolve largely around fear. Fear for oneself and fear for one's sister necessitated implementation of various coping strategies, ranging from increased support provided to sister (as discussed in the previous section) to medical and/or therapeutic intervention. Most prominent of all themes identified in the thirteen interviews was that of heightened fear for one's own well-being. Participants witnessing their sisters' illness developed a heightened sense of mortality, increased perception of their own vulnerability and susceptibility, and increased fear that a sister's breast cancer meant they, too, would inevitably develop breast cancer.

> Well, the first thing it did was of course terrify me that, "Oh no, my mom died, my sister has breast cancer, I'm going to get it next!" So, I think that sort of freaked me out for a while, I'd say maybe the first two months after she was diagnosed I was like getting really paranoid about, "Oh my God, I'm going to get breast cancer someday." (Carol)

> I think the sister aspect of it all, well it of course impacts on my own mortality and my own vulnerabilities to know this is happening to [sister]. This could also happen to me. How would I handle it? So, all of those things go through my mind. (Emma)

> I looked at her and I thought, "Well, how would I look without my hair? What if this happens to me?" Which, unfortunately, is a pretty real possibility. That could happen. So, I have to say, sometimes I do kind of picture the scenario of what would happen if I were gone. (Hannah)

For many women, the fear of increased risk and heightened sense of mortality led to action. Pursuit of genetic testing to more accurately assess personal risk, consideration of surgery to remove their own breasts in an attempt to decrease risk of developing breast cancer, pursuit of preventative medication, and alterations in diet and lifestyle were discussed as methods of managing fear.

Genetic testing presented a mixed bag for many. The majority of participants considered genetic testing, although responses were split between women who highly advocate for genetic testing and those who warn against the risk of having too much knowledge about one's own risk. Each woman who addressed the issue of genetic testing also described a personal journey of information gathering and decision-making.

> There was no question about doing the testing, there was no hesitation to find out the results. Once my sister had it done, then [3rd sister] and I could do it much less expensively. We just felt like it was really important that we be tested. So we went through the testing and we both tested positive.... I guess I would encourage anyone with a mother, a grandmother, or a sister to be tested after my experience. The one thing I've learned though this whole process – it may not be pleasant to sit and wait for those results, but it's such a simple blood test. I mean there's nothing to it as far as having it done, but it can certainly give you some peace of mind or at least give you some direction as to how you should proceed with your life. I think it gives you some control over your life. So, if nothing else, I guess my message to people who are affected is, "Get tested." (Amy)

> We just got the genetic test, just got the results last night actually, and we don't have the gene, which is what we figured because no on else in the family has it. But we just had to do it. We thought, you know, her insurance covers it and it's a very expensive test, so why not? Because if she did come back positive it's likely that the girls came back positive and that I would come back positive and also my mom. So, why not? It's worth it. The more information you have, the better off you're going to be. (Donna)

Carol and Hannah had a different perspective on genetic testing:

> I talked with my regular doctor about it and I talked with the oncologist about getting the gene testing. You know, we talked about it some and I just went, "I know that I have a strong family history. I don't think I need the gene thing to just know that, yeah, you better watch out." And then talking about well, you

> know, if you have this and you do have the gene then you might have problems with insurance and stuff like that, so I decided not to do that and [3rd sister] decided not to get tested either. (Carol)

> I talked with my doctor and she said, "You need to get a mammogram and I'm going to set you up to see an oncologist to discuss your options." In the meantime I was treating a patient whose mother died of breast cancer. So, I mentioned to her that my doctor wanted me to be tested for the gene for breast cancer. And she said, "Oh, I wouldn't do that." She works at the hospital and she said, "You know, you might be denied insurance because it could be seen as a pre-existing condition." So I went back to my doctor and told her this and she said, "Oh yeah, that's correct." And I'm like, "Well, great! I think that is something that I would have wanted to have considered before I ever saw an oncologist!" And luckily I hadn't gone to see the oncologist yet. (Hannah)

Preventative surgery was considered by many participants, although only pursued by one. After receiving confirmation from genetic testing that she did indeed carry a genetic risk of breast cancer, Amy chose to reduce her chances of developing breast cancer by having a double mastectomy.

> I was convinced that what I had to do was prophylactic in order to avoid going through the same thing and, consequently, I just finished those surgeries to try to prevent it and cut my risks. And you know, people look at me and say, "Why would you do such a thing? Is it really worth it?" And to me it is. I mean, it supposedly cuts my risk by 85-95 percent. I like those odds much better.

Several other participants considered surgery as a possibility, but concluded their risk was not high enough to warrant such extreme measures.

> If I had the gene I was going to have a prophylactic mastectomy because I would have had an 85% chance that I would have had breast cancer within the next couple years. So, I would have done that. I've met with the oncologist and my own doctor and the big deciding factor was the genetic testing, at least for the next few years. They are coming out with better detection systems, so right now I've decided to wait just because I am pretty young and she's the only one in our family. If I had another relative that had it, I think I would do it. (Donna)

> We, my other sister and I, did talk about getting prosthetic [sic] mastectomies but we both went, "No. We're not going to let cancer do that to us." I mean, we'll just wait and see what happens. Then, if we do, we'll do it, but we're not going to do it ahead of time. I think it made both of us really angry to even, I don't know,

> it's like this thing out there going, "I'm going to try and control your life." And so we both decided we weren't going to do that. (Carol)

Less drastic measures taken included improved diet, dietary supplements, and consideration of preventative medication (i.e., tamoxifen). For many women, the sense of fear dissipated with time and the urgency of taking precautionary measures waned. Women who had a sister very recently diagnosed and/or undergoing treatment at the time of the interview reported a more intense need to take precautionary measures. For women who had several years of distance between their sister's treatment and the time of the interview, a balance was sought between preventative measures (such as healthy diet, regular exercise, frequent self breast-exams, regular mammograms) and acceptance that life must go on.

> Initially I was really scared. And then I finally, I'm not exactly sure what happened, I think I just got tired of worrying about it. If it happens, it happens. I'll be careful, I'll do my checks and mammograms and all that stuff. I'm trying to be more holistic, eat more organic food and get more exercise, take better care of myself. And, you know, every once in a while it sort of pops up and goes, "Hi, I'm still here." It will always be there, but you just try not to let it run your life too much. (Carol)

Participants described medical appointments, particularly mammograms, as times when fears were again raised and underlying concerns for their own well-being were brought to the surface. Having witnessed their sisters' struggles with breast cancer, routine check-ups became a source of anxiety and fear for many. Irene explains this fear,

> When I'm at the doctor's and they're doing the mammogram, I just get really freaked and worried. Like the first time they had me feel the breast stuff, the little sample, I got really scared and emotional. I felt real vulnerable. And I do, when I have that done. I feel real vulnerable, like maybe they're going to find something.

Through either direct verbalization or indirect nuances uncovered in the language used, it was observed that in addition to fearing breast cancer would or could happen to them, several women actually felt that their sister's breast cancer *was* happening to them.

> So they diagnosed her and it just kind of, you know, the way my other sister and I described it was, "It's happening to all of us, just your body." (Barbara)

> Even though it's my sister, it's almost like it's happening to me. It really is. (Fran)

> So, after that first initial week of trauma and shock wearing off and surgery and finding out more and everything about the actual biology or chemistry of the tumor and what it meant, it made us feel a lot better in a sick sort of way. Because *we knew what we were dealing with.* [emphasis added] (Donna)

Fear for self was the largest, most dominant theme identified in the interviews, although fear for one's sister was referred to with the second-highest frequency. Particularly upon first learning of her sister's cancer diagnosis, the majority of women in this study equated a cancer diagnosis with a death sentence. Much fear of losing one's sister was experienced.

> I just lost it a few times, especially when we first found out, because you read those books and it's just like that is a death sentence. (Donna)

> You're faced with, I don't know how much more time I have left. And I don't know how much time I have with her. She doesn't know how much time she has in this world. (Fran)

> You know, when I was there, I have to say, it was the first time I thought she might not make it. My prayer has been that she lives to see her girls graduate from high school, because I think that's really where we're at now. And that would be an eight-year survival. That's pretty good for someone who, I have not been willing to admit, probably has a pretty advanced cancer. (Hannah)

Seeing a sister looking visibly sick and affected by cancer and/or cancer treatment was particularly troubling for several participants.

> Those first couple months were rough. She was so wiped out and she had something happen called hand-and-foot syndrome and mouth syndrome, where

> the lining becomes bubbled up and blistered. You can't move your fingers or walk on your feet, so she couldn't do anything and the kids just didn't understand it. It was wearing me down, and I consider myself pretty strong mentally to deal with it. But, I went to bed thinking, "I don't think she's going to make it until morning." (Donna)

> The chemo upsets me because it seems so barbaric to break down her whole body this way and turn her into like an AIDS patient. You know, it scares me. It seems like leeches or something. (Gloria)

The fears experienced by participants necessitated coping strategies; many women described a desire to better manage their own stress level for personal well-being, but also to be in better condition for offering support to their sisters. Numerous coping strategies were outlined, including several topics already discussed. For example, women discussed offering assistance to their sisters as being dually beneficial - assistance helped their sisters, but also helped themselves to feel better. Carol described the benefits she yielded from providing assistance to her sister:

> I mean, it helped me too, because I felt like I was doing something. Whether it worked or not, I was doing everything that I could do to try and make a difference. I felt better because I was doing something useful and being there for my sister, and I think she felt better that there was somebody that she could like crunch their fingers when she was scared.

Fran expressed similar sentiments:

> Maybe that's why I call her so much. Kind of support her but support myself, too, in this thing.

Taking action was one way to alleviate feelings of helplessness. Similarly, consultation with medical professionals was described as an indication of women's fears for their own safety; this was also a coping mechanism and a source of feeling empowered and better armed against their worst fears. Gathering information, such as educating themselves about breast cancer and the available treatment options, was another method of helping one's sister while simultaneously helping to alleviate one's own anxiety level.

Positive thinking, described earlier as a method by which participants helped their sisters think positively and optimistically, was oftentimes not unidirectional. In addition to helping their sisters think more positively about their prognosis, participants stated that thinking positively also helped their own outlook and emotional well-being. In fact, several participants described moments when they were the ones being encouraged by their sisters (the patients) to think more positively! At times, several women admitted, their sisters were better able to maintain positive attitudes while undergoing cancer treatment than were the participants observing the process. Fran explains,

> She was still there trying to be tough and strong and like, "Oh well, I'll just have to do the chemo and then I'll just have to do radiation." But all the rest of us are like, "Maybe it's not that easy. Maybe it's not that cut and dry."

Many women described the soothing and reassuring impact of their sisters' ability to think optimistically.

> All of my feelings of fear, my anxieties, my negative feelings, were immediately soothed because she was like, "You know, this is not the worst thing that's ever happened to me. I feel it's kind of an adventure." And that stuck with me, "adventure." With my sister being so positive and almost okay with it, it certainly has changed my reaction. (Gloria)

> And through the phone she just sounded like, "I'm tough and don't worry about me. [Husband]'s here and I can deal with this." And so, I didn't go there. (Julie)

General coping strategies were implemented to help manage the stress of observing a sister's cancer diagnosis and treatment. Participants described increased contact with family and friends, exercise, meditation, and taking time to themselves to release the fear, worry, or sadness. Several women, however, found that such strategies just were not enough and sought additional assistance through therapy and/or antidepressant medication.

> The first thing I did is, after we got the poor prognosis, within a week I called my doctor and got on an antidepressant. I'd never been on one before, but I've seen what they can do for people. They have increased the dosage and I think it's helped with the way I deal with it. (Barbara)

Donna utilized a similar approach:

> I did start taking an antidepressant, just to help. I asked the doctor, I'm like, "Well, could it help to keep me even? I want everything! Give me everything!" So, I did start doing that, and I've noticed some improvement. It keeps me a little bit more even rather than dwelling on some of the really awful things.

Mary and Emma each sought therapy as a means of coping with their emotions.

> I was in a serious depression then. I went on Prozac and went to see a counselor for a period of time. (Mary)

> I have a therapist in town whom I talked extensively with during this time. I already had a counselor in place, and it helped to kind of just deal with my feelings. (Emma)

Several women identified their participation in this study as a coping method. Women described their participation as a way of "giving back" and providing information to other sisters who may benefit from hearing about their experiences. Similarly, half of the participants in the study identified fundraising efforts they have participated in. Opportunities to support breast cancer research were seized by the women, and they oftentimes engaged in the fundraising activities with their sisters.

One last strategy for coping with the emotional strain of a sister's breast cancer was noted by the researcher, but was not identified as such by the participants. Analysis of the interviews revealed a similarity amongst participants in their attempts to differentiate between themselves and their sisters. Perhaps, by doing so, the women were helping themselves to feel distanced from cancer and, in turn, effectively reduced their levels of fear and anxiety.

> My mom's Italian and most of us took after my mom's side, but [sister] doesn't, she really takes after my dad's side in terms of looks and everything. And you know, his side of the family's the one where all the cancer is. And I keep thinking, "I hope I got more of my mom's genetics." (Fran)

> Well, my sister's pretty heavy, she's overweight. And so, I always wonder about people if they're heavy, does that help the cancer to grow or hide it somehow? I don't know if that's true or not. But I kind of look at myself and think, "Well, gee, maybe I won't get it because I haven't ever been really heavy." (Irene)

In addition to the coping methods outlined above, participants identified coping methods they would like to have available to them. Participants who did not independently mention support offered to themselves by their sisters' care providers were specifically asked to describe any support offered and their satisfaction with supported offered or not offered. Participants were split on this issue. Five of the participants felt they did not need counseling or support services and therefore were satisfied with having not been offered any such services:

> I don't think they ever asked about how I was doing, but that was fine. I'm okay with that. They were focused on her and that's how it should be. (Barbara)

> I don't think anyone ever talked to me, other than the niceties of just joking around or whatever. It's always been about her, which is fine. I can find my own support. (Donna)

One participant felt her sister's medical staff addressed her own emotional needs by incorporating her into her sister's medical care:

> I think that being able to help and do something and participate helped me emotionally. I think a lot of people want to help do something, but they don't know what to do. So it helped to have somebody, with this oncology clinic, say, "Here are things that you can do to help out if you want to." I think that's a really positive thing. I mean, it was a positive experience for me, it helped me a lot. (Carol)

Seven participants expressed dissatisfaction with the unavailability of formalized support to address the emotional strain they experienced as a result of their sister's diagnosis:

> One thing I was thinking, and part of the reason why I think this is a really good thing that you're doing, is, you know, like a support group. Well, I know they have breast cancer support groups, but have sisters get together to share their stories, to find out what other people have learned and what you do and don't do. Because I think that first-hand experience and that first-hand knowledge in hearing other people's stories is really valuable. I know there are grief groups, grief and loss, stuff like that. This probably doesn't really fit into that category. But it seems there is probably something deeper, inside of us, and I think it probably is a sort of a grief or a loss or something. Maybe it's inside and maybe we should deal with it or have some guidance on it. (Fran)

> When it's cancer, nobody's died, but you think they might die and it would be good to be able to talk to someone about it. I think therapy and stuff like that, family therapy, treating the whole family and providing information would be really good. I think it would be really helpful for everybody in the family to have somebody. (Irene)

> I think if you had a support group going through the same thing as a sister or a family member or whatever, if there was such a thing, I think you could really benefit from it. I think support groups for sisters of survivors would be good. You carry so much on your shoulders. And even if you're married and have a great husband, so much is within you that you don't, I mean he's not the sister, he never had a sister. It ends to a certain extent, whereas if you spoke with other sisters, they would understand it. I do think it would have been very helpful for me because I think you just hold too much inside. (Lynne)

Impact on the Sibling Relationship

Responses to the Lifespan Sibling Relationship Scale (LSRS)

Due to the small sample size in this study, responses to the Lifespan Sibling Relationship Scale (LSRS) were not analyzed using statistical methods. The LSRS served two purposes in this study: 1) to allow for an alternative means of assessing participants' perceptions of the changes (if any) they experienced in their sibling relationship as a result of a sister's breast cancer for purposes of summarizing the overall perception of all participants; and, 2) to prompt the participants with reminders of various aspects of sibling relationships (including factors pertaining to childhood relations, adulthood affect, adulthood behavior, and adulthood cognition) to facilitate information

gathering in the qualitative interviews. Ratings on the subscales of the LSRS may range from scores of 8 to 40, with 40 representing the highest possible rating of closeness in the sibling relationship and 8 representing the lowest possible rating of sibling closeness. The average ratings for the affective component of childhood sibling relationships was 26.77, average ratings for the behavioral component of childhood sibling relationships was 24.54, and the average ratings for the cognitive component of childhood sibling relationships was 25.15. The average total childhood sibling relationship rating (with a possible range of 24-120) was 76.46. Average ratings for adulthood sibling relationships pre-cancer were: Affect = 33.31, Behavior = 29.92, Cognition = 32.08, and Total = 95.31. Average ratings for adulthood sibling relationships post-cancer were: Affect = 35.77, Behavior = 32.85, Cognition = 34.92, and Total = 103.54. On average, the changes in pre-cancer to post-cancer adulthood sibling relationship ratings were: 7.39% increase in Affect, 9.77% increase in Behavior, 8.87% increase in Cognition, and 8.64% increase in Total. Pre-cancer to post-cancer changes in ratings are limited, however, in that several participants had pre-cancer ratings at the ceiling of the rating scale; consequently, for several of the participants, verbal descriptions were provided of increased closeness in the sibling relationship and yet ratings indicate no pre-cancer to post-cancer change. Please refer to Table 2 for individual and composite questionnaire ratings and to Figure 1 for a graph of changes in pre-cancer to post-cancer sibling relationship ratings.

Qualitative Interview Findings

The majority of women in this study reported an increased closeness in their relationships with their siblings. For several women, this meant overlooking or moving beyond long-standing tensions that had existed in their relationship.

> She did say on more than one occasion, "The good thing about this is it's brought you back to me." We had our times, you know. (Barbara)

> It really has in many ways dramatically changed our relationship. I think in many ways it's forgiven some of those resentments. And even though in some aspects we were kind of estranged before her diagnosis, the fact that you're blood brings it all together. It's my duty to be there to support her. And I love her, because she's my sister, not necessarily because of what I've gotten out of the relationship over the years. This experience I think will change that though. I really do, I think it'll change that concept of love. (Hannah)

For others, an already close relationship became even closer.

> I'm sure that the cancer drew us closer together. There's no doubt in my mind about that. We were close before, but I don't think we were nearly as close as we are now. We had some great talks at that time, and I'm sure that it drew us a lot closer. She's much more open with me than she used to be. There was always some distance there, but I think there was a new respect on both of our parts, and it just made it easier for us to open up with each other. You know, we really feel like friends. We'd been sisters and sisterhood goes so far, but I think when you can call yourselves friends in that relationship it makes a big difference. (Amy)

> We're closer than we've ever been before, which I didn't think was possible. You know, things mean a whole lot more than they used to and in that respective you value your time with each other a whole lot more. (Donna)

Increased closeness in the sibling relationship was described in a variety of ways. The majority of participants described an increased level of honesty and openness in their sibling relationships. Women described having conversations that were "deeper" and "more meaningful" during and following their sister's breast cancer diagnosis compared with the quality of conversations that preceded the cancer diagnosis.

> So, we had some great talks at that time. She's much more open with me than she used to be, and I'm sure that it drew us a lot closer.... I love the fact that we're so much more open with each other now than we ever were before. We were open but we really didn't discuss our personal lives that much, in that much detail, and now it's real easy for us to talk about. It really is nice to have that. (Amy)

> I think when something like this happens, maybe for her for the first time, she feels free to talk about things. Like maybe she's going to die and how her relationship with her husband and kids and all that, which she just never did before, so that's been good, actually. I mean, now we don't just talk about her

> breast cancer, but we talk about anything, you know? We talk about men, relationships, and kids, and her, and yeah. So, it definitely changed. (Fran)

In addition to increased openness and honesty in their relationships, the majority of women described an increased level of respect and admiration for their sisters.

> I think I, my opinion of her when she was younger, she was this flighty younger sister that didn't know what she was doing and I really, I think the biggest thing that's changed is I'm really proud of her, that she really stepped up to the bat and did some really hard things and handled it all really gracefully, with a great deal of good humor. And so I think that's what changed with the relationship, is that I have a much better appreciation for, she is really strong, she's a lot stronger than I ever thought she was, so I think that's probably the biggest thing. (Carol)

> She's been bearing with it very, very well. Like I said, the [sister] that used to complain about every ache and pain, it just seems so different than the person I grew up with, and it is just really a higher reaction than she was ever capable of before, or at least ever demonstrated before. (Gloria)

For many participants, the opportunity to reciprocate in providing care and support added a deeper dimension to the sibling relationship.

> Before, our relationship was her worrying about me, because I've had really unstable relationships in the past. And it's the other way around now, I'm more worried about her. So, this is my opportunity to pay her back. (Barbara)

> For the first time I think she's allowed herself not to be the big sister, but to be the recipient of some care. She's more accepting of the fact that maybe she needs help. (Hannah)

Heightened awareness of the fragility of life and mortality fears led to an increased value placed upon the sibling relationship.

> You have a different perspective on her life and even my life. I have a whole different value for it and everything just becomes a hundred times more important. Every big thing in her life is even bigger and that I want to be a part of, and she wants me to be a part of. (Donna)

> Because our relationship had been good for what, probably a good four years since we got all that worked out, maybe we thought our relationship had really become so important and so wonderful, but I really, truly have to believe that even after the diagnosis and how I felt with, you know, you can't take her away, I

> think it became even stronger. You know, it was important, but maybe it became even more important. The bond was even closer, it was stronger. (Keri)

In addition to reports of increased closeness in the sister-sister relationship, participants reported an increased appreciation for the sisterhood bond they shared. Participants articulated definitions of what sisterhood means to them, describing sisterhood as uniquely different from other relationships in their lives. Sisterhood was described in connection with cancer, it was described as a connection created through family history and/or biology, it was compared to friendship, and it was differentiated from sister-brother or brother-brother bonds. Each woman struggled to find just the right words to describe the qualities of sisterhood; many women commented on the frustration they experienced while attempting to provide a definition of sisterhood. Several definitions follow:

> Breast cancer seems to be, for a woman, so personal and so scary. And so there is something about a sister that, you know no matter how many good friends I've had, and I've had lot of really close friends, but there's that tie, that connection with sisters and you never get that with a friend. I try to think, if I had a friend that was just diagnosed with breast cancer- Sure, I would feel really bad. I'd be there. I'd support her. I'd do all those sorts of things, but it wouldn't affect me like it's affecting me with my sister. (Fran)

> We have this private knowledge, this secret code, this body language. Sometimes you'll look in the mirror and you look like your sister or you hear this voice coming out and you sound just like your sister. It's just so fun. I think it's always been a really close, important thing in my life. I just think sisterhood is a really wonderful experience and I'm very happy for it. (Irene)

> There is something, I don't know what it is, sharing the womb the way we do. You just feel like, you know, there is this bond. There's this uniqueness that is, you know, we shared the same space and place. It's that one person who knows you better than anyone else. You don't put on for them, you don't have to be nice to them, they really know who you are. There's no hiding with sisters. I really believe that, they just know you. They know you. (Gloria)

> In some ways I don't even see her as my sister. You know, I see her more as my friend. I don't really have anyone that's that close to me. Some of the people I

> work with are like, "Don't you have any other people that you hang out with?" I don't want to hang out with anybody else! She's my best friend. (Donna)
>
> It's just different. We've actually talked about that before, my sister and I have talked about it. There's just something that's totally different there. And brothers don't have it. My husband has brothers, but brothers don't have that same thing. With brothers and sisters, well my brother loves us and we love him, but it's just not the same. It's different, just really different. (Lynne)

Discussion of Negative Cases

Negative cases are defined as those that clash with the general themes identified in the majority of interviews. As was previously stated, themes discussed above are those which were addressed by a minimum of ten out of thirteen participants. In addition to outlining the commonalities found between the experiences of the participants in this study, it is important to provide the reader with insight into variations in women's experiences. The majority of women experienced increased closeness in their sibling relationship following a sister's diagnosis, but not all. Similarly, the majority of women experienced fear for their sister's well-being, but not all participants experienced this fear. The reader is provided with several examples of variations in the experiences of sisters of breast cancer patients.

Negative Case #1: Support provided to the sibling was not a choice.

Hannah was the only participant in this study who raised the issue of family obligation. Each participant described support and assistance provided to her sister during the time of breast cancer treatment; however, Hannah explicitly stated that support and assistance were provided to her sister primarily out of a sense of responsibility.

> It was my duty, something I had to do. It's my duty to be there to support her.
>
> I feel a responsibility to do it for my sister. With a friend, I would say that yes, I have a role to play, but it's not my responsibility necessarily. I don't have a

> choice on this. I don't feel, this doesn't feel like a choice. This is a responsibility as a family member.

Negative Case #2: Shift in participant's attitude was not positive.

Hannah was also unique in being the only participant to describe a change in attitude that was in the negative direction. Hannah described her sister as shifting to a more positive attitude and more positive outlook on life as a result of her cancer experience; however, unlike many other participants, the positive attitude expressed by Hannah's sister did not help her to experience a more optimistic outlook. Hannah differentiated her own experience in the following manner:

> To be frank, I think it's been more negative for me. I think with my husband losing his job I kept thinking, "God will take care of us." And then with this, I thought, "Maybe not. Bad things do happen." And so, it has been hard for me to have hope, I think. ...So, for me, it has been, I think it has taken away some of my hope that God will take care of it all and everything will turn out alright, because it may not turn out alright.
>
> ...you know, you hear of people overcoming cancer. I think those are people that really are like, "I want to live!" I didn't feel that... I don't know if she's positive enough to live through it.

Negative Case #3: Participant did not experience fear for sister's well-being.

The theme of fear was not as strong in Amy's case as it was for other participants. Although Amy did experience a heightened sense of fear for her own well-being and felt she was at higher risk for a diagnosis of breast cancer given her sister's diagnosis, Amy was unique in the minimal amount of fear experienced regarding her sister's well-being. Amy's confidence that her sister's treatment would be successful stood out among the participants. Amy stated, "I just was confident with [sister] that they caught it early and she was going to be fine."

Negative Case #4: Changes in the sibling relationships were not all positive.

Irene and Lynne each described a mixture of increased closeness with their sisters, but also negative and/or uncomfortable changes that occurred in the sibling relationship and were attributed to the breast cancer experience. Irene stated that her sister had always been supportive and positive prior to the breast cancer diagnosis; however, following the diagnosis, her sister became more honest and upfront with Irene. Irene explains,

> She just doesn't want to put up with any bullshit in her life, and that's really healthy and I think that's good, but she stopped being, she changed her attitude toward me in some ways about not always being the nurturing, nurturing person. And maybe she's more blunt and honest, and maybe before she was always trying to take care of me no matter what, and she has gotten to where she can be, um, treating me in a different way than she ever used to, which could be like snapping at me and losing her temper or being critical of me. She never was critical of me. So, her stuff, for whatever reason, maybe it was just, "I'm not putting up with anything weird anymore. I'm not going to make-believe." So, you know, and maybe that's good, but it was a real shock.

Although initially troublesome and uncomfortable for Irene, she was able to describe a process of adjusting to this new mode of interacting with her sister.

> I had to learn it as well, to try to be more in my present and be more honest. So, that was something that she was emulating, even if it was hard. So, I learned something from it.

Whereas Irene's shift in her relationship with her sister resulted in initial discomfort but eventual increased closeness, Lynne experienced a different shift in her sibling relationship. Lynne described herself as providing support to her sister in the form of telephone calls and visits immediately following her sister's cancer diagnosis and during cancer treatment. Initially, Lynne and her sister did experience increased closeness in their relationship. Since that time, however, Lynne described increased tension and reduced closeness in their sibling relationship.

> I think we became very close, but then she changed a lot, and I mean, I can understand why she changed. Of course, she can't have hormones of any type, so her tolerance level is, well, there's a couple situations we've had where just out of the blue she just suddenly starts yelling and I haven't done anything. And so I start by being calm, "Now, why are you yelling at me? I don't understand. We were just laughing a minute ago." Because it's that quick, laughing and she's just kind of out of control. And she still can't face that with me.... I'm the one who kind of tries to keep it together, but we're still not as close. It's just really hard.

Negative Case #5: One participant experienced an unchanged sibling relationship.

Whereas Irene and Lynne experienced discomfort in their sibling relationships, Julie indicated that her sibling relationship was unaffected by the cancer experience.

Julie stated, "It was just another thing to deal with within the relationship. It was, truly."

Julie further stated,

> For the most part it remains pretty much the same. We were close beforehand because of the travels that we had gone through and everything we'd been through, and I can't say that it was changed a whole lot.... We were close as teenagers, then she got married and we weren't as close, and then we got close again, but then we got real close. And I would say that's kind of the way it's remained.

Discussion

Summary

The support provided by siblings to breast cancer patients depended somewhat on perceptions of the patients' marital relationships and the degree of support available within the spousal relationship. Although this factor appeared to influence the frequency and intensity with which some siblings became involved in their sisters' breast cancer experience, all participants described multiple methods by which they provided support and assistance to their sister during her breast cancer experience. A variety of approaches to providing support and assistance were described by participants, including: advocating for quality treatment of sisters, providing emotional support, increasing the frequency and duration of telephone contact, voicing a positive attitude and optimistic outlook, gathering information, attending medical appointments, visiting sisters, providing practical support, providing support to nieces and nephews, and helping to manage family dynamics from the family of origin. Despite descriptions of support provided to sisters during their breast cancer experience, several participants expressed feelings of guilt for having not provided more support and assistance.

Participants in this study described a variety of ways in which a sister's breast cancer diagnosis and treatment imposed emotional and psychological distress on them. Most prominent of all themes identified in this study was that of fear for one's own well-being. Participants described a heightened sense of mortality and fears of being vulnerable to developing breast cancer themselves. Although such fears reportedly

decreased over time, experiences such as seeing a magazine advertisement for breast cancer awareness or attending a routine medical examination were described as situations in which mortality fears re-surfaced. In addition, participants experienced fear for their sisters' well-being and expressed difficulty coping with fears of losing one's sister. The emotional toll of a sister's breast cancer led to a variety of coping behaviors, including exercise, meditation, therapy, antidepressant medication, and taking action toward decreasing one's own risk of breast cancer. More than half of the participants in this study expressed a desire for formalized support services, such as a sibling support group, to help cope with the emotional ramifications of a sister's breast cancer.

Responses to the Lifespan Sibling Relationship Scale (LSRS) indicated that, overall, participants perceived an increased closeness in their sibling relationship as a result of their sister's breast cancer. Increased closeness in the behavioral aspect of the sibling relationship was rated highest, followed by increased closeness in the cognitive aspect of the sibling relationship, and finally by the affective component of the sibling relationship. Qualitative interviews conducted with each participant also indicated perceptions of increased closeness in the sibling relationship, particularly in the areas of increased honesty and openness, increased respect and admiration for one's sister, reciprocity of caring, increased value placed upon the sibling relationship, and increased appreciation for the uniqueness of a sister-sister relationship.

Comparison to Literature Review

Review of the literature revealed no specific mention of the role adult siblings may play in providing support and assistance to breast cancer patients, although several authors have proposed that illness in adulthood is one factor that potentially motivates

renewed contact, support, and closeness in the sibling relationship (Cicirelli, 1982, 1989; Goetting, 1986; Kivett, 1985; Scott, 1983). Results of the present study certainly indicate that women interviewed provided increased levels of support and assistance to their sisters during the breast cancer experience. In addition, participants described an increased level of closeness in the sibling relationship that resulted from the cancer experience. In fact, several participants described themselves as the primary source of support to their sibling during cancer treatment, despite alternative sources of available support in siblings' lives (e.g., spouses, grown children, co-workers, friends, etc.). This finding correlates well with research conducted by Cumming and Schnieder (1961) in which sibling relationships were found to be more heavily emphasized, particularly between sisters, than spousal relationships in middle age. Although societal standards may emphasize helping behaviors between parents and children (Cicirelli, 1982) or between husbands and wives (Wilson et al., 1994), many women in this study represented an additional or alternative source of support to sisters during their breast cancer experience.

Literature regarding the impact of breast cancer on the adult patient outlines a variety of emotional responses, including sadness, depression, anxiety, fear, shock, confusion, and anger (Baider & Kaplan De-Nour, 1984; Barraclough, 1994; Maguire et al., 1993; Massie et al., 1989; Northouse, 1988, 1992; Walsh-Burke, 1992; Watson, 1994). The degree to which sisters of breast cancer patients reported many of the exact same emotions is quite notable. Patients' siblings reported fear for their own well-being, fear for their sister's well-being, shock at their sister's diagnosis, and feelings of sadness and depression. Siblings' responses were also quite similar to those described in the

literature on spouses of breast cancer patients. Fengler and Goodrich (1979) have posited that spouses ought to be recognized as "hidden patients" given the degree of stress and declines in mental health experienced by spouses during a partner's cancer experience. Although cancer resides within one partner in the spousal relationship, the emotional consequences of cancer are recognized as occurring in both partners (Gritz et al., 1990). The findings of the present study indicate that perhaps the "hidden patient" concept need not be limited to spousal relationships. Much evidence is provided for the emotional ramifications of breast cancer in a patient's sister, indicating they, too, may be "hidden patients" in need of support and assistance.

A significant component of the emotional distress experienced by sisters of breast cancer patients was that of heightened mortality fears and increased perception of risk for developing breast cancer. Women interviewed in this study were quite aware of statistics, such as those published by the American Cancer Society (2003) and the National Cancer Institute (2000), indicating the risk of developing breast cancer is significantly higher for women who have a mother, sister, or daughter who has been diagnosed with breast cancer. In addition to witnessing their sister's illness and providing increased levels of support and assistance to sisters, participants were faced with decisions regarding their own health care and lifestyles. Many women sought guidance from medical professionals regarding their health and precautions that may be taken in an effort to protect themselves from repeating their sisters' experiences, all the while providing assistance and support to sisters. For some, the burden was too great and coping strategies were supplemented with antidepressant medication and/or psychological counseling. In general, however, participants who were not in the midst of

their sister's cancer treatment at the time of research participation described a decline in emotional distress over time. For participants whose sisters were cancer-free and in remission, the urgency of cancer-related fears had subsided; thus, the "hidden patient" concept may only apply to sisters of breast cancer patients for a limited time period following diagnosis.

Limitations of the Study

The recruitment method employed in this study resulted in a limited pool of participants. Research participants were recruited for the study through newspaper advertisements, and participation in the study required initiative on the part of each participant. It is reasonable to assume that individuals who were proactive in contacting the primary investigator and volunteered to participate in this study are not representative of all sisters of breast cancer patients. Miles and Huberman (1994) note that qualitative research is often flawed in the fact that researchers can only interview people who are willing to be interviewed, and any qualitative researcher risks obtaining data that is skewed by the fact that willing, articulate, and insightful participants may be "atypical" in comparison to the general population of interest.

An additional limitation of the present study is the retrospective nature of reports regarding pre-cancer adult sibling relationships. Participants were asked during the course of one interview to indicate the degree of closeness in their relationship both prior to and following a sister's breast cancer diagnosis; similarly, participants were asked to complete successive questionnaire ratings of pre-cancer and post-cancer sibling relationships. The degree to which retrospective reports differ from reports that would

have been given prior to a sister's cancer diagnosis is unknown and represents a limitation of the study.

Lastly, as was previously mentioned, the researcher originally intended to conduct thorough member checks by providing each participant with a copy of the manuscript and requesting feedback. The revised version of member checks implemented in this study is recognized as less than ideal, presenting a limitation of the study. The degree to which review of the manuscript in greater depth, as opposed to the summary provided, and/or the opportunity to provide feedback in writing, as opposed to verbally providing feedback to the researcher, may have impacted comments from participants regarding the accuracy and applicability of findings is unknown.

Recommendations for Further Research

It is recommended that further research on the experiences of sisters of breast cancer patients be conducted with a random sampling of sisters, thereby presenting findings that have a higher level of generalizability to the greater population of siblings. Perhaps by identifying breast cancer patients in an oncology clinic and actively seeking out the participation of their adult sisters, one could elicit research data more representative of sisters of breast cancer patients. A replication of the present study with such a pool of participants followed by comparison of the findings may yield insight into the relative uniqueness or representativeness of findings in this study.

Further research is needed to identify factors influencing the experiences of sisters of breast cancer patients. The present study was exploratory in nature and intended as a starting point in the examination of sibling relationships impacted by a cancer diagnosis in one sister. Future studies, implementing alternative research designs, are needed to

examine causal factors which impact sisters' experiences with a sibling's breast cancer diagnosis are needed. For example, negative cases are discussed in the present study; however, further research is needed to uncover factors contributing to variations in sisters' experiences. Specifically, exploration is needed regarding factors influencing the degree of support provided by a sibling, the degree and directionality of changes in sibling relationships, differences between siblings who feel they would benefit from formalized support services versus those who do not, and factors contributing to a woman's decision to engage in prophylactic medical procedures.

In addition, further investigation is needed to elucidate clinical needs of sisters of breast cancer patients and means by which mental health professionals and/or medical professionals may better address the psychosocial needs of siblings. More than half of the participants in the present study expressed an interest in receiving formalized support services. Further research is needed to better inform counselors and health care providers in the field of psycho-oncology as to the optimal services to offer sisters of breast cancer patients.

Recommendations for Clinical Practice

The findings of this study provide evidence of emotional distress experienced by adult sisters of breast cancer patients as a result of their sisters' diagnoses. Although nearly half of the participants did not feel they needed formalized support services to assist in coping with their sisters' breast cancer, it is deemed important to address the emotional needs of the participants who did feel that formalized intervention would be both welcomed by siblings and beneficial to their emotional well-being. In the literature review, psychological issues faced by high-risk women considering genetic testing

and/or prophylactic surgery were presented. Many of the issues hypothesized by the National Cancer Institute (2002) appear appropriate given the issues raised by participants of this study; however, the detailed descriptions of siblings' experiences provided within the study allow for more comprehensive treatment recommendations.

Based upon the shared experiences of women who participated in this study, the following treatment recommendations are provided:

- Assist siblings in addressing issues relating to the history of their sibling relationship. For example, issues such as unresolved grievances or long-standing rivalries may impact a sibling's reaction to her sister's breast cancer diagnosis.
- Assist siblings in coping with uncomfortable and/or undesirable changes in their sister's personality or in the sibling relationship.
- Facilitate effective coping with mortality fears and concerns regarding increased risk for developing breast cancer.
- Facilitate effective coping with fears of losing one's sister or, if appropriate, the reality of losing one's sister.
- Educate participants on effective strategies for caregiving, including management of caregiver stress, increased awareness of caregiver burnout, and effective self-care.
- Educate participants on the emotional strain of breast cancer for patients, including information regarding strategies for providing support to patients and helping them through difficult times.
- Educate participants on strategies for helping children cope with a parent's cancer, including developmentally appropriate recommendations for a wide range of ages (i.e., preschool to young adult).
- Strengthen problem-solving skills, with particular emphasis on strategies for managing challenging family dynamics.

- Engage siblings in cognitive restructuring exercises, if appropriate, to address negativism, pessimism, and hopelessness.

- Teach participants relaxation and stress management techniques, including specific discussion of methods for calming oneself during stressful and/or anxiety-inducing medical examinations.

- Monitor for heightened emotional distress and provide referrals for individual counseling services and/or medication consultation when deemed appropriate.

- Assist participants in addressing issues of grief and loss. Help to normalize these emotions despite the lack of physical loss; address existential fears aroused by a sister's breast cancer diagnosis.

- Provide a forum for participants to receive factual information on cancer, cancer treatment, and cancer prevention (e.g., a resource library and/or Q&A with medical professionals).

- Provide a forum for dispensing factual information on genetic testing, prophylactic mastectomies, recommended diets for high-risk women, preventative use of tamoxifen, and other such strategies for protecting one's own health. Incorporate presentations by professionals with expertise in genetic counseling and preventative medicine. Assist participants in making informed decisions given individual circumstances.

- Provide a forum for the benefits of unstructured support from others in similar circumstances. Expected benefits of both structured and unstructured contact between siblings of breast cancer patients include: normalization of emotions, learning from others' positive and negative experiences, and comfort in the knowledge that one belongs to a group of people undergoing similar experiences.

Professionals who are interested in providing formalized support services to sisters of breast cancer patients are encouraged to capitalize on opportunities to target

specific needs of individuals within the group. Participants of this study reported enjoyment and benefit from sharing their stories with the researcher; perhaps a good starting place is to allow each woman to tell her individual story of experiencing a sister's breast cancer diagnosis. Common emotional struggles and areas in which participants would benefit from intervention will surely arise through the process of telling their stories, much as common emotional struggles and areas of recommended intervention have arisen from themes across multiple stories told by participants in the present study.

Final Comment

This paper opened with a description of the emotional impact a sister's breast cancer had on Nancy Goodman Brinker, and the motivation this experience provided in her development of an internationally recognized research and fundraising organization. While Nancy's response to her sister's diagnosis is exceptional in terms of the magnitude of her efforts to fight breast cancer, her personal experience of emotional distress and increased closeness with her sister does not appear to be at all unique. The sisters who participated in this study also described experiences of involvement and support during their sisters' breast cancer diagnosis and treatment, increased fear and anxiety regarding their own well being in addition to their sisters' well being, and increased closeness in the sibling relationship. Previous research endeavors have indicated that the sister-sister bond is uniquely powerful (in comparison to sister-brother or brother-brother bonds); the present study lends additional support to the notion that sisterhood brings a wealth of strength, closeness, and support during times of hardship.

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	Age (participant)	Age (patient)	Living/ Deceased	Marital Status	In-state/ Out-of-state	Siblings in Family	Time Since Diagnosis	Treatment Received	Diagnosis
Amy	53	46	Living	Married	In state	4 (2f, 2m)	12 mos.	Mastectomy, chemotherapy (completed)	Stage III
Barbara	47	53	Living	Married	In state	3 (3f)	24 mos.	Mastectomy, chemotherapy, radiation (in progress)	Stage IV
Carol	45	42	Living	Married	In state	3 (3f)	25 mos.	Surgery, chemotherapy, radiation (completed)	Stage II
Donna	30	34	Living	Married when diagnosed, since divorced	In state	2 (2f)	36 mos.	Mastectomy, chemotherapy, radiation (in progress)	Stage I, Borderline Stage II
Emma	50	54	Living	Divorced, boyfriend out-of-state	In state	3 (2f, 1m)	60 mos.	Lumpectomy, radiation (completed)	Unsure, likely Stage I or Stage II
Fran	48	54	Living	Married	Out of state	13 (5f, 8m)	2 mos.	Surgery, chemotherapy (in progress), radiation planned	Stage III or IV (doctors unsure)
Gloria	42	43	Living	Single	Out of state	6 (f)	3 mos.	Surgery, chemotherapy (in progress)	Stage III
Hannah	40	42	Living	Separated prior to dx	Out of state	4 (2f, 2m)	4 mos.	Chemo (in progress), mastectomy planned	Stage II
Irene	57	59	Living	In long-term committed relationship	Out of state	2 (2f)	48 mos.	Lumpectomy, chemotherapy, radiation (completed)	Unsure of exact diagnosis/staging
Julie	57	60	Living	Married	Out of state	3 (3f)	48 mos.	Lumpectomy, radiation (completed)	Stage II or III (unsure)
Keri	53	51	Living	Married	In state	5 (4f,1m)	36 mos.	Lumpectomy, radiation (completed)	Stage I or II (unsure)
Lynne	52	51	Living	Married	In state	3 (2f, 1m)	36 mos.	Lumpectomy, radiation, chemotherapy (completed)	Stage I or II (unsure)
Mary	50	52	Deceased	Married	Out of state	3 (3f)	36 mos.	Surgery, chemotherapy, radiation (completed)	Stage IV

Table 1

General Facts About Research Participants

	Childhood Affect	Childhood Behavior	Childhood Cognition	Childhood Total	Pre-Cancer Affect	Post-Cancer Affect	**Pre-Post Affect Difference**	Pre-Cancer Behavior	Post-Cancer Behavior	**Pre-Post Behavior Difference**	Pre-Cancer Cognition	Post-Cancer Cognition	**Pre-Post Cognition Difference**	Pre-Cancer Total	Post-Cancer Total	**Pre-Post Cancer Total**
Amy	32.00	20.00	22.00	74.00	35.00	39.00	**11.43%**	25.00	32.00	**28.00%**	27.00	34.00	**25.93%**	87.00	105.00	**20.69%**
Barbara	25.00	21.00	23.00	69.00	38.00	38.00	**0.00%**	35.00	35.00	**0.00%**	39.00	39.00	**0.00%**	112.00	112.00	**0.00%**
Carol	24.00	25.00	22.00	71.00	24.00	32.00	**33.33%**	26.00	30.00	**15.38%**	23.00	31.00	**34.78%**	73.00	93.00	**27.40%**
Donna	27.00	24.00	23.00	74.00	40.00	40.00	**0.00%**	40.00	40.00	**0.00%**	39.00	40.00	**2.56%**	119.00	120.00	**0.84%**
Emma	22.00	18.00	20.00	60.00	33.00	33.00	**0.00%**	29.00	31.00	**6.90%**	33.00	35.00	**6.06%**	95.00	99.00	**4.21%**
Fran	31.00	29.00	31.00	91.00	32.00	36.00	**12.50%**	16.00	26.00	**62.50%**	22.00	28.00	**27.27%**	70.00	90.00	**28.57%**
Gloria	32.00	23.00	31.00	86.00	40.00	40.00	**0.00%**	40.00	40.00	**0.00%**	39.00	40.00	**2.56%**	119.00	120.00	**0.84%**
Hannah	31.00	34.00	32.00	97.00	21.00	28.00	**33.33%**	21.00	27.00	**28.57%**	24.00	30.00	**25.00%**	66.00	85.00	**28.79%**
Irene	36.00	31.00	35.00	102.00	38.00	38.00	**0.00%**	30.00	29.00	**-3.33%**	35.00	36.00	**2.86%**	103.00	103.00	**0.00%**
Julie	19.00	23.00	19.00	61.00	34.00	32.00	**-5.88%**	25.00	27.00	**8.00%**	33.00	32.00	**-3.03%**	92.00	91.00	**-1.09%**
Keri	27.00	30.00	31.00	88.00	40.00	40.00	**0.00%**	40.00	40.00	**0.00%**	40.00	39.00	**-2.50%**	120.00	119.00	**-0.83%**
Lynne	21.00	15.00	15.00	51.00	31.00	33.00	**6.45%**	34.00	31.00	**-8.82%**	31.00	31.00	**0.00%**	96.00	95.00	**-1.04%**
Mary	21.00	26.00	23.00	70.00	27.00	36.00	**33.33%**	28.00	39.00	**39.29%**	32.00	39.00	**21.88%**	87.00	114.00	**31.03%**
Average	26.77	24.54	25.15	76.46	33.31	35.77	**7.39%**	29.92	32.85	**9.77%**	32.08	34.92	**8.87%**	95.31	103.54	**8.64%**

Table 2

Individual and composite ratings on the Lifespan Sibling Relationship Scale (LSRS)

(Range of scores possible for Affect, Behavior, and Cognition subscales = 8-40;
Range of scores possible for Total of all subscales = 24-120)

Figure 1. Graphical presentation of pre-cancer to post-cancer sibling Lifespan Sibling Relationship Scale (LSRS) ratings.