ABSTRACT

Title of Thesis: PERCEIVED THREAT IN DAUGHTERS OF WOMEN WITH
                     BREAST CANCER

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The experience of daughters of women with breast cancer has been virtually ignored in the literature. The few studies that do exist on this population have focused on prevention or daughters' short-term psychological concerns. The current study examined the biopsychosocial variables that affected the reactions of 142 adult daughters of women with breast cancer. Data was collected via a web-based survey and analyzed using cluster and correlational analyses. Anxiety, closeness to one's mother, amount of exposure to cancer, intrusive thoughts, predicted likelihood of getting breast cancer, threat, interest in genetic testing, and styles of coping were the variables of interest. The results show clusters that fell into three broad categories: strong negative reactions, strong positive reactions, and daughters who felt more distant from their mother's breast cancer. The current study has implications for families dealing with inheritable diseases, personal threat assessment, and how individuals make medical decisions including genetic testing.

PERCEIVED THREAT IN DAUGHTERS OF WOMEN WITH BREAST CANCER

by

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 1

Introduction

Take a moment to think about how breast cancer has affected your life. Does a member of your family or a friend have the disease? If so, you are not alone in being touched by breast cancer. Breast cancer is a particularly insidious disease because it causes severe physical problems in the people we love. This is compounded by appearance-altering treatments that are distressing to those close to an individual with cancer. For many women, watching a friend or a family member deal with breast cancer also forces them to question their own susceptibility to the disease.

Most likely, when you thought about how breast cancer has affected your life, you were easily able to think of someone you know with the disease because breast cancer is so common. Approximately 212,600 new cases of breast cancer will be discovered this year and 1 in 9 women will be diagnosed with breast cancer in their lives (American Cancer Society, 2003). Striking as it is, this figure represents only a fraction of individuals affected by breast cancer because all women diagnosed with breast cancer have loved ones whose lives are altered by their diagnosis. Be it a mother, sister, daughter, grandmother, aunt, wife, partner, friend, or other relative; breast cancer touches the lives of nearly every individual in America and all over the world yet there has been a paucity of research on how a cancer diagnosis affects close family members.

One overlooked sufferer in breast cancer is the daughter of the cancer patient. Not only must she deal with the trauma of her mother's diagnosis, the threat of losing her mother, and in some cases, caring for her mother; daughters of women diagnosed with breast cancer must also face their own genetic threat of developing the disease.   This

double jeopardy situation can cause stress and anxiety for these daughters, but in the face of their mothers' physical and emotional suffering, many daughters feel that the struggles they face are insignificant and they may feel that their feelings are invalidated by others (Wellisch & Hoffman, 1998). Even though there are resources for women with breast cancer, few of them provide adequate support for daughters.

Although other first-degree relatives of breast cancer patients may have similar concerns, the scope of this study will focus on daughters. I have chosen to focus on the psychological and emotional reactions of daughters because of their close genetic relationship to their mothers, the unique mother-daughter bond, and the increased number of daughters who either act as caregivers or are intimately involved in the diagnosis, treatment, and post-cancer process of their mothers.

Opening the door to examining how daughters deal with their mother's breast cancer, Gilbar and Borovik (1998) conducted one of the few studies related to the psychological functioning of women with an increased risk of breast cancer. They found that women with a history of the disease in their families were more likely to have regular check-ups than women without such risk. When women were confused about their risk of breast cancer or about the disease in general, they were more likely to ask questions of their health care professionals. These authors also found that daughters of women with breast cancer exhibited fewer coping strategies than the control group. With such a heavy burden to carry, the coping strategies that daughters use are essential to their well being.

Another study that has been important in shaping the foundation of the literature on daughters of women with breast cancer was conducted by Appleton, Fry, Rees, Rush,

and Cull (2000). Through telephone focus groups, Appleton et al. found that women with an increased risk of breast cancer reported experiencing chronic negative emotions and cognitions, sensitivity to breast cancer cues, a change in general health behaviors, and confusion surrounding family issues, surveillance, and the ideal level of knowledge about their risk. All of the women interviewed mentioned concerns about family and children. Some individuals reported that they felt comfortable discussing increased risk with family members, while others avoided those discussions. Certain women wanted to pursue breast cancer-related information about their risks and possible preventative measures, while others fond that this information provoked anxiety. Overall, it is clear that women react differently to a heightened risk of breast cancer, possibly due to their differing levels of chronic anxiety and distress (Appleton, Fry, Rees, Rush, & Cull, 2000). The authors expressed a clear need for more research on how women live with the knowledge of their increased risk of developing breast cancer. The results of the Appleton et al. study illustrate how complicated this issue is for women and their families. There is no easy answer that tells a woman how to best cope with her mother's breast cancer, because each woman copes differently.

The importance of the coping process for daughters has not been adequately studied. One limitation of the existing literature is that the studies have typically investigated how a single variable affects coping. For example, studies have examined how age of the daughters affects coping (Wellisch & Hoffman, 1998), how mothers' post-cancer status and severity of treatment affect the daughters' coping (Wellisch & Hoffman, 1998), how surveillance behaviors change (Gilbar & Borovik, 1998), and how mothers' anxiety related to breast cancer affects the severity of the daughters' anxiety

(Boyer, Bubel, Jacobs, Knolls, Harwell, Goscicka, & Keegan, 2002). Unlike the single variable studies described above, the coping literature informs us that coping processes are affected by a number of different variables. In contrast to these studies, the current study investigated how multiple variables combine to influence the coping process. Another purpose of this study will be to distinguish which variables are most salient in shaping how daughters cope with their mothers' breast cancer and their own vulnerability to the disease. Also, this study attempted to draw comparisons between the different ways that some daughters cope by clustering the participants on a number of variables.

Breast cancer was chosen as the model disease for this study because the media, medical literature, and research have contributed to an increased knowledge of breast cancer and its effects, which has made breast cancer more understandable and accessible to the general population. Because of this, many individuals are informed about their increased risk of developing breast cancer but they do not know how to cope with that threat. Little research has been done on how individuals deal with this heightened awareness of breast cancer, which is an important area to study now that medical advances have changed the way we view breast cancer. With new advances in genetics, it has become possible for individuals to learn more about their own personal risk for developing breast cancer. Emerging questions exist about how women at risk for breast cancer should deal with that threat, what kinds of health behaviors and decisions are most helpful for women at risk, and how living with an increased risk of breast cancer can affect an individual's life choices, coping, and health behaviors. These are the questions the current study addressed.

An important focus of the current study is to help educate mental health care practitioners and physicians about the importance of more positive coping skills in daughters of women with breast cancer. Research has shown that living with breast cancer changes family interactions, friendships, careers, and many other aspects of one's life, but it is also crucial to evaluate how family members deal with the illness. Breast cancer, and its risk for close family members, is a growing concern that psychologists must help their clients face. Counselors need to become educated about adaptive and maladaptive coping styles and how to best help clients struggling with an increased risk of developing a disease.

Chapter 2

Review of the Literature

Breast cancer is a salient issue for many women today because of the biological, psychological, and social implications of the disease. Breast cancer patients and their families are affected by the physical devastation of the disease and its common treatments, the internal emotional turmoil that accompanies it, and the social changes that the patient must go through to maintain friendships and family ties. Breast cancer is an insidious disease that intrudes on the well-being of women, both diagnosed and undiagnosed. Recently promoted as a genetic disease in the media, women with family members who have had breast cancer are forced to reckon with the threat of developing breast cancer themselves. The disease can seem like a time bomb to many young women with mothers, sisters, or close relatives with the disease, and each passing day seems a day closer to developing the disease and being forced to go through the same process that the loved one did. Women can feel like a moving target for breast cancer, navigating the battle field of cancer and watching friends and relatives fall prey to its destructive effects.

Physically, breast cancer ravages one's body. Cancer engenders images of cells attacking other cells inside our organs with the constant threat of metastasis. Breast cancer treatment with chemotherapy or radiation weakens the immune system and causes patients to experience nausea and extreme sickness. Mastectomies that remove one or both breasts forever alter a woman's body and may affect her self-esteem and feelings of femininity. Psychologically, the disease challenges women to confront their own mortality while attempting to maintain normality in their lives. Personal growth and life

reviews are common in individuals with terminal diseases. Socially, family members and friends who witness the effects of breast cancer try to help as much as possible, which can create conflict. Formerly independent women who develop breast cancer are often forced to rely on the assistance of others and consequently lose much of their independence.

It is clear that breast cancer has many complex biological, psychological, and social variables that combine to influence coping in daughters of women with breast cancer. Although these three types of variables inform and relate to one another, I will examine their distinct contributions in this literature review.

Biology of Breast Cancer.

The biological effects of cancer itself are complex and not well understood. It has been shown that breast cancer is passed on through genetic mutations in some families, but only 5-15% of breast cancers are presumed to be genetic in nature (King, Rowell, & Love 1993, as cited in Clark, Bluman, Borstelmann, Regan, Winer, Rimer, & Skinner, 2000; Wellisch, Gritz, Schain, Wang, & Siau, 1991); most types of breast cancer are not hereditary. The causes of breast cancer in these non-genetic cases are in question. Researchers have hypothesized links to hormone treatments, alcohol use, environmental variables, and lifestyle factors; however, there is no model of how to prevent breast cancer.

A recent study found that some women are at risk for the hereditary forms of breast cancer, even if they do not have a history of gynecological cancers in their family (Weiss, 2003). For example, in the Ashkenazi Jewish community, up to one in forty women are believed to have a mutation in either the BRCA1 or BRCA2 gene. Mutations

in either gene have been found to cause breast cancer and ovarian cancer. This study implies that women should not have a false sense of security if they do not have a history of breast cancer in their families; they may still be a carrier of a non-dominant mutated gene, which puts them at the same risk for cancer as women who are aware of a history of cancer in their family (Weiss, 2003). Adding to this complexity is the fact that women with breast cancer can be divided into three groups. 70% are those without a known family history of breast cancer, while the remaining 30% are divided between those with hereditary breast cancer where there is one known dominant gene, and those with polygenic breast cancer, where there is some family history of the disease but it is not passed on through dominant inheritance (SusanLoveMD.org, 2004).

Absolute risk factors.

Aside from the familial and genetic causes of breast cancer, women need to be aware of other unchangeable factors that contribute to their increased risk for breast cancer. These risks are often referred to in terms of absolute risk, the rate of mortality from a specific factor in a general population. The largest contributor to absolute risk is age, which, unfortunately is not something women can change. An older woman is more likely to get breast cancer compared to the general population. Another fixed factor is ethnicity. Caucasian American women have the highest absolute risk followed by African American women, whose risk is slightly higher than Hispanic women, which is slightly higher than Native American women, who in turn have a higher risk than Asian American women (SusanLoveMD.org, 2004). Similar ethnicity effects are seen around the world, with some countries like Japan having a very low incidence of breast cancer (Wellisch & Hoffman, 1998).

Besides age and ethnicity, another risk factor is menstruation history. Basically, the longer a woman has her period, the more likely she is to get breast cancer. Women who reached menarche (first period) before age 12 have a higher risk. A similar phenomenon applies to late menopause, with menopause after age 55 conferring more risk. If a woman has 40 or more years of menstruation, her risk is twice that of a woman with a shorter duration. Having children generally decreases risk for breast cancer, however younger pregnancies confer a preventative factor but older ones are associated with a higher risk. Not having children at all is linked with a higher likelihood of breast cancer (Wellisch & Hoffman, 1998). Although these factors can seem disheartening because they are unalterable, it is important to keep in mind that relative risk is a statistical construct designed to compare women across the entire population. Falling into a higher risk category does not mean that individual will definitely get breast cancer; it simply means that she is at a higher risk. This data is epidemiological in nature and when misunderstood may unnecessarily increase distress in women at risk. It is difficult to know how to evaluate this type of information and some women may inaccurately inflate their risks; therefore it should be interpreted with caution.

Having a relative with breast cancer does increase a woman's risk, but the risk also depends on the relative's age at onset. Having a first-degree relative (mother, daughter, or sister) who develops premenopausal breast cancer puts one at a higher risk than when the onset is postmenopausal. The first degree relatives' fixed factors of ethnicity, menstruation history, and pregnancy history may be considered when calculating one's own risk as well. (Wellisch & Hoffman, 1998).

Lifestyle Factors.

The fixed factors associated with increased risk for breast cancer may lead many women to despair. Indeed, many fixed factors are decided at birth, but risks for breast cancer can be lowered by changes in lifestyle. Women who smoke are at a higher risk for getting breast cancer, as are women who drink more than 7 drinks per week, who live a sedentary lifestyle, who eat a high-fat diet, or who are considered obese (Weiss, 2003). Familial links are tied to these lifestyle factors too, since families tend to have similar health habits. For example, in a household where adults smoke and the family eats a high-fat diet, the children are more likely to continue those behaviors as adults. Conversely, a family may be exposed to carcinogens at the same rate based on where their house is located or the kinds of chemicals found in their food, which confers a similar risk to the entire family. Lifestyle habits may aggravate genetic mutations or even "cause" breast cancer on their own. It is difficult for epidemiologists to identify the contributions of each factor because they are all grouped together in an individual.

Women who have been exposed to high levels of radiation have a higher risk for breast cancer. Exposure to radiation, especially while breast tissue is still developing, confers a greater risk of all types of cancer later in life. Survivors of the Hiroshima and Nagasaki nuclear bombs in Japan had more breast cancer than other women of the same age. When thinking about the risk from radiation, it is important to remember that radiation as a therapeutic tool is meant to kill cancer cells and does not contribute to risk (SusanLoveMD.org, 2004). Other types of environmental factors can contribute to breast cancer as well. Some carcinogens contribute to gene mutations which cause cancer.

Pesticides, electromagnetic waves, and hormones are currently being studied to evaluate their possible carcinogenic properties (SusanLoveMD.org, 2004).

Eating a low-fat, high-fiber diet filled with many fruits and vegetables is seen as a positive preventative lifestyle choice. Also, women who exercise for four or more hours per week have a decreased risk for breast cancer (SusanLoveMD.org, 2004). These guidelines seem to be associated with a general healthy lifestyle that not only reduces breast cancer risk, but also reduces risk for other diseases such as heart disease and strokes.

Hormone use.

A new area of concern for many women is hormone use. Conflicting studies have confused women regarding the benefits and detriments of menopausal hormone replacement therapy (HRT), fertility drugs, and oral contraceptive pills. Higher levels of estrogen are associated with a higher risk for breast cancer. Early forms of birth control pills had higher levels of estrogen than current formulations which are now balanced with progesterone. Women who are overweight or obese have more fat cells, which actually produce estrogen, thus increasing risk. The Nurses' Health Study found that women who have taken HRT for 5-10 years were at a 46% greater risk than women who had not. That study was conducted with 121,700 women and its results seem to be supported by other studies (SusanLoveMD.org, 2004). Women who ovulate more in their lifetime, as discussed in the earlier discussion about menstruation risk, are at a higher risk for breast cancer. Fertility drugs are designed to help women "hyperovulate," which makes a woman's ovaries work harder, and seem to be linked to a greater risk for breast cancer.

However, most women taking fertility drugs are over age 30 and childless, separate

factors that have their own increased risk (SusanLoveMD.org).

Prevention and treatment.

Whether at greater risk for breast cancer due to genetic, familial, or lifestyle

factors, all women are advised to perform monthly BSE to aid in the detection of lumps

and other abnormalities. Once a woman is diagnosed with breast cancer, the treatment

can be as traumatic as the disease itself. There are many facets and levels of treatment

for breast cancer. Suspicious lumps or discolorations on a woman's breast can be

examined with a mammogram, MRI, or needle biopsy. If they are found to be malignant,

lumps that are detected early can be removed by a lumpectomy. More advanced cancer is

often removed with a mastectomy, where all of a woman's breast tissue is removed.

Concurrently, a woman may undergo chemotherapy, which often involves weekly

treatments for an extended period of time. Radiation therapy is another option for some

women. Often, these treatments are combined to improve a woman's chances of being

cancer free. The risk for metastasis, or spread of the cancer to another area of the body,

is higher for cancers that are detected at a later stage. Women who survive for five years

after their diagnosis with breast cancer without metastases are believed to be at a

drastically decreased risk for relapse (Greer, Morris, & Pettingale, 1979). The

complicated and time consuming treatments associated with breast cancer, accompanied

by the physically extreme outcomes such as hair loss and removal of breasts, are difficult

for patients to experience and for their families to observe. Daughters who have seen

their mothers go through more severe types of treatment (e.g. mastectomy versus

lumpectomy) are more likely to have increased breast cancer-related distress than other women (Erblich, Bovbjerg, & Valdimarsdottir, 2000).

Genetic Background and Risk Calculation.

Genetic diseases have recently become an area of professional and personal interest to many people. With the completion of the human genome project in 2001, a wealth of knowledge about human genetics has become available, both in the professional literature and the mass media. Along with that knowledge comes a better understanding of disease processes, but also some tenuous psychological issues and slippery social and ethical dilemmas. What is presently known about many disorders may foreshadow what will be known about the genetic factors of breast cancer in the future.

A variety of medical information is available from one's genes. It is important to keep in mind, however, that genes do not tell us everything about an individual's susceptibility to a disease. Monogenic, or single gene, disorders were the first to be identified. These can be inherited via recessive, autosomal dominant, or sex-linked patterns of inheritance. Recessive inheritance requires each parent to give an altered copy of the gene to the offspring and is the pattern associated with such conditions as Tay-Sachs, cystic fibrosis, and sickle-cell anemia. Carrier testing is often done in recessive inheritance cases when parents or prospective parents are interested in determining the likelihood of passing an affected gene to their child. Autosomal dominance is exhibited when a single copy of an altered gene is enough to cause a disease in the offspring and is found in conditions such as neurofibromatis, Marfan syndrome, and achondroplasia. Sex-linked inheritance is due to the different

chromosomes for males and females (XX for females and XY for males) and confers a different risk depending on one's sex. Disorders such as male pattern baldness and color blindness are due to sex-linked inheritance. With all of the aforementioned disorders, genetic testing is now diagnostic (Lerman, 1997).

In all of the above examples, the penetrance of the gene is 100% (i.e., if you have the genotype described, you will have the disorder). However, some disorders are late onset dominant conditions that develop at a later age. With diseases like Huntington's disease, familial hypercholesterolemia, and polycystic kidney disease, individuals with the affected genotype will not develop the disease until later in life. Genetic testing for these diseases is considered presymptomatic (Lerman, 1997).

Advances in molecular biological technologies have allowed researchers to evaluate diseases with a genetic component that are also influenced by environmental and personal factors. Breast cancer is an example of a monogenic condition that has reduced penetrance and is affected by other factors. Testing for breast cancer is considered susceptibility testing rather than diagnostic or presymptomatic testing. In most cases of breast cancer, the development of the disease is not solely based on genetics, but on a combination of many factors. The ambiguity in this information can be anxiety provoking for recipients of the test, because a positive result does not guarantee breast cancer and a negative result can not alleviate all of the worry surrounding the disease. (Lerman, 1997).

Daughters of women with breast cancer are immediately forced to question their genetic vulnerability when they find out that their mothers have breast cancer. Understanding the complex genetic and environmental factors that contribute to the development of breast cancer is impossible at this stage of medical research, but it is

important to recognize that some types of breast cancer are genetically caused and that fact adds to the anxiety surrounding the disease for many daughters of women with breast cancer.

Biological Implications for Daughters.

When a mother is diagnosed with breast cancer, her daughter often begins to worry about her own genetic makeup. Besides considering her own lifestyle and environmental factors that may affect her possibility of eventually developing breast cancer, the hereditary nature of the disease is often on a daughter's mind.

As described earlier, genetic information about breast cancer is important, even though it does not provide conclusive results. Women who have a first degree relative (mother, sister, or daughter) with breast cancer are two to three times more likely to develop breast cancer than women without a close relative with the disease (Slattery & Kerber, 1993 as cited in Appleton et al., 2000). As women have become more educated about breast cancer risk factors, their interest in genetic testing, risk assessment and genetic counseling has grown. Some women choose to pursue risk assessment using a mathematical model such as BRCAPRO (Berry, Parmigiani, Sanchez, Schildkraut, & Winer, 1997; Clark et al., 2000) that accounts for all of a woman's known risk factors and allows her to estimate her likelihood of developing the disease. The mathematical models are cumbersome and complex, but are a viable option for a woman to pursue if she is interested in a mathematical estimate of her probability of carrying the BRCA1 or BRCA2 genes. After learning more about their risk, some women simply begin heightened surveillance of their own health (Gilbar & Borovik, 1998), while others choose to undergo genetic testing.

Living with the knowledge that breast cancer may have a genetic component and knowing that it runs in one's family is a difficult issue. With the complete human genome sequenced, it has become easier to learn about genetic diseases. The breast cancer 1 and breast cancer 2 genes (BRCA-1 and BRCA-2) have been localized to the short arm of chromosome 17 in humans (Futureal, A., Liu, Q., Shattuck-Eidens, D., Cochran, C., Harshman, K., & Tanigan, S., 1994 as cited in Wellisch & Hoffman, 1998). The search for other genetic factors is underway (Schatzkin, Goldstein, & Freedman, 1995), but currently it is estimated that only 5-15% of breast cancer diagnoses have a genetic basis (King, Rowell, & Love 1993, as cited in Clark et al., 2000; Wellisch et al., 1991). Carriers of BRCA1 and BRCA2 gene mutations have a 56-85% lifetime risk for developing breast cancer as well as an increased risk of ovarian cancer (Easton, 1993, Ford, 1884, Struewing, 1997 as cited in Clark et al., 2000). As mentioned above, besides genetic factors, the absolute risk factors of increasing age, Caucasian race, menarche before age 12, menopause after age 55, nulliparity or late child birth, diet factors, and premenopausal breast cancer diagnosed in a first degree relative are important to consider (Wellisch & Hoffman, 1998). A combination of these factors increases an individual's relative risk of developing breast cancer. Since no completely effective method of preventing breast cancer exists, and the exact etiology of the disease is unclear, women with a familial history of breast cancer may cling to the perceived clarity of genetics to help cope with their own risk.

Media reports and commercial availability of BRCA1 and BRCA2 tests have increased the public awareness of genetic testing (Clark et al., 2000). In a study of 159 women at a high risk for developing breast cancer, 96% of the women chose to have

BRCA1/2 testing; however, since the testing was free, that number is probably higher than what would be seen in the general population. Ninety-five percent of the participants were satisfied with their test decision, although the relatively small sample size and low variability in satisfaction and ultimate test results made further investigation of the participants' satisfaction impossible. Those high numbers were present despite extensive educational materials and genetic counseling offered to the women that provided them with information that could discourage them from testing. Afterwards, the women felt better prepared to make decisions about their future risk of the disease (Clark et al., 2000). Participants in the study were able to consult with family members and physicians prior to making their decision. A possible caveat to the study is that the participants may have felt some coercion from the consultants or researchers. Even though the researchers claim they were not biased, 70% of the participants thought the researchers "definitely" or "probably" wanted them to choose the testing option. Obviously, the question of genetic testing always has implications for other individuals, but potential test recipients generally need to consider their personal well being first. Genetic testing is an option for women in families with breast cancer, but each individual should evaluate whether it is a good idea for her as well as what the results might mean for her family.

Genetic testing is still in its infancy, but its popularity is growing. Lerman, Seay, Balshem, and Audrain (1995) found that 91% of first degree relatives of breast cancer patients were interested in receiving genetic testing. The main reasons for interest in genetic testing in order of highest agreement were to learn children's risk, to take better care of themselves, to increase screening behaviors, to plan for the future, and to make

decisions about childbearing and marriage. The high level of interest in genetic testing is consistent across other studies including the Clark et al. (2000) study mentioned above.

In a study using individuals answering randomly dialed phone numbers for residents from Maine, New Hampshire, and Vermont (Bunn, Bosompra, Ashikaga, Flynn, & Worden, 2002), researchers found that only 32% of the 1,836 respondents were "probably or definitely" planning to get a genetic test for colon cancer in the next six months. Only 18.9% were planning to in the next month. However, respondents rated themselves low on a scale of their own perceived susceptibility of developing colon cancer and only 4.4% reported having a father with the disease. Because only 15% of colon cancers are believed to have a hereditary factor, the percentage of individuals interested in receiving a genetic test is appropriate for this low-risk population. Studies using likelihood estimates of pursuing genetic testing usually overestimate the number of individuals who will actually follow through on their interest, but it is interesting in this study that many more individuals expressed an interest in the genetic test than would be expected based on estimates of their own risk (Bunn et al., 2002). Previous studies have shown up to 80% interest in receiving a genetic test for colon cancer (Croyle, 1993, as cited in Bunn et al., 2002). Therefore, it is important to consider how publicity has affected public interest in genetic testing to perhaps an extreme level.

I have provided extensive information about the genetics of breast cancer and the pros and cons of genetic testing because I believe breast cancer is a uniquely threatening disease to young women. Women can witness family members suffering from other diseases and fear those ailments, but breast cancer seems to elicit a different level of fear because its genetic nature can loom in one's thoughts for a lifetime.

An option for disease monitoring besides genetic testing is frequent surveillance, including mammograms, breast self-exams, and doctor's visits. Recommended surveillance behaviors include yearly mammograms for women over age 40, monthly breast self-exams for all adult women, yearly gynecological exams including a physician breast exam, and consultation with a doctor whenever a suspicious lump, discoloration, or discharge is found in one's breast. These behaviors have been shown to reduce the mortality associated with breast cancer and decrease the severity of treatment if a breast malignancy is detected (SusanLoveMD.org, 2004).

Some studies have found that women with a family history of breast cancer exhibit more surveillance behaviors, while other studies have found the opposite (Wellisch, Hoffman, & Gritz, 1996). Gilbar and Borovik (1998) found that women with breast cancer in their family are more likely to have regular checkups than other women. Gilbar and Borovik interviewed 45 women at a breast health clinic, where they had been referred by their primary care physicians because they felt discomfort or pain in their breasts. The women selected for the study were all daughters of women with breast cancer. However, the finding that those women are more likely to have regular check ups should be questioned because the sample was found in a clinic where they were having those check ups. Perhaps in a larger study of the entire population of daughters of women with breast cancer, similar results might not have been found. In fact, results contradicting those of Gilbar and Borovik were found in a different study of 208 relatives of breast cancer patients (Krischer, Cook, & Weiner, 1988). In this study, 83% of the participants were aware that having relatives with breast cancer put them at a higher risk for developing the disease themselves. That figure grew to 86% in the college educated

section of the sample. Interestingly, only 54% reported conducting breast self exams once a month, a procedure recommended to all women and shown to help detect breast cancer malignancies earlier. Only 32% reported having a mammogram, with only 17% over age 70 ever having had a mammogram, many more women (35% of the sample) with incomes over $10,000 reported having mammograms than those with a lower income (10% of the sample). Those figures are startlingly low, especially since this is a sample of women with at least one relative with breast cancer (Krischer et al., 1988). Although there is a lack of consensus in the literature on surveillance for breast cancer, common trends are that poorer and older women have fewer mammograms or breast self exams (Krischer et al., 1988).

The ambiguity in the surveillance literature may be attributed to the large variety of women with breast cancer and their diverse adaptive strategies. For some women, having more information reduces anxiety and for others, it increases anxiety. Surveillance behaviors, such as doing breast self examinations or receiving mammograms are sources of more information for women with a threat of breast cancer, and it is not surprising that women whose anxiety level is raised with more information may be less likely to monitor their breast health. Lerman, Trock, Rimer, Jepson, Brody, & Boyce (1991) found that women who had received a suspicious abnormal mammogram had significantly elevated mammography-related anxiety and breast cancer worries than women with normal mammogram results. The anxiety interfered with their moods and functioning, even though the doctors ruled out breast cancer. Women with higher levels of breast cancer anxiety are more likely to obtain mammograms. Consistent with this trend, the women in this sample who received abnormal mammograms reported

a higher likelihood of getting another mammogram within the upcoming year. However for some women, excessive fear promoted avoidance of mammograms (Lerman et al., 1991).

These divergent opinions are found in many areas related to breast cancer. For example, in the Appleton et al. (2000) study using telephone focus groups, women expressed divergent opinions on whether they wanted to talk to their families about their disease, pursue breast cancer related information, and increase or decrease surveillance. The authors hypothesized that women react differently to a heightened risk of breast cancer, possibly due to their differing levels of chronic anxiety and distress (Appleton et al., 2000). Persistent trait levels of chronic anxiety are a psychological variable that may affect all aspects of susceptibility to breast cancer. Chronic anxiety as it relates to the development and prognosis of breast cancer will be explored in more detail in the next section.

The Appleton et al. study used telephone focus groups to survey 25 women with a family history of breast cancer. The results of the focus group show that the key issues raised during the discussions were psychological and behavioral adaptation, family issues, clinical surveillance, provision of information (e.g. knowledge and family involvement), and peer support. Women in each of the focus groups mentioned concerns in all of the above areas. A confounding factor of this study is that the focus groups were set up in small groups where women might have been less likely to share their true feelings and thoughts, especially on issues such as anxiety and depression. Also, the groups focused on the six key issues above, but other issues may have been discussed if time constraints and other anonymous participants were not present. Overall, the

Appleton et al. study was an important beginning step in evaluating the kinds of issues that women with a family history of breast cancer must face in their daily lives.

The genetic nature of breast cancer may lead daughters whose mothers have breast cancer to question their own personal life choices such as whether to get married, have children, or adopt (Wellisch & Hoffman, 1998). The issues involved with the genetics of breast cancer raise questions about who should be notified, who should or should not have genetic tests, and if prophylactic measures should be taken. Future insurability and employment opportunities may be jeopardized by having genetic tests (Spira & Kenmore, 2000). The risk of breast cancer affects many areas of a woman's life and the current study is designed to expand the knowledge we have about the multifaceted impact of knowing that your mother has breast cancer.

Beyond the genetic and biological influence that breast cancer has, the psychological stress that breast cancer evokes is present for women with breast cancer and their daughters. Since breast cancer is a physical disease, the psychological ramifications are often overlooked, especially for patients' families. This study will address the need for more information on the psychological effects of breast cancer on women and their daughters.

Coping.

The genetic and biological factors with which a woman with breast cancer and her daughter have to confront raise important psychological concerns as well. To live with the threat of developing the disease, in the daughter's case, or to live with the disease, in the mother's case, requires adaptive coping mechanisms.

The theoretical framework of the coping literature adds insight into how daughters adjust to their mother's breast cancer. Early coping theories focused on the ability to cope as a permanent personality trait that was relatively unchanging. However, more recent models of coping (such as those considered in this paper) conceive of coping as a situational variable that has varied responses in different environments (Lazarus, 1974, as cited in Pearlin and Schooler, 1978). Pearlin and Schooler's (1978) structure of coping for example, pairs particular coping responses to specific strains in various life roles and examines the coping efficacy of strategies in categories of life activities, rather than overall. Lazarus and Folkman's Transactional Theory of Stress and Coping (1984) explains coping as a bidirectional transactional process between a person and his or her environment. This is a process-oriented approach, where the interaction between person and environment can affect the coping process. An individual experiencing a stressful event uses primary appraisal to evaluate an event as stressful, positive, or benign. Then the person evaluates his or her available coping resources to deal with the situation (Lazarus and Folkman, 1984). For example, stressful appraisal of the event occurs when an individual determines that a harm or loss has already occurred, that a threat presents a chance for damage to occur, or that a challenge is available which could inhibit mastery or gain. Thus, the degree to which one feels stress is defined as the interaction between the perceived harm, threat, or challenge and an evaluation of personal coping resources, (i.e. a transactional model between the person and the environment). Coping resources can include physical resources, social support networks, and psychological resources like beliefs, cognitive skills, and problem solving abilities. Taking their transactional model into account, Folkman and Lazarus (1980) define coping as "the cognitive and behavioral

efforts made to master, tolerate, or reduce external and internal demands and conflicts among them (p.223)." The twofold purposes of coping are to manage the person-environment relationship that is causing stress (problem-focused coping) and to regulate stressful emotions (emotion-focused coping).

Similarly, Pearlin and Schooler (1978) define the functions of coping as changing or controlling the "strainful" experience to prevent stress before it occurs and diminishing the stress once it does emerge. Pearlin and Schooler examined coping over four dimensions: marriage, parenting, work life, and dealing with finances. Overall, they concluded that it is important for an individual to have a variety of tools in his or her coping toolbox to deal with each of life's strains. Unfortunately, no magic personality characteristic exists that can help individuals cope with all problems; but instead, a good balance of social resources, psychological resources, and specific coping resources can help.

Pearlin and Schooler's 1978 study examined coping differences across gender and age. They interviewed 2300 people between the ages of 18 and 65 about the social origins of personal stress. Men reported being more likely to exhibit coping responses that minimized stressful outcomes and women more often reported using a response that would result imore stress. It should be noted that this study was conducted approximately 25 years ago, when fewer women were working outside of the home. In addition, participants were selected based on their status as "head of household," a construct that is less relevant today since many families have two working parents who share child care responsibilities. Quite possibly, the finding that men have psychological attributes that enhance coping whereas women do not use as many strategies that enhance

coping would be drastically different now that women are taking on more roles outside the home and are developing coping strategies to deal with their multiple roles.

Pearlin and Schooler (1978) found age differences in the specific forms of coping that are used situationally, but neither younger nor older individuals had an overall advantage. Older individuals were more likely to use the stress limiting response of self-reliance to cope with marital problems instead of asking others for help, while younger participants used the less effective coping strategy of selective ignoring less frequently than older adults. These situational differences balanced out to show equity across age groups in coping strategies. Better educated and more affluent participants were better able to cope across situations than their counterparts. Unfortunately for the less educated and poor who are exposed to more hardships, they were found to have fewer effective coping strategies to deal with those increased stressors. Some coping responses were found across all four of the examined role areas, while others were more specific to one area. These data add validity to the idea that coping is a combination of consistency and variability across stressful situations.

In summary, Pearlin and Schooler (1978) showed that impersonal strains (e.g. occupational or financial), produced coping that was most effective when the individual distanced herself or himself from the problem by manipulating her or his goals and values. Interpersonal problems (e.g. parental or marital) were best handled when the individual remained emotionally connected and engaged with the other people involved. People who stay engaged in their coping rather than disengaged tended to have better health prognoses, a finding which has been shown for several different diseases. Denial and other avoidant coping strategies are most often less adaptive in dealing with health

traumas (Billings, Folkman, Acree, & Moscowitz, 2000). Ironically, dealing with health problems can be seen as a combination of impersonal and interpersonal strains, especially with a disease like breast cancer that forces women to deal with occupational and financial issues as well as relationships and personal concerns. Perhaps this is why the picture of coping with breast cancer is so complex.

The Folkman and Lazarus (1980) theory of coping utilized some of the findings from Pearlin and Schooler's (1978) study to design the Ways of Coping checklist (WOC). They separated coping into problem- and emotion-focused coping strategies. Domains analyzed on the WOC include defensive coping (e.g. avoidance, intellectualization, isolation, and suppression), information-seeking, problem solving, palliation, inhibition of action, direct action and magical thinking. Assessed areas on the revised WOC include confrontive coping, distancing, self-control, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving and positive reappraisal (Folkman & Lazarus, 1988). These domains were used to determine the relationship between emotional change and coping. Folkman and Lazarus found that both problem- and emotion-focused coping strategies had the ability to significantly change one's emotion about a stressful event. Therefore, it is important to recognize the collaborative effect that both methods have in emotional adjustment to stress.

Overall, health contexts favor emotion-focused coping and work contexts favor problem- focused coping. This may be because coping with health issues is more directed towards managing anxiety and fear, restoring self-esteem, and interpersonal relationships. Lazarus and Folkman (1980) define coping as a shifting process that forces an individual to change methods as their situation changes or deepens. This kind of

adaptation is difficult for most individuals and makes the study of coping more complex. In 98% of the situations on the WOC, both problem- and emotion-focused coping strategies were utilized. Thus, a coping pattern was defined as the combined proportion of problem- and emotion-focused coping used in a specific episode.

Another coping factor to consider is personal control. From another viewpoint, personal control in the process of adapting to a health threat is seen as central to the process of coping (Taylor, 1983). When patients perceive having greater control, they experience better recovery and adjustment to their disease (Taylor, Lichtman, & Wood, 1984). Averill (1973, as cited in Shiloh, Berkenstadt, Meiran, Bat-Miriam Katznelson, & Goldman, 1997) defined control as a combination of behavioral control, cognitive control, and decisional control. Combined, these aspects of control influence behavioral choices, change information-processing strategies, and give the individual the ability to choose among different courses of action. Lazarus and Folkman's theory of coping overlaps with the idea of control by viewing control as part of the threat appraisal process. Lazarus and Folkman (1980) found that problem- focused coping strategies were more often used in situations where one could control aspects of the process and emotion-focused strategies were utilized in situations with little potential for control. Thus, the combination of problem- and emotion-focused strategies often can be helpful.

Another important piece of the coping puzzle is cognitive adaptation. According to Taylor (1983), most individuals who suffer through a traumatic event regain their original level of happiness or even surpass it at some point after the event. Cognitive adaptation theory proposes that regained happiness is caused by a combination of three factors: searching for meaning in the experience, regaining mastery over the event and

life in general, and struggling to regain self-esteem after the setback. Individuals who have faced a serious illness or trauma often discuss how the experience forced them to reconsider their priorities and find meaning in their lives, especially in their relationships.

Self mastery as a cognitive adaptation is related to personal control and can best be illustrated by a common belief among cancer patients that they can personally keep the cancer from returning. Approximately one-third of the cancer patients interviewed in Taylor, Lichtman, and Wood's (1984) study believed they had a great deal of control over their cancer not coming back, while another third believed they had some control, and the final third believed they had no personal control over the cancer, but their doctors or medications might have some control. Family members and significant others of cancer patients had less belief in direct control over cancer, and, instead emphasized the cancer patient's need for personal mastery. The need for direct control is often seen in patients' causal attributions about their cancers, e.g. living near hazardous chemical plants or experiencing traumas to one's breasts. For some individuals, it is easier to believe they did something to cause their own cancer, rather than relegating control to an external factor.

Self enhancement is the last piece of the cognitive appraisal model. Interviewed patients viewed themselves as better adjusted after the cancer than during the treatment process, but many viewed themselves as better adjusted than even before they had cancer. Almost all breast cancer survivors in Taylor, Lichtman, and Wood's (1984) study thought they were doing better or as well as most other women going through the same process; this leaves an 'imaginary woman' at the bottom to serve as a comparison subject. These techniques are cognitive illusions that individuals use to bring about psychological

adaptation. Unlike traditional views of illusions as defenses and delusions, Taylor et al. see illusions as a natural and beneficial part of the cognitive healing process. A natural concern regarding cognitively-induced illusions is the impact on patients when their cognitions are disproved by a recurrence of cancer or they recognize that they are not really as well off as they once believed. Despite these potential problems, Taylor et al. concluded that the disproval of illusions is not as problematic as it could be, since cognitions are flexible and may change their meanings across situations.

Coping theory, cognitive appraisal, and the need for self mastery over a situation provide a framework for understanding how daughters cope with their mother's breast cancer. For daughters, the coping mechanisms discussed above may be applied to dealing with the threat of developing breast cancer. Literature on coping with a genetic threat adds insight into these daughters' situations.

Coping Theory Applied to Breast Cancer.

The potential genetic component of breast cancer implies that individuals in families with breast cancer often worry about their genetic threat. Certainly, not all women with family histories of breast cancer will have a genetic mutation, but many will still be wondering about their genetic make-up. McConkie-Rosell and Sullivan (1999) applied Lazarus and Folkman's coping theory to a genetic threat. They found that adaptive behaviors such as pursuing hope, learning information, constructing meaning, acquiring new knowledge, developing new coping methods, increasing perceived control, and minimization were used to positively adapt to genetic testing (Kessler, 1984 as cited in McConkie-Rosell & Sullivan, 1999). The positive strategies that the participants used were connected with their overall personality traits.

The stress of a mother's diagnosis, the bewildering information on the genetics of breast cancer, the threat of developing breast cancer, and the lack of empathy from others may create an anxiety-provoking situation for daughters of women with breast cancer. Dealing effectively with stress and anxiety is crucial for these daughters. A variety of adaptive and maladaptive techniques are often chosen by the daughters of women with breast cancer. Participants in the Clark et al. (2000) study used a variety of coping techniques before, during, and after the genetic testing decision process. The most common were prayer (57%), talking to a family member about testing (45%), relaxation techniques (20%), exercising more or less than usual (19%), talking to a doctor about the testing (13%), and eating more or less than usual (12%). These techniques are commonly used coping strategies.

When breast cancer is the traumatic event that forces women to consider their own genetic make up, few of the factors affecting coping have been investigated (Wellisch & Hoffman, 1998). Overall, little research in this area has dealt with coping mechanisms, while more research has focused on surveillance behaviors. In general, daughters of women with breast cancer show fewer coping strategies than other women, are less likely to be convinced that things will work out, and are more likely to be involved in the medical setting and seek medical information (Gilbar & Borovik, 1998). More research on coping with the threat of illness is needed, especially on coping with the stress and anxiety surrounding the decision to seek genetic testing. Investigating the ways in which daughters of women with breast cancer cope with the risk will lead to increased understanding of how to help individuals at risk for other diseases.

All people deal with threat differently and each individual has a distinct set of coping mechanisms they can use to deal with various situations. Genetic testing is not necessarily the answer for everyone, but it is an option that may help women deal with the threat of breast cancer in their family. It is a choice that each individual has to make, with the help of family, friends, and counselors.

Environmental variables that may affect an individual's decision about genetic testing include the severity of the disorder and treatment availability, the number of affected individuals in the family, and the amount of contact with affected individuals (McConkie-Rosell & Sullivan, 1999). Personal and social variables include the individual's self-concept, family characteristics, social support, and desire for children or grandchildren, among many other factors. These variables affect an individual's initial appraisal of the level of threat as well as their secondary appraisal of coping resources. Enhancing personal control in the decision to seek genetic testing can be helpful for individuals considering a test. The decision to be genetically tested can provide empowerment to individuals and help them make informed decisions regarding their health, regardless of the outcome of their test (McConkie-Rosell & Sullivan, 1999). Within the framework of the Lazarus and Folkman (1980) model of coping, genetic testing is a good example of a decision that combines personal and environmental variables into the appraisal process. It is a situation in which we would expect both problem and emotion coping strategies to be used.

Pursuing a genetic test implies a certain level of recognition of personal threat. Women who are educated about breast cancer seem to fall into two categories: those confronting the threat and those avoiding it. In a study of 100 patients referred to a breast

clinic for investigation of a suspicious breast lump, 74 were "nonidentifiers" and did not think the lump was a real problem; these women all used denial as a coping mechanism (Styra, Sakinofsky, Mahoney, Colapinto, & Currie, 1993). The remaining women identified the lump as a problem, and were more likely to have a family history of breast cancer than nonidentifiers. Nonidentifiers used three times the number of avoidant coping mechanisms as identifiers who, in turn, used more active problem solving strategies (Styra et al., 1993). Wellisch et al. (1991) found that women with a family history of breast cancer were more likely to use problem-focused and seeking-of-support modes of coping than emotion-focused coping.

When threatened, the amount of desired control varies among individuals. The broadly defined dichotomy between identifiers and nonidentifiers, as discussed above, can be expanded to include control over one's environment. Those who confront the environmental factors often desire more control while others who use denial may desire less control over the environment. This relates to the way an individual copes with stress. If a person is very sensitive to cues of threat in their environment, they are considered high monitors, e.g. identifiers (Styra et al., 1993). Other individuals who tend to avoid or distract themselves from threat are low monitors, or alternatively, high blunters, e.g. nonidentifers. Schwartz, Lerman, Miller, Daly, & Masny (1995) have shown that high monitors are more susceptible to psychological distress. Applying these findings to daughters of women with breast cancer suggests that those daughters who monitor their environment excessively are at the greatest psychological risk from the threat of breast cancer. The results of the Schwartz et al. study suggest that the best intervention for these women is to decrease stress without affecting their adherence to health regimens

and surveillance behaviors. Providing accurate information to these women is crucial, since myths and misinformation may contribute to their high monitoring and stress (Schwartz, Lerman, Miller, Daly, & Masny, 1995).

In the Schwartz et al. study, women at an increased risk for ovarian cancer were more likely to be distressed if adequate information was not available to them. With a medical threat, the potential for misinformation and unnecessary anxiety is great. The media stresses that first-degree relatives of breast cancer patients are at an increased risk, but does not help to dispel the inaccurate perception that all daughters of women with breast cancer will get the disease. As discussed earlier, only 5-15% of breast cancers are based on identifiable genetic factors. The media attention to genetic risk factors for breast cancer is both beneficial and alarming. While women have become more aware of the genetic factors for breast cancer, many women have more anxiety about developing the disease. Providing accurate and truthful information, supportive psychological interventions, support groups, and simply fostering empathic friendships may be important ways for women to learn about breast cancer while also helping them to maintain a sense of personal control over their situations. This approach may help generate accurate risk perceptions and fewer intrusive thoughts.

Self mastery, or a sense of personal control, is an important variable in predicting how individuals will cope with medical threats. Caregiving men, non-whites, adult children rather than spouses, healthy, and higher SES individuals who act as caregivers have been found to have a higher sense of mastery over their own lives (Skaff, Pearlin, Mullan, 1996). Mastery is a relatively stable characteristic but is susceptible to change in response to situational differences. Mastery is lower among caregivers who continue to

care for a sick friend or relative, reaches a plateau after the patient is placed in a hospital or treatment facility, and is higher after bereavement (Skaff et al., 1996). Mastery and self-efficacy are related concepts because mastery is the belief that one has the ability to cause an outcome; it is also related to one's sense of control, in that both involve a sense of personal control and the belief that one has the ability to influence outcomes in one's life (Lefcourt, 1983 as cited in Skaff et al., 1996). However a sense of mastery does not predict whether an individual has an internal or external locus of control.

Shiloh et al. (1997) found that perceived personal control mediated one's emotion focused coping strategies. Subjects who perceived higher control in a medical threat situation were more satisfied with genetic testing and genetic counseling and used fewer emotion coping strategies. This corresponds with findings that when people perceive that they are unable to exert control over a situation, they change their emotional responses instead (Lazarus & Folkman, 1984). Thus, a balance of control exists within the individual, between the individual's degree of perceived control and his or her use of emotion-focused coping strategies.

Threat.

An important variable in the coping puzzle is how threatening the daughter perceives her situation to be. Assessing the daughter's perceived threat related to her own risk of developing breast cancer as well as her general threat level in medical situations is important in determining her coping style and how she confronts anxiety.

Simply asking a woman about her perceived level of threat has been shown to be a valid way of evaluating threat. In a study by Erblich et al. (2000), participants were asked to estimate how likely they felt they were to develop breast cancer in their lifetimes

on a scale of 0% (not at all likely) to 100% (extremely likely). They found that estimated

likelihood was significantly correlated with scores on the Impact of Events Scale (IES,

Horowitz, Wilner, & Alvarez, 1979), avoidance coping mechanisms, and global levels of

anxiety. However, likelihood estimates were not associated with mother's health status

or caregiving (Erblich et al., 2000). Similar results were found in a study conducted by

Lloyd, Watson, Waites, Meyer, Eeles, Ebbs, and Tylee (1996) when they interviewed 62

patients undergoing genetic counseling. Sixty-six percent of the patients in the study

could not accurately recall their lifetime risk for breast cancer and the investigators found

it difficult to help people understand their true lifetime risk for breast cancer. Similarly,

Shiloh, Petel, Papa, and Goldman (1998) found that women were more likely to

overestimate their risk and were likely to estimate their risk to be higher than medical

information would suggest.

Evans, Burnell, Hopwood, and Howell (1993) conducted an in depth study of

women's perception of risk in women with a family history of breast cancer. Asking

similar likelihood questions as described above, they found that most women chose

estimates that were different than the correct population lifetime risk. Only 11% of the

155 women surveyed chose the correct lifetime risk, while 41% underestimated and 46%

overestimated. The women in the study were asked to estimate what they believed the

overall population risk of developing breast cancer was and those answers were

compared to their personal estimates. About a quarter of the women had difficulty

separating their own risk from the population risk, perhaps indicating confusion about

these probabilities. The study did not compare risk estimates to other psychological

variables, but indicates that women frequently perceive their risk incorrectly. However,

these results might be different today with the prevalence of media information on risk and breast cancer genes compared to the Evans et al. study conducted 11 years ago.

Dealing with a personal risk of developing breast cancer causes different reactions in women. Some may refuse to consider their own risk by avoidance mechanisms. Others may believe that worrying about breast cancer may protect them from it. Another possibility is the belief that thinking about their own personal risk and other negative thoughts can cause cancer (Kelly, 1983). A common irrational belief surrounding diseases is that thinking about it causes the disease or somehow makes it more contagious to others.

Daughters of women with breast cancer may question their personal risk because they observe their mother's physical struggles and the mental anguish that accompanies the disease. Daughters witness the depression, anxiety, stress, and intrusive thoughts that their mothers experience, which can compound their own fear of breast cancer. Women with breast cancer symptoms are more likely to be depressed than women without those symptoms (Howard & Harvey, 1998), show signs of Posttraumatic Stress Disorder including intrusive thoughts and avoidance behaviors (Naidich & Motta, 2000) and experience more general anxiety (Wellisch & Hoffman, 1998) than other women. As presented these findings are not surprising, but realizing that these psychological effects extend to family members is somewhat alarming.

Anxiety surrounding breast cancer may not just be limited to first-degree relatives of breast cancer patients. Women in general appear to be aroused by breast cancer-related stimulus material as measured by the Stroop test, in which the majority of women had a delayed response time to breast cancer words compared to general words (Naidich

& Motta, 2000). In an interesting study, Naidich and Motta showed cue cards to women with breast cancer. One set of cards contained words related to breast cancer including things like "breast," "tumor," "cancer," "chemo," and "sick". Women were asked to state the color of the word on the card while the investigators measured the response time. Women with breast cancer took significantly longer to name the colors of the breast cancer words than sets with positive, neutral, or obsessive-compulsive disorder-related words. Surprisingly, that same result was found in women without breast cancer as well. One caveat of Naidich and Motta's conclusion is that the women without breast cancer were asked to volunteer for a breast cancer-related study. Perhaps the women who volunteered were more likely to have had a significant experience related to breast cancer, so their unexpected response may be due to a selection bias. However, it is clear that breast cancer is a worry for most women. Matthews, Ridgeway, Warren, & Britton (2002) found that Nottingham Prognostic Index scores, used to assess the severity of cancer, were not predictive of one's level of worry about their cancer. The most reliable predictor of worry was simply thought frequency, not severity variables. As indicated by the preceding studies, many demographic, personality and psychological variables may predict one's psychological reaction to breast cancer, but a range of reactions and coping styles is to be expected in most patients.

Anxiety.

Women with a family history of breast cancer tend to have more general anxiety than other women. General anxiety, or trait levels of anxiety, is often found in women with mothers with breast cancer. A possible reason for this is that they are worrying

about their mothers' breast cancer or their own potential to develop it. Measuring trait level anxiety is important because it gives a baseline estimate of how anxious the participant normally is on a daily basis. The State-Trait Anxiety Inventory (STAI) (Spielberger, 1983) is a common instrument used to study anxiety. In a study of women with breast symptoms, Howard and Harvey (1998) used only the trait section of the measure to assess the participants' general anxiety. They found that for most women with benign symptoms, their level of anxiety stayed constant over three time points.

Similar to their mothers with the disease, when compared to a control group, those women with a familial risk had higher non-specific distress, intrusive thoughts, and avoidance about breast cancer (Valdimarsdottir, Bovbjerg, Kash, Holland, Osborne, & Miller, 1995). Intrusive thoughts interfere with normal functioning and are linked to increased anxiety levels. Intrusive thoughts may be a cause of increased distress or they may be a way of adapting to the increased risk of the disease. Zakowski, Valdimarsdottir, Bovbjerg (2001) found that emotional expressivity moderates the relationship between intrusive cognitions and distress. Therefore, women who are naturally more expressive may experience less distress over intrusive thoughts.

Intrusive thoughts pervade a woman's consciousness after her mother is diagnosed with breast cancer. Valdimarsdottir et al. (1995) found that women at a higher risk of developing breast cancer had more intrusive thoughts even after receiving the results of a normal mammogram. Intrusive thoughts were measured by the Impact of Events Scale (IES, Horowitz, Wilner, & Alvarez, 1979), a commonly used assessment of intrusive thoughts and anxiety. Carriers of the BRCA1 gene had higher levels of intrusion and avoidance than non-carriers (Croyle, Smith, Botkin et al., 1997 as cited in

Sundin & Horowitz, 2002). Also, women with higher levels of general distress report more intrusive thoughts (Zakowski et al., 2001). In women with recently diagnosed breast cancer, Koopman, Butler, & Classen, et al. (2002) found that younger women, women whose lives were strongly affected by the diagnosis, individuals with lower self efficacy, and women with intense treatments scored higher on the IES. They concluded that it is crucial for health care providers to intervene if traumatic stress symptoms are observed in women with recent breast cancer.

Since intrusive thoughts are observed in daughters of women with recently diagnosed breast cancer as well, the directive to be aware of stress should apply to daughters as well. Examining daughters' intrusive thoughts is important to understanding her overall coping strategies and well being. In this vein, Matthews et al. (2002) found that frequency of thoughts regarding breast cancer were the best predictor of anxiety level in women with breast cancer. Even more so than severity of the disease, thought frequency, which is related to intrusive thoughts, predicted distress level in women. Assessing intrusive thoughts seems to be a more manageable way for clinicians to assess anxiety than including a lengthy anxiety inventory in a regular screening (Matthews et al., 2002). It is clear that scores on the IES are related to measures of general distress.

The Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996) is a revised version of the Miller Behavioral Styles Scale (MBSS) which evaluates how individuals deal with threat in a variety of situations. The TMSI is only focused on medically threatening scenarios. It is used to measure the coping styles of monitoring (cognitive confrontation) and blunting (avoidance). Shiloh, Ben-Sinai, and Keinan (1999) gave 209

participants both the MBSS and the TMSI. They found that the TMSI, which was designed for medical situations, was a better predictor of behavior related to medical threat. The participants were chosen from a sample of individuals interested in predictive genetic testing. Participants who were found to be monitors were more interested in genetic testing and that general trend was more significant when the genetic test in question offered more certainty. The results of the Shiloh et al. (1999) study lend credibility to the idea that more information is beneficial to some people (monitors) but not to others.

Social variables.

Breast cancer has a profound impact on an individual's relationships with others. A woman diagnosed with breast cancer may find that some friends are very supportive, while others shy away from visiting her. Family relationships change too as women must renegotiate their roles in the family.

The mother-daughter relationship in particular may be influenced by a cancer diagnosis. When a mother is diagnosed with breast cancer, the daughter's reaction may vary based on the type of relationship she has with her mother.

Previous studies have found that the kind of attachment style a daughter has with her mother and the type of relationship they have has an effect on the daughters well being as her mother goes through an illness. Cicirelli (1995) conducted a study on 138 daughters of elderly mothers who were engaged in caretaking of their mothers. The study found that daughters who lived with their mothers, had mothers with greater needs, and felt more love, trust, and attachment to their mothers were more likely to give more caregiving help to their mothers.

The trauma of breast cancer is almost as intense for daughters as it is for their mothers with the disease (Boyer et al., 2002). Daughters who develop PTSD related to the diagnosis or show symptoms consistent with partial PTSD are nearly as common as the mothers themselves developing PTSD and mothers with PTSD were significantly more likely to have daughters with PTSD. Also, 94% of the daughters believed their mother's diagnosis and treatment to be a traumatic event whereas 92% of the patients themselves responded in that way (Boyer et al., 2002). Clearly, the daughters experienced just as much stress as their mothers did with the disease. Thus, it is important to examine the daughters of breast cancer patients and to help them cope with the trauma of their mother's diagnosis.

If a daughter has been taking care of her mother during her breast cancer, that daughter is more likely to be aware of the damaging effects it can have on one's body and how it affects other relationships. Seeing her mother deal with cancer can make the daughters more fearful of developing cancer themselves. Caregiving status has been shown to be an important predictor of coping with a relative or friend's illness. In other words, women who act as caregivers to friends or relatives with breast cancer are more likely to have a significant reaction to the disease and to have difficulty coping (Billings et al., 2000). A daughter's level of closeness with her mother has also been found to affect the daughter's reaction to her mother's diagnosis (Spira & Kenmore, 2000; Lichtman, Taylor, Wood, Bluming, Dosik, & Leibowitz, 1985). In a study of caregivers to men with AIDS, it was found that those who attempted to disengage from the caregiving had a more negative mood and those who used interpersonal types of coping were more positive (Billings et al., 2000). About a third of the caregivers were HIV

positive themselves, and when those caregivers used avoidance coping, their own physical symptoms increased. These results highlight the need to address psychological issues that arise during caregiving for patients with a terminal illness. In other words, it is important for daughters who are caregivers to deal with the stress of caregiving in a productive and confrontive way rather than denying that the stress exists.

Ability to cope with a mother's diagnosis varies with age. Adolescent daughters were more likely to have difficulty coping with their mother's diagnosis of breast cancer than preadolescent or adult daughters or sons of any age (Spira & Kenmore, 2000, Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell, & Malcarne, 1994). The Compas et al. study suggests that the stress for adolescent girls may be because they are more aware of how the disease will affect their parent and their entire family, they may receive more information about the disease than younger children, they may be burdened with additional household responsibilities, and they may be facing their own vulnerability to cancer.

The increased stress in adolescent daughters has been observed from the mother's perspective as well. In interviews with 78 women with breast cancer, Lichtman et al. (1985) found women with breast cancer were more likely to have a strained relationship with their daughters (17%) than their sons (8%), possibly due to increased demands on the daughter for support or the daughters' fears of their own heightened risk. Problems with children were more likely when patients had a bad prognosis, more severe surgery, poorer adjustment, or difficulty with chemotherapy or radiation (Lichtman et al., 1985). The authors attributed some of the relationship strain to the daughters' own fear of developing breast cancer and the increased demands on the daughter for support. Family

concerns are frequently on the minds of women with breast cancer because they must mend those strained relationships and try to hold the family together. Early studies of women with breast cancer found that having an only child is seen as a source of support, but more than one child is perceived to be stressful. Bloom, Stewart, Johnston, Banks & Fobair (2001) hypothesized that the increased number of children is directly related to more family conflict, thus causing stress. Family support can be both a blessing and a curse during breast cancer.

Daughters whose mothers died of breast cancer or faced severe treatment had more cancer related distress compared to those whose mothers had a better prognosis (Erblich et al., 2000, Compas et al., 1994). Erblich et al. (2000) surveyed 148 healthy women, about a third of whom had family histories of breast cancer. Unlike the Compas et al. study that found that adolescent daughters were more distressed than other children, the Erblich et al. study found no effect for the age of the daughter when her mother was diagnosed.

The women in the Erblich et al. study completed inventories of general psychological distress as well as the Impact of Events scale (IES) and one question on their perceived likelihood of developing breast cancer (0%-100%). Women whose mothers had died had much higher scores on both the intrusive thoughts and avoidance scales of the IES than women whose mothers were still alive and women whose mothers had died of other causes. A woman who was a caregiver for her mother and whose mother subsequently died had the highest levels of cancer-specific distress. A caveat of the study was that the survey did not delineate levels of caregiving, which perhaps contributed to the existence of an interaction effect with caregiving but not a significant

effect of caregiving alone. Women with a family history of breast cancer had higher levels of distress surrounding breast cancer than other women. A higher level of perceived likelihood of getting the disease was correlated with high levels of intrusive thoughts and avoidance. These result are not surprising because the more severe effects they witness are, the more likely individuals are to be distressed.

These results taken together suggest that a daughter's age, relationship with her mother, and mother's outcome all have an effect on the daughter's coping. Wellisch and Hoffman (1998) suggest that women can be divided into groups based on the timing of their mother's diagnosis, the mother's survival status, and the quality of the mother-daughter relationship to determine their ability to cope and adjust to the trauma of their mother's diagnosis. The current study will use that hypothesis to cluster women based on these variables.

Summary

Through personal work with patients with breast cancer, I have come across a surprising number of different reactions. One vivid memory of mine is of a woman who told me that she and her daughter were diagnosed with breast cancer at the same time and were going through treatment together. This pair was from a rural area, with insufficient medical care and little information about breast cancer. They were obviously unaware of the current medical dictate to do breast self exams at home every month, to visit a gynecologist yearly for a professional exam, and to receive mammograms yearly after age 40.

Both women noticed bleeding from their breasts, found many lumps, and experienced great pain. Due to lack of adequate health care, little education, and a

shortage of money, these women let the problem get worse. Finally, after the urging of the daughter's fiancé, the mother and daughter went together to the doctor and were both diagnosed with breast cancer. Their cancers were very far along and treatment required both of them to stay in inpatient care at a large teaching hospital. The mother was told she had the most severe form of breast cancer that the nurses had ever seen. Both women survived, and each told me that they could not have done it without the other. They were each other's support system and faced the pain of treatment together.

From such experiences as these, and being a woman myself, I became curious about what was known about daughters' reactions to their mothers' diagnosis of breast cancer. As indicated by the preceding literature review, much is known about how women cope with their own breast cancer but much less is known about how their daughters cope with the knowledge of their own increased risk for breast cancer, the assessment of genetic risk, or the amount of anxiety generated by their mother's diagnosis. For these reasons, I have proposed the current study to increase our knowledge of daughters' reactions to their mothers' diagnoses of breast cancer and to assess ways of meeting the clinical needs of such clients.

Chapter 3

Statement of the Problem

The experience of daughters of women with breast cancer has been virtually

ignored in the literature. Some studies have focused on the medical aspects of prevention

in these women and a few have addressed the short-term psychological concerns of the

daughters. However, no studies could be found that have examined the overlap between

medical information and psychological distress in daughters of women with breast

cancer. Undoubtedly, with the increase in accessible medical information available to

families of women with breast cancer, there has been a heightened level of anxiety

surrounding the disease (Naidich & Motta, 2000). Daughters of women with breast

cancer have an abundance of facts and theories presented to them by doctors, concerned

friends, and the media, so they must find a way of coping with the information, their own

personal threat, and their mother's diagnosis.

This study attempted to characterize women based on their preferred strategy for

dealing with threat and by selected situational variables. These daughters were faced

with difficult choices of their own: Should they calculate their genetic risk of developing

breast cancer? Should they get genetically tested for BRCA1 or BRCA2? Should they

undergo prophylactic mastectomies? Should they make lifestyle changes? Should other

family members be notified or tested? This study aimed to help determine the ways

daughters approach their personal threat of breast cancer and the impact of their mother's

breast cancer diagnosis on them, with the goal of helping other women make decisions

that are best suited for their personalities and situations. The implications of this study

are beneficial for counselors and medical professionals who work with individuals

making health decisions, and provide insight into the differential benefits of different adaptive strategies for daughters of women with breast cancer.

The purpose of this study was to understand how daughters react to the implications of their mother's diagnosis of breast cancer and their own perceived threat of developing the disease and to characterize daughters into groups based on their demographic variables, mother's disease severity, relationships with their mothers and their families, genetic variables, personal perceived risk, control over the situation, coping strategies and amount of trauma related to their mother's diagnosis.

Research Questions and Hypotheses

Question 1: How do natural groupings of women form with regards to their psychological adjustment to their mother's breast cancer and their own perceived risk of developing breast cancer?

This question combined all of the variables used in the study to conduct an exploratory analysis of the different variables that affect a daughter's reaction to her mother's breast cancer. A number of studies have examined correlations between several of the personality characteristics investigated in this study and reactions to an increased risk of breast cancer, but no studies have examined the multiple variables in an exploratory way like in the current study. For those reasons, research question one was designed to explore the exact relationship between some of the variables that had not been previously investigated. Question one used an exploratory statistical approach, and hence was structured as a research question instead of a hypothesis, to see if there are natural groupings between daughters of women with breast cancer as a first step in the research. Some of the hypothesized correlations look more closely at the specific

relationships set up in the cluster analysis. This research question was of primary interest in this study, however other correlations were examined to further clarify relationships through the following hypotheses:

Hypothesis 1: Daughters whose mothers are deceased will report more distress than daughters whose mothers are still alive.

Hypothesis 1a: Daughters whose mothers are deceased will report higher levels of intrusive thoughts than daughters whose mothers are still alive.

Hypothesis 1b: Daughters whose mothers are deceased will report higher predicted likelihoods of their own risk of breast cancer than daughters whose mothers are still alive.

Hypothesis 1c: Daughters whose mothers are deceased will report more general anxiety than daughters whose mothers are still alive.

Witnessing a parent's death is difficult for any child, but daughters of women with breast cancer have a unique situation because their mother's death may seem to foreshadow their own. Daughters whose mothers died of breast cancer or faced severe treatment had more cancer related distress compared to those with mothers with a better prognosis (Erblich et al., 2000, Compas et al., 1994). The Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979) and the State TraitAnxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, 1970) have both been shown to measure general distress (Zakowski et al., 2001), so the current study re-evaluated the distress of daughters of women who died of breast cancer. Erblich et al. found women whose mothers died of breast cancer had a higher perceived likelihood of developing breast cancer and had more

intrusive thoughts. The women who experienced the highest levels of distress were women who acted as caregivers for mothers who died after the caregiving process.

Hypothesis 2: Daughters who report more contact with their mothers during the diagnosis and treatment of their mother's breast cancer will report more distress than daughters who had less contact with their mothers.

Hypothesis 2a: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively correlated with intrusive thoughts.

Hypothesis 2b: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively related to their own predicted likelihood of developing breast cancer.

Hypothesis 2c: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively correlated with general anxiety.

Daughters who are closer to their mothers have stronger reactions to breast cancer than those that are not as close (Spira & Kenmore, 2000, Lichtman et al., 1985). This relationship has been shown in many studies, but was evaluated here using the IES, STAI, and perceived likelihood of getting breast cancer as measures of distress. Similarly, women who act as caregivers to friends or relatives with breast cancer are more likely to have a significant reaction to the disease and have difficulty coping (Billings et al., 2000).

Hypothesis 2d: Daughters reported amount of contact with their mothers during the diagnosis and treatment of her breast cancer willbe positively correlated with personal control.

Skaff et al., (1996) found that adult children who cared for a sick parent had higher self mastery than spouses or other caretakers of the sick family member. Mastery is similar to one's sense of control (Skaff et al., 1996). If one has low scores on the Self Mastery Scale (Pearlin & Schooler, 1978), it is hypothesized that a person believes they cannot control the situation. Perhaps this is because spouses are closer to the afflicted family member than an adult child and it is easier for the child to understand what is happening. However, in this study, breast cancer's unique genetic component may have made adult daughters feel less control over the situation, and thus, have lower mastery scores. It is hypothesized that the more contact a daughter has with her mother, the higher her self-mastery scores will be.

Hypothesis 3: Daughters who reportless personal control will report being less likely to have a strong interest in getting a genetic test than daughters who report more personal control.

Interest in genetic testing has been found to be higher among women that believe there is something they can do to control the situation after the test (Shiloh et al, 1999). Therefore, women with low self mastery may be less likely to want a genetic test.

Hypothesis 4: Daughters' threat of getting breast cancer will be positively related to intrusive thoughts

Hypothesis 4a: Daughters' perceived threat of getting breast cancer will be positively correlated with intrusive thoughts.

Hypothesis 4b: Daughters threat level will be positively correlated with intrusive thoughts.

Valdimarsdottir et al. (1995) found that women with a familial risk of developing breast cancer had higher non-specific distress and intrusive thoughts about breast cancer. Erblich et al (2000) found that women with a higher perceived risk of developing breast cancer had higher scores on the IES. This hypothesis included the Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996) as a measure of threat level, as well as the perceived likelihood score, to assess if higher threat levels are related to intrusive thoughts.

Research Questions.

Question 2: Do daughters who were more involved with their mother's medical decision making and information gathering processes report more distress than daughters who were removed from the process?

Question 2a: Do daughters who were more involved with the medical decision making and information gathering processes report more intrusive thoughts than daughters who were removed from the process?

Question 2b: Do daughters who were more involved with the medical decision making and information gathering processes report higher predicted likelihoods of their own risk of breast cancer than daughters who were removed from the process?

Question 2c: Do daughters who were more involved with the medical decision making and information gathering processes report higher levels of general anxiety than daughters who were removed from the process.

Based on the literature about daughters who serve as caregivers to their mothers, this question was added to investigate the role that medical decision making plays in the daughter's distress. Since medical decision making and information gathering seem to fall under the umbrella of caregiving, this is an extension of hypothesis 2 and the literature that supports the idea that caregivers have more distress than non-caregivers.

The above hypotheses and research questions are based on the idea that women with an increased risk of breast cancer experience more distress. Studies have shown that women with breast cancer symptoms are more likely to be depressed than women without those symptoms (Howard & Harvey, 1998), show signs of Posttraumatic Stress Disorder including intrusive thoughts and avoidance behaviors (Naidich and Motta, 2000) and experience more general anxiety (Wellisch & Hoffman, 1998) than other women. This knowledge, combined with other studies that have researched how closeness affects a daughter's well being, formed the basis for these hypotheses. Women who are close to their mothers presumably have a heightened sense of awareness surrounding breast cancer, therefore the distress that is found in most women with breast cancer seems to be higher in women that are closer to their mothers or who have felt the effects of breast cancer strongly through the death of their mothers.

Chapter 4

Method

Design

This study collected data from daughters of women who have been diagnosed with breast cancer. The design is a descriptive field study. Data were analyzed using Ward's (1963) method of cluster analysis to identify natural groupings in the data. The goals of cluster analysis are exploration, confirmation, and simplification of data (Borgen & Barnett, 1987). Pearson correlations were also used to analyze the data. Survey data, as well as some qualitative descriptive data were collected for the analysis.

Participants

Participants for this study were 142 women who self-identified as daughters of women with breast cancer. Participants were adult women whose mothers have been diagnosed with breast cancer at some point in the daughter's lifetime. No restrictions were placed on the amount of time since the mothers were diagnosed with breast cancer to achieve more variability in the sample. It was believed that recruiting participants with mothers at all stages of diagnosis would contribute to the formation of clusters in the cluster analyses and would provide more rich data comparisons. The participants represented at least 6 different ethnicities, ranged in age from 18 to 75 (M=36.37; SD=11.7) and represented a wide range of occupations, education levels, and income levels. Overall the sample was highly educated and at a high income level (See Table 1). The sample represented women whose mothers had diverse experiences with breast cancer. The mothers' cancer diagnosis ranged from occurring 2 months prior to completing the survey to over 25 years previously (M= 9.7 years; SD= 7.6) and occurred

when the mothers were at a wide range of ages. The participants' mothers had a range of

outcomes (See Table 2).

Table 1: Demographic Data for Participants		
Ethnicities	*N*	*Percentage*
Indian/Pakistani	2	1.4%
Black	2	1.4%
Hispanic	4	2.8%
Middle Eastern/Arab	2	1.4%
White	130	91.5%
Foreign National/Other	2	1.4%
Education Level	*N*	*Percentage*
High school or less	9	6.3%
Some college or technical school	30	21.1
Four-year college degree	45	31.7
Some graduate school	22	15.5
Masters degree	20	14.1
Doctorate or professional degree	15	10.6%
Income	*N*	*Percentage*
No personal income	21	14.8%
$20,000 per year or	21	14.8%
$20,000-$40,000	36	25.4%
$40,000-$60,000	33	23.2%
$60,000-$80,000	17	12.0%
$80,000-$100,000	11	7.7%
$100,000 or more	3	2.1%

Table 2: Demographic Data for Mothers of Participants

Mother's age at diagnosis	N	Percentage
Under age 21	3	2.1%
21-30	2	1.4%
31-40	13	9.2%
41-50	39	27.5%
51-60	52	36.6%
61-70	21	14.8%
71-80	10	7.0%
Over age 80	2	1.4%

Mother's outcome	N	Percentage
Still undergoing treatment	5	3.5%
Cancer-free	84	59.2%
Recurrence	2	1.4%
Metastsized cancer	3	2.1%
Deceased	39	27.5%
Other	7	4.9%

Forty-six percent of the participants had children and fifty-four percent did not. Their mothers'cancer affected the participants differently with 10% reporting they moved to be closer to their mothers (while 90% did not, though daughters' proximity to their mother was not assessed, presumably many of those daughters lived close to their mothers) and 29% saying their mothers' diagnosis affected their life decisions (71% said it did not).

Participants were recruited through multiple online methods including mass e-mails sent out to various breast cancer and professional list-servs that the author was a part of, breast cancer chat rooms, links on breast cancer organization home pages, and through e-mails from breast cancer clinics. Because there were many online recruiting methods and it was possible for participants to be recruited from multiple sources, no data was kept to distinguish participants based on their recruitment differences. Passwords were alternated in each recruiting e-mail and posting. Two forms of the survey existed with the same measures ordered differently that corresponded with the two different passwords. Participants were directed to a form of the study based on the password they entered and measures were counterbalanced to avoid bias in the order of the measures. The data was entered directly into a database when the participants submitted the survey. The database was programmed to automatically sort questionnaire responses to match one another. For example, even though the Threatening Medical Situations Inventory was presented in a different order for both forms, the responses to those questions were sorted to appear in the same place in the database for both forms.

Paper copies of the survey were available at the request of the participants, though ultimately no respondents requested paper copies. The number of participants needed for

the study was based on preliminary data analyses to determine the saturation in cluster

formation.

Response Rate. The response rate could not be calculated because it was not

possible to determine how many people received an e-mail or saw an internet posting

about the study. No data was recorded about the number of hits on the survey website.

Research Assistants. A web-page designer was hired for assistance with web-page

design and technical support.

Measures

Demographic Questionnaire. Basic demographic data was collected through a

demographic questionnaire (See Appendix A). This included participant's age, length of

time since mother's diagnosis with breast cancer, race/ethnicity, education level, yearly

income, and occupation. Other demographic variables collected related to the daughter's

risk for developing breast cancer herself. These data were age at menarche and

menopause for self and mother, number of pregnancies and age at childbirth, number of

relatives with breast cancer (or other types of cancer) and relation to them, personal

history of cancer, mother's age at diagnosis, mother's type of treatment (chemotherapy,

radiation, surgery, alternative, other), and mother's outcome (alive, deceased, remission,

metastasis, other).

Perceived Risk of Threat. Participants were asked to state their perceived risk

estimate that they will get breast cancer in their lifetimes on a scale from 0-100% using a

question that was designed for this study (See Appendix B). This was based on a

common procedure used in several studies (Wellisch & Hoffman (1998), Valdimarsdottir

et al. (1995), Erblich et al. (2000), Shiloh et al. (1998), Evans et al. (1993), Lloyd et al.

(1996), Lerman et al. (1995), & Capelli et al. (2001)). Previous use of an estimated likelihood scale by Capelli et al. (2001) has shown a Crohnbach's alpha of 0.80. For the current study, one question was used to assess the participant's perceived risk of breast cancer, therefore the Cronbach's alpha for the current sample cannot be calculated.

Genetic testing likelihood. Participants were asked if they have been tested for any breast cancer genes (see Appendix C). Participants were then asked to rate the level of interest they have in receiving a genetic test and to estimate the likelihood that they will get a genetic test in the next six months. These questions were based on a procedure outlined in studies such as Clark et al. (2000), Lerman et al. (1995), Bunn et al. (2002), and Capelli et al. (2001). For the current study, one question was used to assess the participant's interest in genetic testing, therefore the Cronbach's alpha for the current sample cannot be calculated.

Family Exposure to Cancer Rating. The daughter's involvement with her mother during her mother's cancer experience was assessed based on the amount of contact she had with her mother, frequency of their visits, amount of exposure to other friends or relatives with breast cancer, daughter's perceived role as primary caregiver, secondary caregiver, or uninvolved in the direct care process and the daughter's involvement in medical decision making for her mother. Caregiving status has been shown to be an important predictor of coping with a relative or friend's illness (Billings et al., 2000). These data were based on information collected through the Family Exposure to Cancer Rating (FECR) (Boyer et al., 2002). The Family Exposure to Cancer Rating was originally a 2-item inventory with 7-point Likert scales based on the amount of contact a participant had with her mother. Based on personal correspondence with Dr. Boyer,

slight revisions to the original FECR scale were made. These revisions were used in the current study, which is now a 6-item measure (See Appendix D). Two open-ended questions about major life changes that daughters made during the time of her mother's breast cancer diagnosis and treatment were added to the original FECR and the endpoints on the Likert scale were changed to eliminate overlap and positive skew that Dr. Boyer found in the original study. The points on the Likert scale were made more definitive. Also, the original definition of contact with one's mother was expanded to distinguish between visits and phone or e-mail communication. The first four questions on the measure were based on the original 7-point Likert scale and the final two are open-ended questions. Higher scores indicate greater contact, caretaking, and involvement with medical decisions with one's mother during her treatment of breast cancer. The Cronbach's alpha for the current sample was $\alpha=0.72$.

    Threatening Medical Situations Inventory. The ways in which a daughter copes with her threat of breast cancer were examined using the Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996) (See Appendix E). It was designed to measure the coping styles of cognitive confrontation (monitoring, M scale) and avoidance (blunting, B scale). It consists of four medically threatening scenarios that are different in predictability and controllability. Participants are asked to answer 6 questions after each scenario with 3 monitoring and 3 blunting items on a 5-point Likert scale, ranging from 1=not at all applicable to me, to 5=strongly applicable to me. Scores on the TMSI range from 24-120 total points, with higher scores indicating more monitoring and avoidance. The TMSI is shorter, more medically oriented, and easier to complete than the Miller

Behavioral Style Scale (MBSS); (Miller, 1987), which was its precursor. Cronbach's

alpha levels have been greater than .70 for many samples (dental patients, students, HIV

patients, surgery patients, and working adults) and indicate satisfactory levels of

consistency (van Zuuren et al., 1996). The M and B scales have been shown to be

significantly different from each other. In the current study, the correlation between the

two scales was found to be r=0.21, p < .05. The correlation was significant, but not so

highly correlated that the subscales are seen as measuring the same construct. Test-retest

reliability is .82 for the M scale and .83 for the B scale. The Cronbach's alpha for the

current sample was α=.81 for the overall scale, α=.86 for the M subscale, and α=.83 for

the B subscale.

Impact of Event Scale. The Impact of Event Scale (IES); (Horowitz, Wilner, &

Alvarez, 1979) was used to measure intrusive thoughts in the participants in this study

(See Appendix F). The Impact of Events Scale was designed to explore the

psychological impact of a variety of traumas, and the wording has been changed to

specify the traumatic situation being examined in each study. The IES has been validated

in women at an increased risk for breast cancer (Croyle et al., 1997; Valdimarsdottir et

al., 1995). The scale is a 15-item self-report inventory that assesses intrusive thoughts

and avoidance. It is based on a 4-point Likert scale (1=Not at all, 4=Often). Across 23

studies, Cronbach's alpha levels of 0.86 for intrusion and 0.82 for avoidance were found.

Content validity has been verified and the scales are relatively independent of one

another. The original study found a correlation of .41 between the two scales and across

23 studies a correlation of .63 was observed (Horowitz et al., 1979; Sundin & Horowitz,

2002). In the current study, the intrusion subscale was the most meaningful and relevant

to assessing daughters' levels of threat about breast cancer, so it was chosen for the overall analyses. A Cronbach's alpha level of .86 was reported in a study of women with a familial risk of breast cancer (Valdimarsdottir et al., 1995). Cronbach's alpha for the current sample was α=.89 for the intrusion scale.

State Trait Anxiety Inventory. The State-Trait Anxiety Inventory (STAI-T) (Spielberger, Gorsuch, Lushene, 1970) was used to assess the daughter's overall trait level of anxiety (See Appendix G). The measure asks participants to rate 20 items on a scale from 1 (almost never) to 4 (almost always). The measure has been found to have good internal consistency and test-retest reliability (Spielberger, 1983). Only the trait section of the inventory was used in this study. Scores for the scale can range from 20 (high levels of anxiety) to 80 (low levels of anxiety) though for the purposes of this study and ease of comprehension, that has been reversed so higher scores signify higher attachment when data is displayed graphically. Cronbach's alpha for the current sample was α=.91.

Self Mastery Scale. The Self Mastery Scale (Pearlin & Schooler, 1978) is a global measure of one's sense of personal control over their environment (See Appendix H). It is a 7-item scale with responses on a 5 point Likert scale (strongly agree to strongly disagree). Five items are negatively phrased and reversed scored. Higher scores on the inventory indicate mastery over one's environment. The Self Mastery Scale has been found to have satisfactory psychometric properties (Pearlin & Schooler, 1978) including an internal consistency reliability alpha of .77 (Marshall & Lang, 1990). The Cronbach's alpha for the current sample was α=.77.

Ways of Coping Scale. The original Ways of Coping scale (WOC) (Lazarus & Folkman, 1980) is a 68-item checklist of various coping strategies that an individual might use to cope with a specific event. The questionnaire is designed to be given with a specific stressful event in mind. It is a binary yes-no checklist. The items were classified as either problem-focused or emotion-focused. Twenty-seven items were classified as problem-focused (P) and 41 were classified as emotion-focused (E). Cronbach's alpha levels of 0.80 for the P scale and 0.81 for the E scale were observed. The mean correlation between the two scales is .44, so the scales have been determined to be measuring different constructs, but ones that are used together in the normal coping process. Items for the scale have been derived from defensive coping (e.g. avoidance, intellectualization, isolation, and suppression), information seeking, problem solving, palliation, inhibition of action, direct action, and magical thinking.   Factor analysis of the original scale suggested eight different coping scales: confrontive coping, distancing, self-control, seeking social support, accepting responsibility, escape-avoidance, planful problem solving and positive reappraisal. The original Ways of Coping scale was designed to measure coping styles in a process-oriented, not trait-oriented manner. However, in this study, I was interested in coping within the context of breast cancer, so the present study used a shortened form of the WOC containing only pertinent items (See Appendix I).

The shortened version of the WOC was composed of 30 items and reported in the Scherer, Wiebe, and Luther (1988) study on factor congruency with the Lazarus and Folkman results. Items are on a 4-point Likert scale which ranges from 0 (does not apply or not used) to 3 (used a great deal). High scores on any particular scale indicate

extensive use of that coping style. Participants were asked to reflect upon their experience with their mother's breast cancer and choose the response which best describes how they coped with that situation. Scoring of the Ways of Coping scale is done by conducting a factor analysis on all of the items. Cronbach's alpha for the current sample was $\alpha=.89$.

Adult Attachment Scale. The Adult Attachment Scale (AAS); (Cicirelli, 1995) is a measure of adult daughters' attachment to their mothers (See Appendix J). It includes items that assess distress upon separation, joy upon reunion, feelings of love, and seeking security or comfort with one's mother. It is a 16-item scale with items on a 7-point Likert scale (strongly agree to strongly disagree). Lower scores on the inventory indicate a closer emotional attachment to one's mother, though for the purposes of this study and ease of comprehension, that has been reversed so higher scores signify higher attachment when data is displayed graphically. The Adult Attachment Scale has been found to have adequate psychometric properties with an internal consistency alpha of .95 and a 1-year retest stability at .73 (Cicirelli, 1995). Cronbach's alpha for the current sample was $\alpha=.96$.

Procedures

Selection of participants. Participants were recruited via e-mails and online postings. Eligible participants were individuals over age18 whose biological mother had been diagnosed with breast cancer.

Development of the Website. All surveys were tailored for online use by formatting them for online usage. For example, in the instructions of some surveys, the directions were structured for pencil and paper administration. Those were adapted to

include wording that was appropriate for the web-based survey. The website was then developed and password protected for the security of the data and measures. It was posted through a commercial web space provider and maintained regularly.

    Participant Protocol. After participants were recruited, they were directed to a website and asked to fill out the questionnaires. Participants were notified that their participation in the study indicated their informed consent and that they were allowed to discontinue participation at any time. Eligible participants filled out the demographic questionnaire, perceived risk of threat, genetic testing interest and likelihood questionnaire, Family Exposure to Cancer Rating, Threatening Medical Situations Inventory, State-Trait Anxiety Inventory, Impact of Event Scale, Self Mastery Scale, Adult Attachment Scale and the Ways of Coping Scale. Open-ended questions were asked at the end of the survey to get qualitative responses to other aspects of the coping process that were relevant to the participants (See Appendix K). At the end of the survey, participants were thanked for their participation and given contact information for the primary investigator to contact if they had questions. The participants were allowed to enter their e-mail address if they were interested in learning about the results of the study or if they were willing to be contacted for future studies. Their e-mail addresses were kept separate from their data and were password protected. Submitted surveys were checked for obvious fraud and errors to ensure that the website was functioning correctly and had not been tampered with by non-eligible participants. All surveys seemed to appear valid so no surveys were excluded from the study.

    Statistical Justification. Correlational analyses and cluster analysis were conducted on the resulting data. As discussed in the review of the literature, few studies

have examined the complex interplay of biological, psychological, and social variables related to breast cancer. For those reasons, cluster analysis was used in the current study to concurrently examine those multiple variables. A MANOVA was run on the clusters that emerged to determine their statistical significance.

Daughters of women who have been diagnosed with breast cancer react and cope in very different ways. Breast cancer is not limited to striking individuals in families with well-developed social support networks or individuals with a history of depression and/or anxiety. Because there are so many different ways to cope with a mother's diagnosis and so many demographic, personal, and psychological variables affecting the chosen coping method, cluster analysis was chosen to analyze the data in the current study.

Borgen and Barnett (1987) describe the purpose of cluster analysis as "to identify homogenous subtypes within a complex data set (p. 456)." Clustering algorithms can be used to separate people into relatively distinct groups, especially when the natural groupings and subgroups are difficult to identify or are blurred.

Cluster analysis has been used to study a variety of different groupings. For example, Ogles and Masters (2003) used cluster analysis to define subgroups of marathon runners for descriptive purposes. Other studies, like Heppner et al. (1994) have used cluster analysis to distinguish clients based on their presenting problems at a university counseling center. This study identified subgroups of daughters of women who have been diagnosed with breast cancer for descriptive purposes and to identify interventions.

Another purpose of developing groupings based on cluster analysis in this study was to target interventions to different groups or individuals based on their own

personalities and coping styles. For example, helpfulness of information provided to therapy clients is hypothesized to differ among groups. Counselors can provide differing levels of information based on predisposition towards information.

Counseling interventions have been recommended in numerous studies addressing the trauma that daughters of breast cancer patients face (Wellisch & Hoffman, 1998, Wenzel & Robinson, 1995). One study found that high-risk women report 27% more psychological symptoms than other women, a level that justified psychological treatment (Kash et al. in Wellisch & Hoffman, 1998). Five common emotional states that relatives with an increased familial risk of developing breast cancer face are fear, denial, guilt, anger, and grief (Wellisch & Hoffman, 1998). Each of those emotions itself is enough to warrant therapy, but when combined, create an even more immediate need for therapeutic interventions. Often, mental health services are underutilized by daughters of breast cancer patients, so equipping counselors to help these individuals when they do seek out therapy is important.

Support groups are a valuable resource for relatives of breast cancer patients. The design of this study was chosen to help counselors assess the needs of women seeking support groups or group therapy and to effectively group them in ways that maximize the benefits of therapy. This study should also help therapists focused on individual therapy determine the most pressing concerns for their clients facing issues related to genetic disease, as well as set up a framework for conceptualizing daughters of women with breast cancer compared to other women in similar situations. Wenzel and Robinson (1995) found that group counseling can be effective for newly diagnosed gynecologic cancer patients, especially for those with serious mood disturbances. One aim of this

study was to set up a framework for future studies on group counseling with women at

risk for breast cancer. Implications for counseling different groups of women is provided

in the discussion of the results.

Chapter 5

Results

This chapter is divided into preliminary analyses, analysis of hypotheses and research questions, and additional analyses.

Preliminary Analyses

See Table 3 for means, standard deviations, and internal consistency values for each of the measures administered. All measures and subscales had adequate internal consistency.

Analysis of hypotheses and research questions

Question 1: How do natural groupings of women form with regards to their psychological adjustment to their mother's breast cancer and their own perceived risk of developing breast cancer?

This question was explored by using Ward's (1963) cluster analysis method. A factor analysis was conducted on the measures before the cluster analysis to see if the measures should be grouped. None of the variables were too highly correlated, so the cluster analysis was conducted using the variables themselves.

Cluster analysis. Ward's (1963) method was used to group those participants who had responded to all questions necessary for the cluster analysis (N= 136). The Ward method is included in the Statistical Package for the Social Sciences and is a common clustering method used in psychology. Clusters are constructed into related branches (pictorially represented by a dendrogram) from $n - 1$ clusters until they are all linked. In essence, the analysis begins by pairing together the two most similar participants, then adding new pairings, combining pairings into clusters, and combining

clusters into increasingly larger clusters. Thus, the clusters are created in such a way that within-cluster variability is minimized and between-cluster variability is maximized at each stage of grouping (Borgen & Barnett, 1987).

Examining the resulting dendogram and a graph of squared coefficient changes (similar to a Scree plot) clarified a six cluster solution. The graph of squared coefficient changes indicated that the largest changes in error began when a seven cluster solution was reduced to 6, therefore a 6 cluster solution was chosen. This method for determining the number of clusters was based on the technique used by Heppner et al. (1994).

MANOVA on cluster factors by cluster. To determine if the clusters were significantly different from one another, a MANOVA was conducted. The MANOVA suggests that the overall cluster model was significant, $F(45, 635) = 12.52$, $p < .001$. This significant response is not surprising, given that cluster analysis aims to separate participants into significant clusters. In this analysis, cluster membership served as the dependent variable. Tukey HSD post-hoc comparisons were used to control for the number of tests and to examine the differences between means. The results of those comparisons are shown in table 4.

Table 3: Means, Standard Deviations, and Internal Consistencies for Measures Used					
Measure	*Range*	*Scoring*	*Mean*	*SD*	*Alpha*
Adult Attachment Scale (AAS)	7-112	Likert range 1-7 (lower=more attachment[1])	40.29	18.79	0.96
Threatening Medical Situations Inventory- Monitoring	12-60	Likert range 1-5 (higher=greater use of strategies)	46.71	7.74	0.86
Threatening Medical Situations Inventory- Blunting	12-60	Same as above	39.38	7.45	0.83
Impact of Events Scale- Intrusion (IES)	7-28	Likert range 1-4 (higher= more intrusion)	17.53	5.31	0.89
Family Exposure to Cancer Rating (FECR)	4-28	Likert range 1-7 (higher=more exposure)	15.75	4.47	0.72
Perceived Risk of Breast Cancer	0-100	Open ended rating	56.77	24.95	N/A
Self Mastery Scale (SMS)	7-35	Likert range 1-5 (higher=more mastery)	26.35	4.54	0.77
State-Trait Anxiety Inventory (STAI)	20-80	Likert range 1-4 (lower=more anxiety[2])	39.85	8.97	0.91
Ways of Coping (WOC)	0-90	Likert range 0-3; Factor analysis scored into 4 subscales	65.42	14.65	0.89
Genetic Testing Likelihood	0-100	Open ended rating	46.36	37.22	N/A

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[1] For ease in understanding the data, this has been reversed in visual displays of the data so higher scores represent more attachment. This will be noted when it occurs.

[2] For ease in understanding the data, this has been reversed in visual displays of the data so higher scores represent more anxiety. This will be noted when it occurs.

Due to the nature of cluster analysis, between-cluster comparisons were significant on all variables. AAS: $F(5, 131) = 10.34$, $p < .001$; TMSI-monitoring: $F(5, 131) = 14.48$, $p < .001$; TMSI-blunting: $F(5, 131) = 7.65$, $p < .001$; IES-intrusion: $F(5, 131) = 14.89$, $p < .001$; FECR: $F(5, 131) = 21.18$, $p < .001$; Breast cancer likelihood prediction: $F(5, 131) = 27.52$, $p < .001$; SMS: $F(5, 131) = 18.26$, $p < .001$; STAI: $F(5, 131) = 16.34$, $p < .001$. The statistical significance of these between group differences is not surprising since they were the differences used to construct the clusters and thus, are a natural result of cluster analysis.

Cluster comparisons. Figure 1 shows how the 6 clusters differ on each of the 8 variables used in the cluster analysis. To distinguish between the groups, clusters that differed from the mean by ± 0.5 Z-score (a half standard deviation) were considered different than the others. Figure 1 shows a graphic representation of the differences between the clusters.

Table 4

Means, Standard Deviations, and Comparisons by Cluster[3]					
Name	N in cluster	Varaible	Mean (Z)	SD (Z)	Tukey comparisons
Cluster One	19	AAS	.46	.79	1>3. 1>5
		TMSI-M	-.28	.85	1<4. 1<5. 1<6
		TMSI-B	.22	.90	1>2
		IES-I	.43	.61	1<2. 1<6
		FECR	.67	.63	1>4. 1>5
		BC Lik	-1.36	.67	1<2. 1<3. 1<4. 1<5. 1<6
		SMS	.43	.74	1>2. 1>5
		STAI	.51	.54	1>2. 1>5
Cluster Two	21	AAS	.45	.51	2>3. 2>5
		TMSI-M	-.84	.79	2<4. 2<5. 2<6
		TMSI-B	-.55	1.02	2<1. 2<3. 2<6
		IES-I	.50	.91	2>1. 2>3. 2>5
		FECR	.26	.65	2>3. 2>5
		BC Lik	.21	.62	2>1. 2<4. 2>5
		SMS	-.81	.55	2<1. 2<3. 2<4. 2<5
		STAI	-1.05	.69	2<1. 2<3. 2<4. 2<6
Cluster Three	14	AAS	-.94	.97	3<1. 3<2. 3<4. 3<6
		TMSI-M	-.59	.73	3<4. 3<5. 3<6
		TMSI-B	.86	.47	3>2. 3>4. 3>5
		IES-I	-1.10	.61	3<2. 3<4. 3<5
		FECR	-.86	.42	3<1. 3<2. 3<4. 3<6
		BC Lik	.00	.79	3>1. 3<4
		SMS	.45	.52	3>2. 3>5
		STAI	.33	.72	3>2. 3>5
Cluster Four	32	AAS	.19	.66	4>3. 4>5
		TMSI-M	.33	.73	4>1. 4>2. 4>3
		TMSI-B	-.24	.83	4<3. 4<6
		IES-I	0.03	.79	4>3. 4<6
		FECR	-.11	.75	4<1. 4>3. 4>5. 4<6
		BC Lik	.94	.63	4>1. 4>2. 4>3. 4>5. 4>6
		SMS	.59	.62	4>2. 4>5. 4>6
		STAI	.43	.95	4>2. 4>5
Cluster Five	21	AAS	-.79	1.18	5<1. 5<2. 5<4. 5<6
		TMSI-M	.65	.56	5>1. 5>2. 5>3
		TMSI-B	-.25	.68	5<3. 5<6
		IES-I	-.19	.82	5<2. 5>3. 5<6
		FECR	-.90	.80	5<1. 5<2. 5<4. 5<6
		BC Lik	-.53	.90	5>1. 5<2. 5<4. 5<6
		SMS	-.30	.63	5<1. 5<3. 5<4
		STAI	-.64	.66	5<1. 5<3. 5<4. 5<6
Cluster Six	30	AAS	.19	.79	6>3. 6>5
		TMSI-M	.42	.71	6>1. 6>2. 6>3
		TMSI-B	.45	.87	6>2. 6>4
		IES-I	.75	.72	6>1. 6>3. 6>4. 6>5
		FECR	.73	.78	6>3. 6>4. 6>5
		BC Lik	.01	.71	6>1. 6<4. 6>5
		SMS	.12	.50	6>2. 6<4
		STAI	.00	.65	6>2. 6>5

[3] AAS and STAI scoring reversed here and in Figure 1.

Figure 1: 6 Cluster Solution
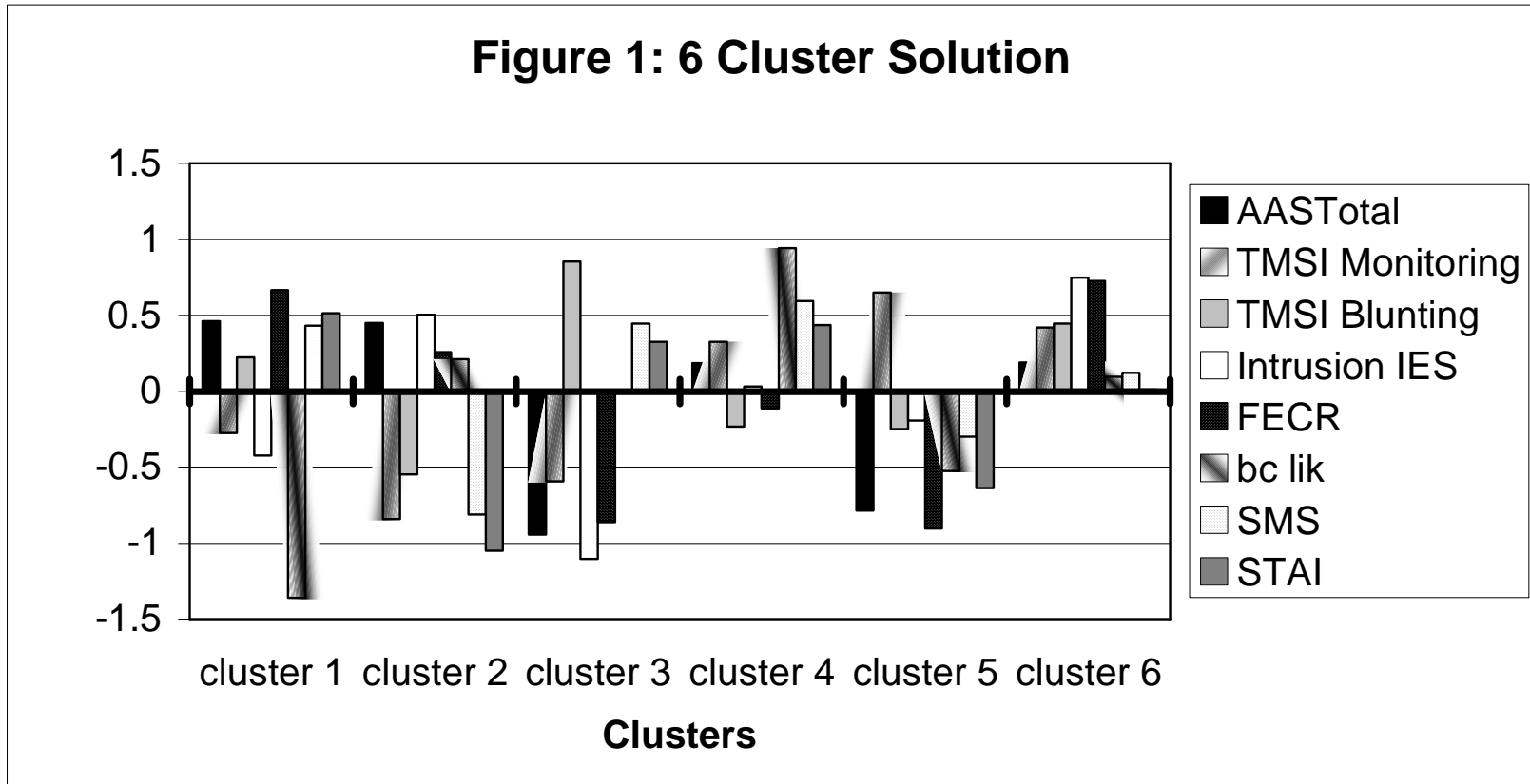
Participants in Cluster One (N=19) were significantly less likely to think they were going to get breast cancer in their lifetime, and had the highest levels of anxiety of all of the clusters. This group had high scores on the Adult Attachment Scale and high scores on the Family Exposure to Cancer Rating, thus indicating that their level of involvement in their mother's treatment and diagnosis process corresponded with the level of closeness they felt to their mothers. Because their relationships with their mothers were so strong and they were the least likely to think they were going to get breast cancer yet the most anxious, this group was named the *Conflicted Impermeables*.

The second cluster (N=21) had low monitoring and blunting scores as well as low self mastery and low anxiety. The significantly low self mastery scores combined with low anxiety scores led this group to be named the *Adaptive Externalizers*.

Cluster Three (N=14) daughters had low levels of emotional closeness with their mothers and high scores on the blunting scale but low levels of monitoring, intrusion, and exposure to cancer. The low closeness scores and low involvement in treatment scores as well as the low monitoring and intrusion scores helped define this group as the *Distanced Blunters*.

The participants in Cluster Four (N=32) had the highest perceived likelihood of breast cancer for themselves and high levels of self mastery. All other scores fell close to the mean. Hence, this group was named the *Threatened Controllers*.

In Cluster Five (N=21), the participants had low exposure to cancer, low anxiety, and low levels of perceived risk of breast cancer. They had low levels of closeness with

their mothers and tended to be monitors. Because their anxiety and threat was low, they were named the *Healthy Monitors*.

Finally, the members of Cluster Six (N=30) had high levels of intrusion and high exposure to cancer, with trends of high monitoring and blunting. This group had the highest scores on the Family Exposure to Cancer Rating and highest levels of intrusion. Those facts led this group to be named the *Ruminating Caretakers*.

External variable ANOVAs. Clusters were compared on other variables to determine if significant differences existed between clusters. Chi-square tests indicated that demographic variables were not significant across clusters. Those included race/ethnicity (white vs. non-white), χ^2 (5, N=137)= 4.63, p= 0.46; education level (less than college vs. some college or beyond), χ^2 (5, N=137)= 7.59, p= 0.18; income (under $20,000, $20,000-$40,000, $40,000-$60,000, and $60,000 and above), χ^2 (15, N=137)= 12.57, p= 0.64; mother's age at diagnosis (under 50 vs. 50 or above), χ^2 (5, N=137)= 10.25, p= 0.07; and whether their mothers were living or deceased, χ^2 (5, N=137)= 5.50, p= 0.36. Other chi-square analyses revealed no significant differences in whether the daughters had children of their own (one or more child vs. no children), χ^2 (5, N=136)= 3.94, p= 0.56; whether the daughters had moved to be closer to their mothers, χ^2 (5, N=135)= 6.16, p= 0.29; whether the daughters reported that their mother's breast cancer affected their life decisions, χ^2 (5, N=135)= 6.64, p= 0.25; and whether the daughters themselves had already undergone genetic testing for BRCA1/2, χ^2 (5, N=135)= 3.35, p= 0.65.

One-way ANOVAs were then conducted on continuous (or nearly continuous variables) that were categorized for the above chi-square analyses to further examine the

differences between the clusters. When the non-significant categorical demographic data were analyzed using continuous categories, some significant differences emerged. Three separate one-way ANOVAs that were conducted on education level, age, and mother's age at diagnosis were found to be significant. Age: $F(5, 131) = 6.23$, $p < .001$; education level: $F(5, 131) = 3.37$, $p < .007$; and age of mother at diagnosis: $F(5, 131) = 2.77$, $p < .021$. Tukey HSD post-hoc analysis revealed that there were significant differences between clusters (See Table 5). No other significant differences emerged when conducting the one-way ANOVAs on demographic variables. This inclded income: $F(5, 131) = 0.457$, $p = .81$; years since mother's diagnosis $F(5, 131) = 1.78$, $p = .12$; and interest in genetic testing $F(5, 131) = 1.99$, $p = .085$. See Figure 2 for a representation of these differences by cluster.

Construct validity. Borgen and Barnett (1987) recommend leaving several variables out of the cluster analysis in order to test for differences between the clusters after they have been formed. The Ways of Coping (WOC) factors and the demographic variables were kept out of the cluster analysis. In order to score the Ways of Coping, a factor analysis was conducted.

A principal-axis factor analysis with a Varimax rotation was conducted on the 30-item Ways of Coping scale based on the scoring guidelines set forth in other studies (Parker, Endler, & Bagby, 1993). The Kaiser-Meyer Olkin (KMO) index was .85, indicating that these 30 items were sufficiently intercorrelated to justify a factor analysis. Tabachnick and Fidell (1996) suggested that the KMO Index should be above .60. The initial factor analysis revealed 8 factors with eigenvalues of 1.0 or greater (8.53, 3.46, 2.39, 1.52, 1.33, 1.16, 1.08, 1.00), which accounted for 68.24% of the entire variance.

Examining the scree plots for three, four, five, six, seven, and eight factor solutions led to the conclusion that a four-factor solution was the best fit. Previous studies using the Ways of Coping have shown factor models with four, six, and eight factor solutions (Parker, Endler, & Bagby, 1993). Factor loadings were determined for each of the items on the Ways of Coping Scale (See Table 6).

Table 5: Significant Differences Between Clusters on other variables

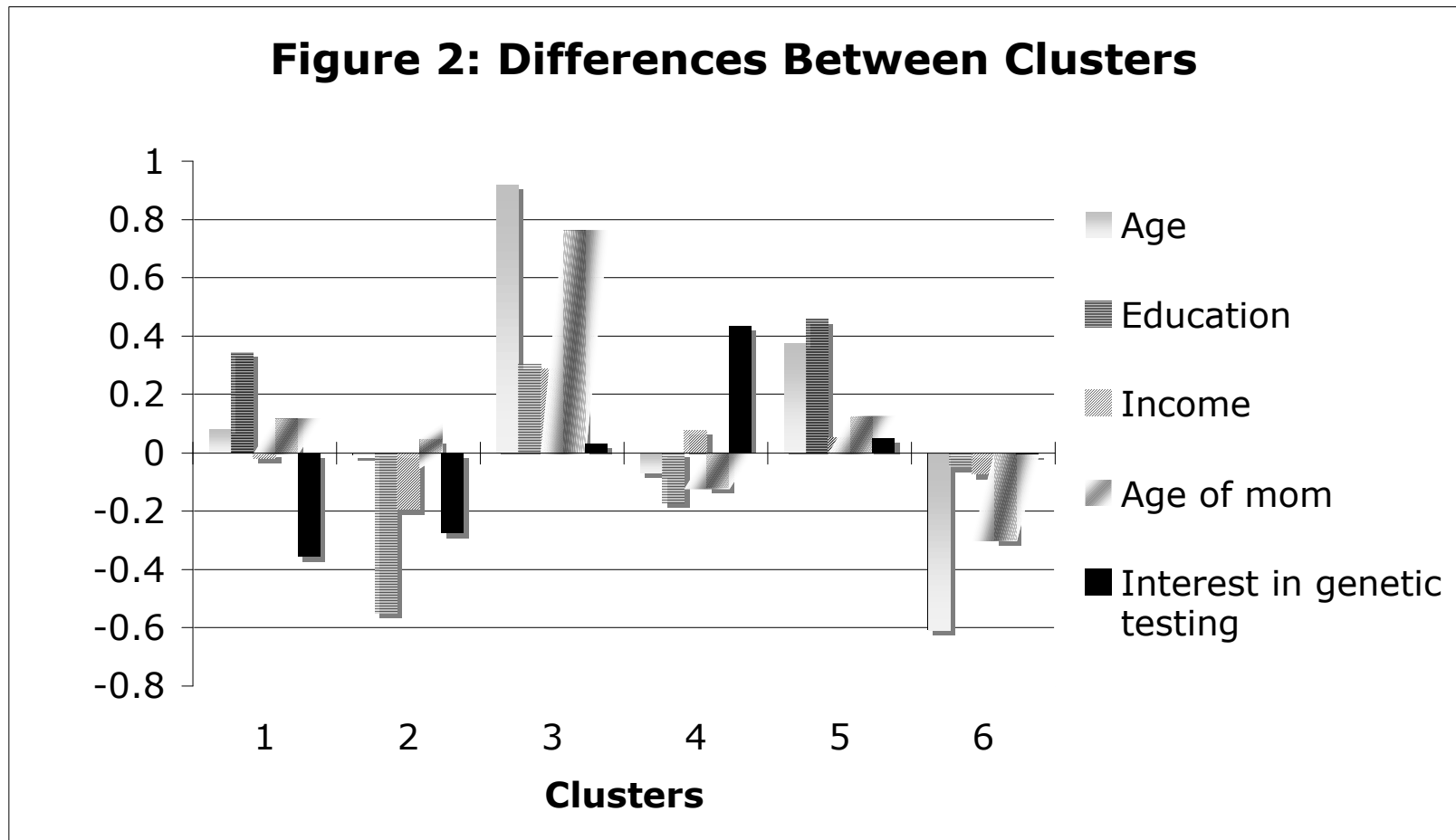| Cluster	Participant's Age	Mother's Age at Diagnosis	Education Levels
1	No significant differences	No significant differences	1>2
2	2<3	No significant differences	2<1, 2<5
3	3>2, 3>4, 3>6	3>4, 3>6	No significant differences
4	4<3	4<3	No significant differences
5	5>6	No significant differences	5>2
6	6<3, 6<5	6<3	No significant differences

Figure 2: Differences Between Clusters

Figure 2a: Differences on WOC factors
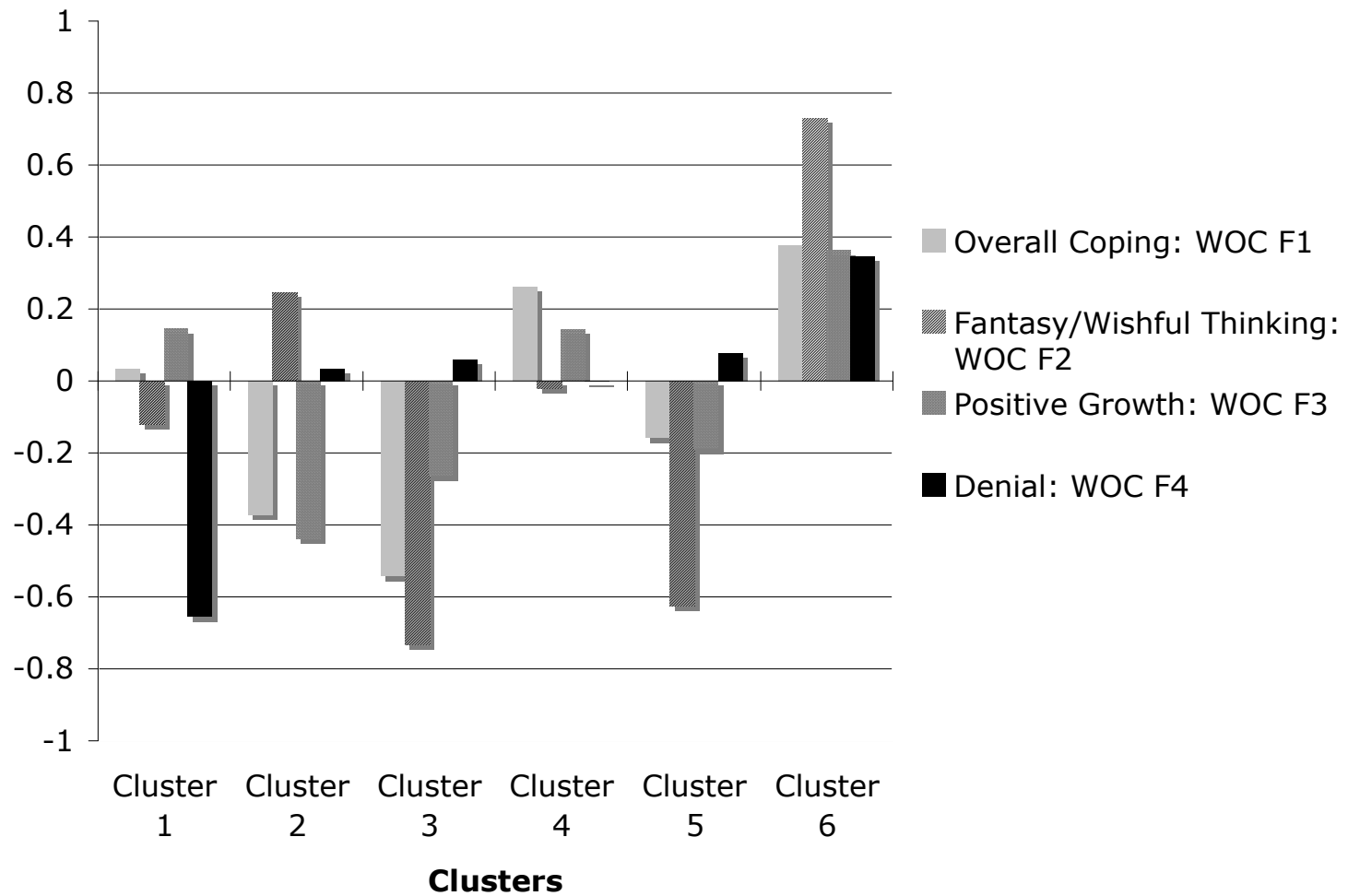
To distinguish the factors, the qualification that an item needed to have a loading of at least 0.4 on one factor with a difference of at least 0.1 from the next highest factor was chosen, but items were not included on multiple factors. The loadings were determined for the four-factor solution (See Table 7). Based on the items that loaded on each factor, names were assigned to each of the factors based on the similar characteristics of the items that loaded highly on each factor (See Table 8).

Typical of other factor analyses, Factor One (overall coping) included a large number of items that seem to represent the overall construct being measured (21, 19, 22, 17, 18, 3, 15, 20, 23, 13, 16) with an internal consistency of $\alpha =0.90$. Factor Two (fantasy/wishful thinking) primarily included items based in magical thinking, wishing the problem away, or fantasy (27, 28, 26, 25, 4, 1, 29, 8) with an internal consistency of $\alpha=0.89$. Factor Three (positive growth) included items with a positive perspective (11, 7, 30, 9, 14) with an internal consistency of $\alpha=0.80$. Studies have found that post-traumatic growth is a common after-effect of disease (Tedeschi & Calhoun, 1995) and the emergence of Factor Three on the Ways of Coping factor analysis seems to support those findings. Factor Four (denial) consisted of items related to denial, waiting, and forgetting (12, 6, 2, 10, 24) with an internal consistency of $\alpha=0.65$. The resulting four-factor solution accounted for 53.03% of the variance. Internal consistency was assessed on the overall 29-item measure and was found to be $\alpha=0.89$.

As indicated by the above one-way ANOVAs, significant differences between clusters on age, mother's age at diagnosis, and education levels were found. Significant differences also exist between the clusters on their scores on the Ways of Coping

measure. One way ANOVAs indicated significant differences in Factor One: $F(5, 126) =$ 2.90, $p < .016$; Factor Two: $F(5, 127) = 8.36$, $p < .001$; and Factor Four: $F(5, 129) = 2.50$, $p < .034$. No significant differences exist on Factor Three: $F(5, 129) = 2.17$, $p < .06$. See Table 9 for those differences.

The six clusters were differentiated by their coping styles in a number of ways. Specifically, Factor Two (fantasy/wishful thinking) was most different by cluster. The members of Cluster Three (*Connected Blunters*) and Cluster Five (*Healthy Monitors*) used significantly fewer fantasy-oriented coping skills while Cluster Six (*Ruminating Caretakers*) used many more fantasy-oriented coping skills than other clusters. Additionally, participants in Cluster One (*Conflicted Impermeables*) used much less denial to cope than other clusters.

Table 6: Factor Loadings for Ways of Coping by item	F1	F2	F3	F4
1. I went over the situation or event again and again in my mind to try and understand	.32	.65	.11	-.07
2. I felt that time would make a difference and the only thing to do was to wait.	-.02	.13	.24	.60
3. Talked to someone to find out more about the situation.	.62	.45	.13	-.01
4. Hoped a miracle would happen.	.06	.75	.25	-.11
5. Went along with fate; sometimes I just have bad luck.	-.01	.03	-.14	.33
6. I went on as if nothing had happened.	-.26	-.07	-.11	.67
7. Looked for the silver lining, so to speak, tried to look for the bright side of things.	.14	.09	.60	.28
8. Tried to seek out sympathy.	.24	.47	-.06	.19
9. Tried to do something creative.	.31	.16	.52	.08
10. Tried to forget the whole thing.	-.32	.17	.00	.58
11. Tried to make changes in a good way.	.34	.11	.69	-.04
12. Decided to wait and see what would happen.	-.08	-.19	.24	.69
13. Tried to come up with a plan of action.	.56	.13	.46	-.15
14. Did not go with my first hunch.	.08	.25	.52	-.16
15. Tried to let feelings out.	.59	.23	.20	-.06
16. Decided to rediscover life.	.49	.12	.44	-.18
17. Asked a friend what s/he thought.	.66	.30	.05	-.07
18. Decided to try to change something.	.63	.10	.40	-.14
19. Talked to someone about how I was feeling.	.71	.38	-.04	-.05
20. Drew on past experience.	.57	-.08	.27	-.09
21. Thought about what could be done.	.77	.11	.21	-.08
22. Considered different solutions.	.70	.03	.37	-.09
23. Tried to accept the situation.	.56	-.09	.03	.40
24. Tried to keep my feelings from interfering with other things too much.	.34	.26	-.11	.56
25. Wished that I could change what had happened or how I felt.	.12	.78	-.04	.09
26. I daydreamed or imagined a better time.	.03	.79	.26	-.07
27. Wished that the situation would go away or somehow be over with.	.01	.84	-.03	.18
28. Had fantasies or wished about how things might turn out.	.09	.81	.31	.03
29. I went over in my mind what I would say or do.	.20	.54	.39	.09
30. Tried to see other perspectives.	.49	.06	.53	.09

Table 7: Factor Loadings for Ways of Coping by factor	F1	F 2	F 3	F 4
Factor One				
21. Thought about what could be done.	.77	.11	.21	-.08
19. Talked to someone about how I was feeling.	.71	.38	-.04	-.05
22. Considered different solutions.	.70	.03	.37	-.09
17. Asked a friend what s/he thought.	.66	.30	.05	-.07
18. Decided to try to change something.	.63	.10	.40	-.14
3. Talked to someone to find out more about the situation.	.62	.45	.13	-.01
15. Tried to let feelings out.	.59	.23	.20	-.06
20. Drew on past experience.	.57	-.08	.27	-.09
23. Tried to accept the situation.	.56	-.09	.03	.40
13. Tried to come up with a plan of action.	.56	.13	.46	-.15
16. Decided to rediscover life.	.49	.12	.44	-.18
Factor Two				
27. Wished that the situation would go away or somehow be over with.	.01	.84	-.03	.18
28. Had fantasies or wished about how things might turn out.	.09	.81	.31	.03
26. I daydreamed or imagined a better time.	.03	.79	.26	-.07
25. Wished that I could change what had happened or how I felt.	.12	.78	-.04	.09
4. Hoped a miracle would happen.	.06	.75	.25	-.11
1. I went over the situation or event again and again in my mind to try and understand it.	.32	.65	.11	-.07
29. I went over in my mind what I would say or do.	.20	.54	.39	.09
8. Tried to seek out sympathy.	.24	.47	-.06	.19
Factor Three				
11. Tried to make changes in a good way.	.34	.11	.69	-.04
7. Looked for the silver lining, so to speak, tried to look for the bright side of things.	.14	.09	.60	.28
30. Tried to see other perspectives.	.49	.06	.53	.09
9. Tried to do something creative.	.31	.16	.52	.08
14. Did not go with my first hunch.	.08	.25	.52	-.16
Factor Four				
12. Decided to wait and see what would happen.	-.08	-.19	.24	.69
6. I went on as if nothing had happened.	-.26	-.07	-.11	.67
2. I felt that time would make a difference and the only thing to do was to wait.	-.02	.13	.24	.60
10. Tried to forget the whole thing.	-.32	.17	.00	.58
24. Tried to keep my feelings from interfering with other things too much.	.34	.26	-.11	.56
Eliminated				
5. Went along with fate; sometimes I just have bad luck.	-.01	.03	-.14	.33

Table 8: Names of the Ways of Coping Factors	
Factor One	Coping
Factor Two	Fantasy/wishful thinking
Factor Three	Positive growth
Factor Four	Denial

Table 9: Differences Between Clusters on the Ways of Coping factors

Cluster	Factor One: Coping	Factor Two: Fantasy/Wishful Thinking	Factor Three: Positive Growth	Factor Four: Denial
1	No significant differences	1<6	No significant differences	1<6
2	No significant differences	2>3, 2>5	No significant differences	No significant differences
3	3<6	3<2, 3<6	No significant differences	No significant differences
4	No significant differences	4<6	No significant differences	No significant differences
5	No significant differences	5<2, 5<6	No significant differences	No significant differences
6	6>3	6>1, 6>3, 6>5	No significant differences	6>1

Additional analyses.

In addition to the cluster analysis, further analysis was conducted on the data. The following information was used for the analysis of the hypotheses and exploration of the sample. Frequency data were collected and it was noted that a majority of the mothers were still living (71.5% still living) and that few daughters had undergone genetic testing (3.70% had been tested). The sample was predominantly white (126) with 2 Indian/Pakistani, 2 Black, 4 Hispanic, 2 Middle Eastern/Arab, and 2 Other respondents. Overall, only 8.02% of the sample was non-white. The participants in the study were fairly well educated and affluent with 116 (84.67%) reporting at least some 4-year college and 97 (70.80%) reporting a personal income of at least $20,000 per year. Sixty-two participants (45.59%) had biological children of their own. Fourteen (10.37%) daughters indicated that they moved to be closer to their mothers and 39 (28.89%) said their mother's breast cancer had affected their personal life decisions. See Table 10 for correlations of these data with the measures used in the study.

Analysis of Hypotheses

Hypothesis 1: Daughters whose mothers are deceased will report more distress than daughters whose mothers are still alive.

Survival status of the mother was set up as a dichotomous variable and compared to the other continuous variables listed below using a point-biserial correlation. In the sample, 72% of the mothers were still living and 28% were deceased.

Hypothesis 1a: Daughters whose mothers are deceased will report higher levels of intrusive thoughts than daughters whose mothers are still alive.

This hypothesis was tested by examining the point-biserial correlation between the mother's survival status (living or deceased) and the Impact of Events intrusion subscale score (IES) (Horowitz, Wilner, & Alvarez, 1979). As indicated in Table 10, no significant relationship was found.

Hypothesis 1b: Daughters whose mothers are deceased will report higher predicted likelihoods of their own risk of breast cancer than daughters whose mothers are still alive.

This hypothesis was tested by examining the point-biserial correlation between the mother's survival status (living or deceased) and the likelihood score (0-100%) that a participant

estimated as their lifetime risk of developing breast cancer. As indicated in Table 10, no significant relationship was found.

Hypothesis 1c: Daughters whose mothers are deceased will report more general anxiety than daughters whose mothers are still alive.

This hypothesis was tested by examining the point-biserial correlation between the mother's survival status (living or deceased) and the score on the trait section of the State Trait Anxiety Inventory State-Trait Anxiety Inventory (STAI-T) (Spielberger, Gorsuch, Lushene, 1970). As indicated in Table 10, no significant relationship was found.

Hypothesis 2: Daughters who report more contact with their mothers during the diagnosis and treatment of their mother's breast cancer will report more distress than daughters who had less contact with their mothers.

Contact scores were taken from the Family Exposure to Cancer Rating Scale (FECR) (Boyer et al., 2002).

Hypothesis 2a: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively correlated with intrusive thoughts.

This hypothesis was tested by examining the Pearson r correlation between the contact score from the FECR (Boyer et al., 2002) and the Impact of Events intrusion subscale (IES); (Horowitz, Wilner, & Alvarez, 1979) score. As indicated in Table 10, contact with mothers during breast cancer significantly correlated with intrusion (r=0.27; $p < 0.01$) such that daughters who had more contact with their mothers reported higher levels of intrusion than daughters who reported less contact.

Hypothesis 2b: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively related to their own predicted likelihood of developing breast cancer.

This hypothesis was tested by examining the Pearson r correlation between the contact score from the FECR (Boyer et al., 2002) and the likelihood score (0-100%) that a participant estimates is her lifetime risk of developing breast cancer. As indicated in table 10, no significant relationship was found.

Hypothesis 2c: Daughters reported amount of contact with their mothers during the diagnosis and treatment of their mother's breast cancer will be positively correlated with general anxiety.

This hypothesis was tested by examining the Pearson r correlation between the contact score from the FECR (Boyer et al., 2002) and the score on the trait section of the STAI-T (Spielberger, Gorsuch, Lushene, 1970). As indicated in Table 10, no significant relationship was found.

Table 10: Correlation Matrix[4]

	AAS	tmsim	tmsib	age	educ	inc	yrs si	kids	IES-I	FECR	SMS	bc lik	gt int	STAI	status	F1	F2	F3	F4	tmsi
AAS	1.00																			
tmsim	-.067	1.00																		
tmsib	-.095	**.208**	1.00																	
age	**-.185**	-.075	.162	1.00																
educ	**-.184**	.140	-.015	.041	1.00															
inc	-.121	.049	.100	**.187**	_.295_	1.00														
yrs si	-.017	.054	-.035	_.520_	.080	.053	1.00													
kids	.050	-.008	-.045	_-.547_	.161	.019	_-.290_	1.00												
IES-I	_.250_	_.235_	-.038	_-.252_	-.086	.006	-.066	.006	1.00											
FECR	**.175**	.015	.163	-.088	**-.181**	.003	-.015	-.037	_.266_	1.00										
SMS	.049	_.228_	_.321_	.102	.166	.124	.119	-.075	.127	_.234_	1.00									
bc lik	-.047	.013	-.085	-.127	_-.279_	-.086	-.071	.030	.155	.070	.027	1.00								
gt int	-.039	.163	.063	-.055	-.107	.050	.029	.050	-.006	-.074	.137	**.175**	1.00							
STAI	-.108	-.040	**-.190**	-.075	-.029	-.120	-.076	.146	**.204**	-.008	**-.184**	.064	.008	1.00						
status	**.167**	.035	-.099	_.299_	-.079	.084	_.396_	_-.258_	.154	.091	.120	-.052	-.030	-.039	1.00					
F1	_.222_	_.310_	.150	.042	.091	_.229_	-.139	-.092	_.427_	**.180**	_.303_	-.015	**.175**	-.131	.075	1.00				
F2	_.377_	**.183**	-.041	_-.303_	-.116	.028	-.070	.093	_.668_	_.277_	-.061	.127	.171	.082	**.184**	_.507_	1.00			
F3	**.178**	_.238_	_.284_	.058	.024	**.212**	-.059	-.150	_.302_	**.202**	_.283_	-.017	**.181**	-.155	.046	_.804_	_.443_	1.00		
F4	_-.220_	-.141	**.214**	-.080	.019	.133	-.080	.064	.043	-.114	.033	.043	.087	.059	-.087	.061	.100	.105	1.00	
tmsi	-.104	_.791_	_.756_	.055	.090	.094	.014	-.036	.134	.111	_.350_	-.045	.148	-.144	-.042	_.324_	.103	_.362_	.042	1.000

Key to abbreviations in Table 10: AAS (Adult Attachment Scale); Tmsim (Threatening Medical Situations Inventory-Monitoring); Tmsib (Threatening Medical Situations Inventory-Blunting); Age (age of participant); Educ (participant's education level); Yrs (Years since mother's diagnosis); Kids (does the participant have children?); IES-I (Impact of Events Scale-Intrusion); FECR (Family Exposure to Cancer Rating); SMS (Self Mastery Scale); BC lik (estimated likelihood of breast cancer); GT int (interest in genetic testing); STAI (State-Trait Anxiety Inventory); Status (Mother alive or deceased); F1 (Coping, WOC Factor One); F2 (Fantasy/ Wishful Thinking, WOC Factor Two); F3 (Positive growth, WOC Factor Three); F4 (Denial, WOC Factor Four); Tmsi (Threatening Medical Situations Inventory-total); Correlations significant at the p < .05 level shown in bold and correlations significant at the p < .01 level shown in underlined *italics*.

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[4] AAS and STAI reversed here

Hypothesis 2d: Daughters reported amount of contact with their mothers during the diagnosis and treatment of her breast cancer willbe positively correlated with personal control.

This question was tested by examining the Pearson r correlation between the contact score from the FECR (Boyer et al., 2002) and the total score on the Self Mastery Scale (Pearlin & Schooler, 1978). As indicated in Table 10, more contact with mothers significantly correlated with mastery (r=0.23; $p < 0.01$) such that daughters who had more contact with their mothers reported higher levels of mastery than daughters who reported less contact. The hypothesis was supported.

Hypothesis 3: Daughters who report less personal control will report being less likely to have a strong interest in getting a genetic test than daughters who report more personal control.

This hypothesis was tested by examining the Pearson r correlation between the total score on the Self Mastery Scale (Pearlin & Schooler, 1978) and the interest (0-100) that a participant shows in getting a genetic test. As indicated in Table 10, no significant relationship was found.

Hypothesis 4: Daughters' threat of getting breast cancer will be positively related to intrusive thoughts.

This hypothesis was evaluated by using the breast cancer likelihood rating as an indicator of threat as well as scores on the Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996).

Hypothesis 4a: Daughters' perceived threat of getting breast cancer will be positively correlated with intrusive thoughts.

This hypothesis was tested by examining the Pearson r correlation between the likelihood score (0-100%) that a participant estimates is her lifetime risk of developing breast cancer and the Impact of Events intrusion subscale score (IES) (Horowitz, Wilner, & Alvarez, 1979). As indicated in Table 10, no significant relationship was found.

Hypothesis 4b: Daughters threat level will be positively correlated with intrusive thoughts.

This hypothesis was tested by examining the Pearson r correlation between the scores on the Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996) and the scores on the Impact of Events Intrusion subscale (IES) (Horowitz, Wilner, & Alvarez, 1979). The subscales of the TMSI were significantly correlated with each other. As indicated in Table 10, threat monitoring was significantly correlated with threat blunting (r=0.21; $p < 0.05$) such that participants who scored highly on the TMSI monitoring scale were more likely to score highly on the TMSI blunting scale than those participants who did not. As indicated in Table 10, threat monitoring was significantly correlated with intrusion (r=0.24; $p < 0.01$) such that individuals who scored highly on the TMSI monitoring scale were more likely to score highly on the IES intrusion scale. The total scores on the IES and the TMSI were not significantly correlated with each other, as indicated in Table 10.

Research Questions

Question 2: Do daughters who were more involved with their mother's medical decision making and information gathering processes report more distress than daughters who were removed from the process?

Scores for involvement in medical decision making and information gathering were taken from the Family Exposure to Cancer Rating (FECR) (Boyer et al., 2002).

Question 2a: Do daughters who were more involved with the medical decision making and information gathering processes report more intrusive thoughts than daughters who were removed from the process?

This question was tested by examining the Pearson r correlation between the involvement score on the FECR scale and the score on the IES Intrusion subscale. Examining the correlation between the FECR involvement score (question 4 on the FECR) and the IES-I subscale yielded no significant relationships (r=0.06 FECR 4 with IES intrusion, not shown in Table 10 since it is just one question on the measure), however the overall FECR score was significantly related to the IES intrusion score. As indicated in Table 10, contact with mothers during breast cancer was significantly correlated with intrusion (r= 0.27, $p < 0.01$) such that daughters who had more contact with their mother reported higher levels of intrusion than daughters who reported less contact.

Question 2b: Do daughters who were more involved with the medical decision making and information gathering processes report higher predicted likelihoods of their own risk of breast cancer than daughters who were removed from the process?

This question was tested by examining the Pearson r correlation between the involvement score on the FECR scale and the likelihood score (0-100%) that a participant estimates is her lifetime risk of developing breast cancer. No significant relationship was found (r= -0.02, not shown in Table 10).

Question 2c: Do daughters who were more involved with the medical decision making and information gathering processes report higher levels of general anxiety than daughters who were removed from the process.

This question was tested by examining the Pearson r correlation between the involvement score on the FECR scale and the score on the trait section of the State Trait Anxiety Inventory. No significant relationship was found (r= -0.11, not shown in Table 10).

Chapter 6

Discussion

This chapter presents a discussion of the results of the hypotheses and research

questions. Limitations of the study, implications of the results, possible conclusions, and

reflections about the study also are presented in this section.

Hypotheses and Research Questions

Question 1: How do natural groupings of women form with regards to their

psychological adjustment to their mother's breast cancer and their own perceived risk of

developing breast cancer?

The six clusters that resulted from the cluster analyses appear to tap into six

different ways that daughters of women with breast cancer react to their mother's

diagnosis. Generally, the groups seem to present six different prototypes of reactions that

one might have to a mother's breast cancer. Perhaps the implications extend beyond

breast cancer. These results may compare to how an individual might react when a

family member (of any degree relation) is diagnosed with a genetic disease and may also

correspond to reactions to non-genetic diseases as well. The implications of these

groupings are helpful for counselors to consider when they are working with daughters of

women with breast cancer.

Recognizing that simplifying data removes some of the richness of the data, and

generalizing the reactions of a member of a cluster surely will not capture the entire

breadth of the experience of these daughters of women with breast cancer, the discussion

of the characteristics of each cluster should be considered a broad generalization used for

the purposes of understanding the clusters better. With that in mind, I have attempted to

simplify each cluster by naming it. I will also include a word or quote that seems to represent each cluster, but those names and titles should not be misconstrued to represent the entirety of the experiences that these women go through.

The members of Cluster One, the *Conflicted Impermeables*, showed contradictory results. They had high emotional attachment to their mothers and had a lot of contact with their mothers during treatment and diagnosis. These daughters were least likely to think they were going to get breast cancer but showed the highest levels of anxiety. Interestingly, these seemingly conflicting results were not just minor, the disparity between their scores was greater than most of the other groups. For example, Cluster One had the highest scores on anxiety and the lowest scores on their likelihood of getting breast cancer. Comparisons on other variables revealed that Cluster One had significantly lower scores on Factor Four (denial) of the Ways of Coping Scale than other groups. Although this difference was not statistically different from that of the other groups, a trend of less interest in genetic testing was present when compared to the other clusters.

The results for these *Conflicted Impermeables* indicate a presence of invincibility. These daughters are highly anxious but also state that they believe they have a low chance of getting breast cancer in their lifetimes, a potential contradiction. This may reflect that their reported anxiety is unrelated to the possibility that they may get cancer; or, that they are disconnected or in denial over the anxiety they are experiencing related to their cancer risk. Counseling treatment ideas for *Conflicted Impermeables* include assisting them in more accurately assessing their feelings of threat, reducing anxiety, and addressing contradictory feelings.

The *Adaptive Externalizers* in Cluster Two reported less monitoring and blunting than other groups. These daughters also had low anxiety and low scores of self mastery. These results indicate that *Adaptive Externalizers* were using coping techniques that tend to be different from those used by the other groups. However, their significantly low anxiety scores indicate that their strategies seem to be working for them because of their low levels of anxiety. The *Adaptive Externalizers* had significantly less education than the other groups. Members of Cluster Two appear to externalize their experiences and not to claim a lot of control over their situation. The women in this category may have a tendency to place the blame and strain of their mother's breast cancer on other people.

A way to describe this group is the "head in the sand" or "ignorance is bliss" group. Their avoidance of their mother's breast cancer is adaptive; however, they do not spend time considering how their mother's situation may affect their own health or considering other implications of their mother's breast cancer for their own lives.

Counseling implications for the *Adaptive Externalizers* would include assessing how their coping strategies are working for them in combination with those around them. The potential exists for these *Adaptive Externalizers* to burden other people with their concerns, which may create interpersonal difficulties. Also, if these daughters are avoiding the reality of breast cancer in their families, considering the effects of their mother's breast cancer may be helpful to them. Assessing their use of health protective behaviors and encouraging them to monitor their health, if they are not already doing so, may be important as well.

Contrasted with Cluster Two are the Cluster Three *Distanced Blunters*. This group seemed to want nothing to do with their mother's breast cancer, as illustrated by

their low levels of intrusion, monitoring, blunting, and exposure to cancer. These daughters were significantly less close to their mothers when compared with the other groups, perhaps indicating that their distant relationship with their mothers makes confronting the realities of their mother's breast cancer less important to them than other groups. This group was also older than the other groups (an average age of 47 versus the overall average of 37). They had lower scores on Factor One (overall coping) and Factor Two (fantasy/wishful thinking) of the Ways of Coping Scale than the other groups. These low coping scores could indicate a lack of coping or, conversely, a lack of need for coping. Though it was not a significant difference, the length of time since their mother's diagnosis was longer for *Distanced Blunters* than any other group (13.2 years versus an average of 9.9 years for the other groups). Thus, an alternate explanation for the results of the *Distanced Blunters* is that they are not exhibiting monitoring or reporting intrusion related to their mother's breast cancer because the diagnosis occurred in the distant past and they are not in distress over their mother's cancer at this time. Perhaps their distance from their mothers can be explained by their age and the length of time since their mother's diagnosis.

A word that might describe the individuals in *Distanced Blunters* is remote. Their low levels of emotional attachment with their mothers and low levels of intrusion, monitoring, and blunting may indicate that, if they feel the need to cope at all, they are doing it by themselves instead of in conjunction with their mothers. Perhaps their low attachment serves as an advantage for their emotional reactions to their mother's breast cancer. Low emotional attachment with one's mother may serve as a protective advantage for the daughter's well-being.

To work with this group in a therapeutic setting, analyzing if they have residual negative feelings about their mother's breast cancer and assessing how they handle any current implications of their mother's illness would be important. Their emotional distance from their mothers should be assessed, if it is relevant for their lives.

The *Threatened Controllers* of Cluster Four present as a more straightforward group. They had the highest predicted likelihood of breast cancer for themselves and high levels of self mastery. The results indicate that *Threatened Controllers* like to take action, as is represented by their scores on the interest in genetic testing inventory. The *Threatened Controllers*' scores were higher than the scores of any other cluster. The *Threatened Controllers* appeared close to average on all other variables except their perceived likelihood of breast cancer, interest in genetic testing, and high self mastery, their three defining characteristics.

Control appears to be the central feature for this cluster. The *Threatened Controllers* are attempting to control their own risk of breast cancer. These daughters want to have as much control over their situation as possible so they can handle the realities of breast cancer on their own terms. Counseling implications for this group would be understanding the importance of control for these *Threatened Controllers* and assisting them in finding other ways of coping with their mother's breast cancer and their own threat for the disease. Additionally, helping these individuals visualize how a lack of control would affect them would be important.

Cluster Five individuals are *Healthy Monitors*. This group seems to be taking their mother's breast cancer in stride, as evidenced by their low levels of anxiety and low perceived risk of breast cancer. Their distance from their mothers and their high levels of

monitoring indicate that they are aware of the reality of breast cancer but are handling

that reality it in a way that may be beneficial for them. The *Healthy Monitors* are aware

of their mother's breast cancer, as indicated by their low scores on Factor Two

(fantasy/wishful thinking) of the Ways of Coping Scale, and are not using avoidant

coping strategies.

The adages "one day at a time," and "I'll cross that bridge when I come to it,"

seem applicable to the *Healthy Monitors*. Counseling implications for the *Healthy*

Monitors include helping them to maintain adequate levels of monitoring without

interfering with their well-being. Also, encouraging them to accurately assess their risks

and vulnerabilities may be important since they present as a rather laid back group.

Cluster Six, the *Ruminating Caretakers*, have high levels of intrusion and

exposure to cancer as well as high monitoring and blunting. This group is significantly

higher on the denial, overall coping, and fantasy scales of the WOC than other cluster

groups. They scored high on many measures of distress. This group had the highest

scores on the FECR scale, indicating their higher levels of caretaking and involvement in

their mother's cancer. These daughters also were significantly younger than the average.

In general, the *Ruminating Caretakers* appear to have a lot going on. They seem

to be spinning a number of different plates and juggling responsibilities. One has the

sense that the *Ruminating Caretakers* are grasping at straws to find ways of coping, as

indicated by their high scores on so many measures. The *Ruminating Caretakers* appear

to be attempting to do everything they can to deal with their situation. These daughters

seem to have a lot going on in their heads. Their significantly high scores on Factor Two

(fantasy/wishful thinking) of Ways of Coping Scale represents their active minds. Due to

their active fantasy lives, high levels of intrusion, monitoring, and blunting, this group can be called cogitators.

In a therapeutic setting, *Ruminating Caretakers* may need help monitoring their cognitions and finding a base in reality. Additionally, they showed high levels of distress overall so reducing their problematic symptoms may be a necessary first step in therapy.

Overall, the results show that the six clusters fell into three broad categories: daughters with strong negative reactions, daughters with strong positive reactions, and daughters who felt more distant from their mother's breast cancer. Both clusters that showed a negative reaction had high levels of anxiety and high levels of involvement with their mother's cancer. One cluster, the *Ruminating Caretakers*, fit a typical model of reacting to trauma with many intrusive thoughts and use of monitoring, blunting, and wishful thinking coping mechanisms. The other cluster that had a negative reaction described the *Conflicted Impermeables*, who were emotionally close to their mothers and engaged in some caretaking. They had high levels of anxiety even though they did not believe they would get cancer.

The two clusters that showed a positive reaction were split between those who have realistically dealt with the situation and have few psychological reactions (*Healthy Monitors*) and those who believe they have a real threat but are tackling it with a sense of personal control and exploration of their preventative options (*Realistic Controllers*). The *Realistic Controllers* were highly interested in genetic testing and had the highest perceived likelihood of cancer. The *Healthy Monitors* showed low levels of anxiety, exposure to cancer, attachment, and wishful thinking, while still monitoring their own

risk of cancer. Members of both clusters indicated that their mother's breast cancer had spurred them to take preventative action regarding their own health.

Daughters who felt more distant from their mother's experience fell into two clusters. The *Distanced Blunters* had low levels ofintrusive thoughts and exhibited few coping strategies, though they did have high levels of blunting. Their low levels of closeness with their mothers, low exposure to cancer, low use of wishful thinking, and older age suggest their mother's breast cancer is not salient for them. The *Adaptive Externalizers* showed similar results, but expressed low levels of personal mastery over the situation and low use of blunting. The difference between these two groups was that the *Distanced Blunters* were farther from their mother's diagnosis with breast cancer, temporally and proximally, whereas the *Adaptive Externalizers* seem to have had a minimal reaction to the event overall.

Overall, it was found that clusters were most defined by the daughter's coping styles, levels of intrusive thoughts, and their strategies for dealing with threat, suggesting that those are the areas of greatest importance when exploring these reactions. The cluster solution also suggests that psychological response to a mother's breast cancer appears to have at least three phases. The first phase includes addressing the implications of the mother's disease, realizing one's own increased risk and coping with that threat, and occasionally making life changes. Secondly, daughters often pass through a phase of intense distress that includes increased anxiety and intrusive thoughts. Finally, daughters of women with breast cancer encounter a third phase focused on adaptive coping strategies and positive personal growth.

The cluster analysis was an important part of this study. It allowed me to look at the groupings of daughters in more complex ways than had happened in previous studies. The descriptions and names of the clusters should provide a framework for future studies, clinical case conceptualizations, and validation of the reactions of daughters of women with breast cancer. Though cluster analysis was the primary contribution of this study, the analysis of the following hypotheses adds insight into the daughters' reactions as well.

Hypothesis 1: Daughters whose mothers are deceased will report more distress than daughters whose mothers are still alive.

Contrary to the hypothesis, no significant differences were found in levels of distress between daughters of mothers who were still alive and daughters whose mothers were deceased. This may be explained by a number of different factors. First, the cause of death was not distinguished for deceased mothers. Some mothers died from breast cancer but others may have died from other causes later in life. This may have confounded the results for hypothesis one. Second, participants were recruited through e-mail snowballing. Many e-mails were sent to the researcher questioning whether all daughters of women with breast cancer could participate and if it was okay for women whose mothers had died to participate. This leads to the conclusion that some filtering of the snowballing method occurred. Perhaps initial e-mail recipients debated about who to forward the e-mail to, and some may have decided against sending it to women whose mothers had died (due to confusion about who was eligible) or against sending it to women who were known to have a strong emotional reaction to their mother's death (perhaps to avoid traumatizing those e-mail recipients). Another type of filtering that

may have occurred is that some e-mail recipients may not have forwarded the study e-mail at all. Third, the study was piloted on a number of acquaintances who had mothers with breast cancer. One of the mothers with breast cancer who read the survey suggested that she believes her daughter has coped with her breast cancer well because of their closeness. She attributed that belief to the idea that she and her daughter had resolved many of their conflicts and going through the cancer process led them to banish some of the resentment they held for each other. Perhaps she was experiencing less distress because they had spoken with each other about all possible outcomes of the mother's breast cancer and they had emotionally prepared each other for her death.

Closeness with one's mother appears to be more related to personality variables than whether or not the mothers have died. Quantifying closeness dependent upon mothers being alive or dead ignored the many intricacies of a mother-daughter relationship. Another possibility is that once a mother is deceased, the daughter's distress may lessen over time, and resolution may occur. Similarly, when mothers were still living, the daughters may have been more consumed by the process of dealing with breast cancer or may have been uncertain about the outcome of their mother's illness, thus leading to distress. Another explanation is that the participants' mothers died at many different points in time and those differing amounts of time has given some of the daughters more time to cope with their mother's disease than others.

It was hypothesized that the daughters of mothers who had died would report a higher likelihood of their own breast cancer, but since the reasons for the mother's death were not asked in the survey, there is no reason to believe that the mothers died from breast cancer. This hypothesis was designed to measure severity of the mother's breast

cancer, but the data indicate that the mothers did not all die from breast-cancer related causes. In other words, for a daughter whose mother died in a car crash ten years after her breast cancer, no reason exists for her to believe that her mother's breast cancer was any more severe than any other person's cancer.

Another possible explanation for the lack of significant results is that only a small portion of the participant's mothers had actually died, thus making comparisons between daughters with mothers who were still living versus mothers who were deceased statistically invalid. The treatment outcomes for the mothers in the study were so varied that comparisons were difficult to make. Also, deciding which types of cancer treatment are more severe than others is very subjective. For example, is observing a mother going through chemotherapy more or less difficult than watching her go through radiation treatments? Those subjective differences vary between individuals, so teasing out which treatments were more or less severe was impossible. Finally, most of the daughters reported multiple treatments for their mothers, thus confounding the comparisons.

The results of hypothesis one contradict the findings of previous studies like Erblich et al. (2000) which found that women whose mothers had gone through more severe types of treatment were more likely to be distressed and to report a higher likelihood of their own risk of breast cancer. In the Erblich et al. (2000) study, severity was assigned to treatments (e.g. mastectomy was considered more severe than a lumpectomy). The results of the current study suggest that a number of complex variables exist that predict the distress of a daughter. Put more simply, very few of the hypotheses of the current study were supported when based on a simple correlational design. Also, more variability occurred than in previous studies, a finding due in part to

the web-based survey and relatively large sample size of the current study. Previous studies (like the Erblich et al. study) were conducted in one location. The current study accessed participants from many locations, possibly contributing to the greater variability in this study. The greater variability occurring in this study suggests that some trends can be supported, but an overall picture of a daughter's well-being needs to be assessed by incorporating many situational, relational, biological, and personality variables.

Hypothesis 2: Daughters who report more contact with their mothers during the diagnosis and treatment of their mother's breast cancerwill report more distress than daughters who had less contact with their mothers.

As discussed in the results chapter, the Family Exposure to Cancer Rating (FECR) scale was positively correlated with the Adult Attachment Scale (AAS). This correlation indicates that daughters who feel more attached to their mothers are more likely to be involved in caretaking and exposure to their mother's cancer.

Daughters who had more contact with their mothers reported more intrusion as measured by the Impact of Events Intrusion subscale. It is important to recognize that even though the correlation was significant at the $p < .01$ level, the correlation value of $r=0.27$ is not especially robust, given that it only accounts for about 7% of the variance. In this hypothesis, the Family Exposure to Cancer Rating Scale was used to measure contact with one's mother during her cancer. Given that spending more time with one's mother and being more involved in the caretaking and medical decision making process requires more mental energy and commitment which may translate more easily into intrusive thoughts than general anxiety, it is not surprising that other measures of distress did not correlate with exposure to cancer.

Perhaps daughters who had more contact with their mothers during treatment were also more exposed to information about breast cancer and became more educated about the risks associated with breast cancer, thus leading them to be less likely to believe that they will get breast cancer. These daughters may have a more realistic idea of their risk than daughters who were not around their mothers as much.

Spira and Kenmore (2000) and Lichtman et al. (1985) found that daughters that are closer to their mothers have stronger reactions, thus setting up the framework for this hypothesis. However, the results of the current study have shown that FECR is not a total measurement of closeness; it is a measurement of amount of contact with one's mother, which is in fact correlated with the scores on the Adult Attachment Scale, but suggests that both attachment and exposure, among other constructs, are important factors in measuring the mother-daughter relationship. It is not surprising that the FECR scores were not significantly correlated with one's predicted likelihood of developing breast cancer or general levels of anxiety, since the AAS scores clearly represent another component of closeness. However, it was correlated with intrusion and self mastery. Intrusion and mastery are variables that have been more easily swayed by situational changes (Zakowski et al., 2001; Skaff et al., 1996). Both intrusion and mastery have direct situational components that are more likely to be affected by exposure to one's mother's cancer. Also, previous studies have found that likelihood estimates were not correlated with mother's health status or caregiving (Erblich et al., 2000), thus indicating that previous studies have found conflicting results as well.

Studies have shown that the personal belief that one can control their health has great advantages. Taylor, Lichtman, and Wood (1984) found that patients who perceive

greater personal control have better recoveries and adjustments to their diseases. In this hypothesis, daughters who were frequently involved with their mother's treatment had a higher sense of personal control. Perhaps seeing their mother's experience with cancer more closely than other women gave participants a higher sense of control. Skaff et al. (1996) found that adult children who cared for a sick parent had higher mastery scores than other family members. In the current study, that finding was supported. Like the results of Skaff et al., caretaking is a way for family members to stay active, perhaps leading to a greater sense of control over the situation. Also, one component of the FECR scale is involvement in medical decision making, which adds an element of control for the daughter.

Examining the correlations between the AAS and other measures of distress used in this study does not yield significant correlations either, perhaps indicating that the measures chosen for this study were not measuring closeness in the same way that the earlier studies which found significant relationships between exposure to cancer and distress did.

Hypothesis 3: Daughters who report less personal control will report being less likely to have a strong interest in getting a genetic test than daughters who report more personal control.

Interest in genetic testing was affected by many variables and mastery did not account for enough of the variance in interest to be significant. Previous studies have found mastery to be a relatively stable characteristic, but one that can change over time (Skaff, Pearlin, Mullan, 1996). Confronted with a new and unusual situation like facing a mother's diagnosis with breast cancer may be one of those situations where mastery is

more changeable than in other situations. Also, other variables tend to mediate the relationship between mastery and emotions including coping styles (Shiloh et al., 1997); self-efficacy (Lefcourt, 1983 as cited in Skaff et al., 1996); mood (Taylor, Lichtman, & Wood, 1984) and amount and type of caregiving (Skaff et al., 1996). Those variables along with other potential mediating variables may have confounded the results for this hypothesis. Studies like the Taylor, Lichtman, and Wood (1984) study have found that personal control is a complicated construct that may be mediated by other factors, which may partially explain the lack of a correlation found in the current study.

Hypothesis 4: Daughters' threat of getting breast cancer will be positively related to intrusive thoughts.

These hypotheses were evaluated by using the breast cancer likelihood rating as an indicator of threat as well as scores on the Threatening Medical Situations Inventory (TMSI) (development, van Zuuren & Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996).

No relationship was found between perceived threat and intrusive thoughts, however a significant correlation was found between threat monitoring and intrusive thoughts. Overall, the relationships between threat and intrusion and exposure to cancer and intrusion have been supported in the current study. It is clear that intrusion of events plays a significant role in how daughters cope with their mother's breast cancer. The IES-I subscale seemed to tap into a unique set of reactions that other measures of distress did not. The TMSI scale also seemed to represent threat more accurately than the perceived likelihood scale, suggesting that one's perceived likelihood cannot serve as a representation of threat.

The current study was the first study to compare intrusion with the TMSI. The significant relationship that was found here should be further examined in future studies. Pervious studies have consistently shown that women at a higher risk for breast cancer have more intrusive thoughts (Valdimarsdottir et al., 1995; Erblich et al., 2000) so the results for this hypothesis confirm previous findings.

Research Questions

Question 2: Do daughters who were more involved with their mother's medical decision making and information gathering processes report more distress than daughters who were removed from the process?

Similar to the results for question 2, scores on the FECR are significantly correlated with intrusion. However, no significant relationship was found between involvement and predicted likelihood of getting breast cancer or general anxiety. As discussed above, it is clear that intrusion is capturing a unique aspect of distress that other measures used in the current study did not.

Previous studies have shown that women at a high risk for breast cancer are more likely to be depressed (Howard & Harvey, 1998), show signs of Posttraumatic Stress Disorder including intrusive thoughts and avoidance behaviors (Naidich and Motta, 2000) and experience more general anxiety (Wellisch & Hoffman, 1998) than other women.

The current study supported the relationship of involvement with intrusion, but overall we did not find a relationship between involvement in medical decision making and distress. Due to the variability in the current study, involvement in the cancer process of one's mother clearly held different meanings for different individuals. For

some, involvement was related to closeness to their mothers, however, for others it appears to stem from obligation. Due to the variety of meanings that caring for one's mother might have, it is not surprising that this hypothesis was not supported. Also, the current study was the first study of its kind to use web-based surveying so more variability might have been found due to sampling methods.

Limitations.

The current study has a number of limitations. The study was a web-based survey, which has inherent benefits and detriments. Due to the specific nature of the population sought for the study, the internet provided a way of reaching many eligible participants quickly and easily. On the other hand, sampling bias due to the web-based nature of the survey is an important consideration. Participants who did not have access to a computer with internet capabilites, or were not familiar with the basic skills needed to take a web-based survey (e.g. clicking on circles to indicate a response or working with drag-down menus) most likely did not participate.

For protection of the data, a password-protected website was used. If potential participants did not receive an e-mail about the username and password, they could not participate, even if they were eligible. In other words, someone who just happened upon the website, perhaps via an internet search for related terms, could not access the survey itself and therefore could not participate. Most likely, this limited the scope of participants to people who were associated with the researcher or her acquaintances. The limited span of the snowballing e-mails may have affected the demographics of the sample which included little racial/ethnic diversity, high levels of education, and relatively high incomes.

Additional information would have been helpful in determining if the sample bias was based on the recruiting methods. Daughters of mothers who were deceased were not asked to report their mother's cause of death, therefore the study includes women whose mothers died of cancer as well as those who died of natural causes, accidents, or other diseases. Distinguishing among these differing causes of death may have contributed valuable information about distress in daughters whose mothers died of breast cancer. The wording on the Adult Attachment Scale (AAS) was set in the present tense and may have been confusing to women whose mothers were deceased. After receiving feedback from early participants, the researcher added a disclosure on the website that asked participants to consider the questions in the AAS as they remember their relationships with their mothers. This disclosure also may have added to the difficulty of assessing the distress in women whose mothers had died.

No record of the participants' geographic location, method of recruitment, or form of the study was kept. The study may have disproportionately included participants from one region of the country. Since the measure was only available in English, participation from non-English speaking individuals was precluded. Anecdotally, within the first five days of the initial recruitment, a friend of the researcher e-mailed her to inform her that she had received an e-mail about the study from a business colleague in London and not via the expected path of mutual friends. This e-mail suggested that some international circulation of the survey occurred and that the e-mail was passed outside the researcher's circle of acquaintances. Keeping track of how the participants heard about the study to see if that had an affect on their responses would have been informative. Also, due to the limited scope of my web design knowledge, no record of which form was used by which

participant was kept. The counterbalancing of the measures possibly was biased, but those data were not kept. In addition, a website counter to track the number of hits that the website received would have been interesting. Since a counter was not included in this study, assessing the response rate of the participants was not possible. Also, due to the limited eligibility requirements, the e-mails were circulated among people who did not qualify for the study in the hopes of increasing the network of people who were aware of the study.

I received a number of e-mails from people who were questioning to whom they should forward the recruitment e-mail. Some people expressed concern that sending the e-mail to a friend or family member whose mother was recently diagnosed with breast cancer or recently passed away would be too emotional for them. Thus, some screening may have occurred on the part of the e-mail recipients about who was able or who should participate in the study. The somewhat sensitive and personal nature of the study may have prevented some people from forwarding the e-mail to a wider range of people.

An overarching limitation of the current study is that I looked at women at only one point in time. Clearly, time has a significant impact on coping with a mother's illness, so perhaps future research could be longitudinal in nature. The self-report nature of the study restricted the generalizability of the study as well. It would be interesting to compare daughter and mother dyads on some of the measures (specifically the Adult Attachment Scale and Family Exposure to Cancer Rating Scale) to see how well their responses correspond.

Describing one's personal reactions can be a myopic exercise, so having other-report measures about a daughter's responses to her mother's breast cancer (e.g. other

siblings, friends, or a spouse/partner) would be beneficial in future research. The correlations for the current study were relatively insignificant overall, indicating that there are other pieces of variance that need to be added to the puzzle. Additional research could include a broad-based personality inventory, more robust analysis of trait-level anxiety compared to state-specific anxiety, and social support scales.

Future research.

This descriptive study has highlighted many areas for future research. One area in need of more examination is the issue of threat. This study included a wide range of responses to the question, "How likely do you think it is that you will get breast cancer in your lifetime?" Future studies can investigate how perceived risk of threat relates to other indicators of threat.

Additionally, future studies can investigate other measures of the closeness between a mother and daughter. What are the explicating factors between a daughter's closeness with her mother and her corresponding likelihood of being involved in caretaking and exposure to cancer during her mother's treatment and diagnosis? More exploration of how the clusters that were found in the current study relate to overall well-being and other personality characteristics would be valuable for future research.

If I were to conduct the study over again, I would focus more on threat and risk instead of coping. That is, I would focus more on the problem rather than the solution. The way the study was conducted blurred the boundary between problems and solutions, as did some of the measures used. Since this was a descriptive study, the goal was to gather as much broad information as possible. A potential next step would be focusing

on each step of the model, from threat and risk, through anxiety and intrusion, to coping and positive growth, and analyzing each layer of the process in more detail.

Implications.

The prevalence of breast cancer makes it likely that most individuals know someone with breast cancer. For counselors, helping clients deal with health-related concerns can be a source of stress, especially when clients expect medical information in addition to emotional support. Working with clients with genetic diseases or with concerns about developing or passing on a genetically related illness is becoming more common. Therapists should make themselves aware of the complex psychological issues that accompany genetic diseases to assist them in helping troubled individuals. In addition, valuable medical information and answers for a client's hard questions are available from many sources (Kelly, 1983; Stefanek, 1990).

Counselors should remember that disease in a family, specifically diseases that can have a genetic component, can significantly affect family members. As is often the case in daughters of women with breast cancer, finding out about another person's ailments often makes us question our own vulnerability and can lead to existential crises that may be expressed in therapy. Remembering that health problems do not exist in isolation also is important. The current study showed that the amount of caretaking that a daughter of a woman with breast cancer is involved in and her emotional closeness with her mother affect her overall mental well-being.

One goal of this study was to examine the extent to which daughters of women with breast cancer are affected by their mother's disease in a variety of ways. The participants in the study showed a wide range of variability in the ways they were

affected by their mother's breast cancer. Some were troubled, others were not particularly affected; some used cognitive confronting, others used avoidance and denial; and some were worried about their own risks for breast cancer, while others were not as concerned about their risk of breast cancer in the future. The wide range of reactions speaks to the variety of needs that these individuals have. Depending on a daughter's reaction and personality, she may want to talk about the event or she might prefer distancing herself from her mother's diagnosis. The variability found in the current study corresponds with the difficulty that counselors may have in working with clients who are encountering a similar situation. It is clear that counseling interventions may need to be tailored to individual clients based on their needs, but it is hoped that the current study will shed some light on potential coping strategies and variables that may affect people in similar situations.

Overall, it is clear that intrusion plays a clear role in a daughter's reaction to her mother's breast cancer. The ways in which a daughter copes with her intrusion and distress about her mother's illness is critical in determining what kind of reaction she will have to the event. The results of the cluster analysis suggest that daughters of women with breast cancer react to their mother's diagnosis in a variety of ways. Awareness of the variety of reactions was a goal of the study. Hopefully, these results will represent prototypical reactions of daughters of women with breast cancer. In addition, these results may serve to normalize the strategies used by some individuals. They also serve as a basis for future research.

Counselors and health practitioners need to be aware that when one member of the family is in crisis, an appropriate response is to reach out to other family members.

Additionally, previous studies have shown that when mothers are anxious about their breast cancer, their daughters are more likely to be anxious as well (Boyer et al., 2002). Consequently, when daughters are anxious about breast cancer, other family members also may be affected. For example, if a family consists of multiple daughters and one of the daughters becomes more vigilant about her health, the other daughters may feel more threat and thus increase their own health vigilance. If one daughter chooses to undergo genetic testing, those test results have implications for other members of the family. Then the test recipient must decide if she will share with her family members that she is undergoing testing and if she will share her results with the rest of the family. Future research on entire family interactions related to coping with a disease diagnosis may add insight into the reactions of individuals.

The current research informs us that disease affects entire families and appropriate mental health supports should be in place when a family is facing a health crisis. This study lends credibility to the variety of emotional reactions of family members and verifies that relatives do experience trauma when another member of the family is sick.

Conclusion.

This study provided an outlet for daughters of women with breast cancer to express their fears, joys, and feelings related to their mothers' breast cancer and their own threat of developing the disease. Overall, interesting descriptive information was collected about how daughters of women with breast cancer react to their situation. The variety of reactions and coping methods is striking to consider. There is no one right way

to cope, and I hope that daughters of women with breast cancer find validation in the many reactions found in other women.

The current study has implications for families dealing with breast cancer and other inheritable diseases, personal assessment of threat and risk, and how individuals make medical decisions including genetic testing. Thus, this study is informative for counselors and medical professionals who work with individuals making health decisions. Finally, it provides insight into the strategies that people use to address personal threat and familial illness.

Personally, hearing back from participants was an especially meaningful aspect of conducting the current study. It became clear to me that expressing concern for these daughters (through the pages of the study) was a powerful experience for them. Their reactions had not been tapped before participating in this study and this research provided a way for them to sort through their feelings and reactions to the event.

For participants that are reticent to consider therapy, studies of this type can also serve as an opening to therapy. One participant wrote: "I just wanted you to know that I took your survey… I thought the survey was great and that I think you found a way to touch on a lot of different topics related to the subject. It was funny because I hadn't really thought about how I felt about that time in my life - and your survey really got me to open up to those feelings and be honest about those emotions. It was almost sort of cleansing!" Participation in the study was therapeutic for some of the participants, which is both gratifying and exciting. Hopefully, thinking about some of the issues that were raised by participation in the study will encourage daughters to further contemplate their reactions to their mother's breast cancer and their own perceived threat.

In closing, I hope that the results of the current study will be of value to both medical and mental health care professionals as well as daughters of women with breast cancer.

Appendix A

Demographic Form

1. What is your age?

2. What is your gender?

3. Race/Ethnicity (Check all that apply)
   - Asian American/ Pacific Islander
   - White/ European-American
   - Middle Eastern/ Arab
   - Asian Indian/ Pakistani
   - Hispanic/Latino
   - Biracial/ Multiracial
   - Black/ African-American
   - Native American/ Native Alaskan
   - Foreign National (please specify)
   - Other race (please specify)

4. What is the highest level of education that you have completed?
   - Elementary school
   - Middle school/ Junior High school
   - High School
   - Technical school
   - 2-year college
   - Some 4-year college
   - 4-year college degree
   - Some graduate school
   - Master's degree
   - Doctorate or professional degree

5. What is your current occupation?

6. What is your yearly income?

7. How long ago was your mother diagnosed with breast cancer?

8. How old was your mother when she was diagnosed with breast cancer?

9. Had your mother started menopause when she was diagnosed with breast cancer?

10. What kind of treatment or surgery did your mother undergo? (select all that apply)

- Lumpectomy
- Mastectomy
- Chemotherapy
- Radiation Therapy
- Hormone Therapy (tamoxifen, etc.)
- Alternative Therapy
- Other (please specify)

11. What is your mother's current health status?
- Deceased
- Still undergoing treatment
- Completed initial treatment and is cancer-free
- Completed initial treatment but more cancer has been found
- Cancer has spread to other parts of her body
- Other (please specify)

12. How old were you when you started your first period?

13. Do you have biological children?

14. If yes, how old were you when your child(ren) was born? (Please list all)

15. Besides your mother, do you have other relatives with breast or ovarian cancer?

(Please list all)

16. Have you ever had any type of cancer? (If yes, please indicate type and date

diagnosed)

Appendix B

Perceived Risk of Threat

How likely do you think it is that you will get breast cancer in your lifetime?(On a 0-100% scale)

0%= I won't get breast cancer…………………………...100%=I know I will get breast cancer

_____%

Appendix C

Genetic testing likelihood

1. Have you ever been tested for a breast cancer gene? If yes, what is your status?

2. How interested are you in receiving a genetic test? (On a 0-100 scale)

0=I am not interested in a genetic test……………………………..100=I am very interested

3. How likely do you think it is that you will receive a genetic test in the next 6 months? (On a 0-100 scale)

0=I will not get tested in the next 6 months…………..……………….100=I know I will be tested

Appendix D
Revised Family Exposure to Cancer Rating (Boyer et al., 2002)

1. **How often did you see your mother as she underwent the diagnosis and treatment of her cancer?**

1=Never saw my mother throughout her treatment
2=Saw my mother less than once every month
3=Saw my mother at least once every month
4=Saw my mother at least once every two weeks
5=Saw my mother at least once every week
6=Saw my mother at least twice every week
7=Saw my mother at least once every day

2. **How often did you communicate (either via phone, e-mail, letters or other methods) with your mother as she underwent the diagnosis and treatment of her cancer?**

1=Never communicated with my mother throughout her treatment
2=Communicated with my mother less than once every month
3=Communicated with my mother at least once every month
4=Communicated with my mother at least once every two weeks
5=Communicated with my mother at least once every week
6=Communicated with my mother at least twice every week
7=Communicated with my mother at least once every day

3. **To what degree did you take care of your mother as she underwent treatment?**

1=I did not take care of my mother at all during the treatment
2=Even though someone else was the primary caretaker, I helped a little to take care of my mother
3=Even though someone else was the primary caretaker, I helped a great deal to take care of my mother
4=I shared evenly with other caretakers to assist my mother during her treatment
5=I was the primary caretaker for my mother with a great deal of help from others
6=I was the primary caretaker for my mother with only a little help from others
7=I was the only caretaker for my mother during treatment

4. **How much were you involved in the medical decision-making processes?**

1=I never helped my mother make decisions about treatment
2=I rarely helped my mother make decisions about her treatment
3=I occasionally helped my mother make decisions about her treatment
4=I shared in the process of medical decision making with others
5=I helped my mother make decisions about her treatment, with the help of others
6=I helped my mother make most decisions about her treatment
7=I helped my mother make all of her decisions about treatment

5. **Did you move to be closer to your mother during her treatment? If yes, please explain.**
6. **Did your mother's treatment affect any major life decisions (e.g. marriage, children, career change, etc.)? If yes, please explain.**

Appendix E
Threatening Medical Situations Inventory (TMSI) (development, van Zuuren &
Hanewald, 1993; analysis, van Zuuren, de Groot, Mulder, & Muris, 1996)

Instructions

The next pages contain descriptions of situations you actually may have found yourself in or you can imagine yourself in. Each situation is followed by several statements about thoughts, concerns and action tendencies people may have in such a situation. Please try to imagine that you are in the situation described and indicate for **each** statement to what degree it is applicable to you. There are no right or wrong answers. Please indicate for each statement below to what degree it is applicable to you, by encircling your answer.

1=not at all applicable to me; 2=not very much applicable to me; 3=a tiny bit applicable to me; 4=rather applicable to me; 5=strongly applicable to me

1. Imagine you suffer from headaches and dizziness for some period of time already. You visit your doctor. He or she tells you things don't look good and refers you to a specialist for a rather trying medical exam.
   a.   I plan to ask the specialist as many questions as possible
   b.   I think things will turn out to be all right
   c.   I will get more information at other medical centers first
   d.   I plan to start reading about headaches and dizziness
   e.   For the time being I try not to think of unpleasant outcomes
   f.   I am not going to worry: such an examination is not as bad as suffering from headaches all
   the time

2. Imagine you work hard and you are overweight. Your doctor told you several times already this is unwise. During a visit he or she observes hypertension.
   a.   I look on the apparatus too in order to ensure he or she is not mistaken
   b.   I take things rather easy
   c.   I decide to live on normally
   d.   I ask my doctor extensively about the risks and consequences involved
   e.   I tell myself, "Some ailments are worse than this one"
   f.   I plan to start reading a lot about hypertension

3. Imagine you have heart complaints. Your specialist advises an operation. He tells you that you will have to wait four months for it and that it is not certain whether the operation will be effective.
   a.   I take the line that, in my case, the operation will be effective
   b.   I decide to delve deeply into all that is known about heart surgery
   c.   I decide to undertake as many pleasant and useful activities as possible for the next few
   months
   d.   I am going to find out whether there is a chance that the operation will make things worse
   e.   I decide to contact other patients with the same medical problem, for information
   f.   I tell myself, "Things will turn out to be all right"

4. Imagine you visit your doctor with problems of the bowel that don't appear severe. He or she diagnoses acute appendicitis and tells you that you have to have an operation in the hospital as soon as possible.

   a.   I tell him or her I want to know precisely what they are going to do with me
   b.   I decide to relax in the face of what is happening
   c.   I ask think about what can go wrong
   d.   I take things easy
   e.   I tell myself, "Things will turn out to be all right"
   f.   I immediately try to call somebody who will inform me about this operation

Appendix F
Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979)

Below is a list of reactions people often have after stressful life events. Please check each item indicating how frequently these comments were true for you regarding your mother's breast cancer, during the time since the date she was diagnosed. If they did not occur during the time, please mark the "not at all" column.

1=Not at all
2=Rarely
3=Sometimes
4=Often

1. I thought about it (my mother's breast cancer) when I didn't mean to.
2. I avoided letting myself get upset when I thought about it.
3. I tried to remove it from memory.
4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.
5. I had some strong waves of feelings about it.
6. I had dreams about it.
7. I stayed away from reminders of it.
8. I felt as if it hadn't happened or it wasn't real.
9. I tried not to talk about it.
10. Pictures of it popped into my mind.
11. Other things kept making me think about it.
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.
13. I tried not to think about it.
14. Any reminder brought back feelings about it.
15. My feelings about it were kind of numb.

Appendix G

State-Trait Anxiety Inventory (STAI-T; Spielberger, Gorsuch, Lushene, 1970)

Directions: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

1=Almost never

2=Sometimes

3=Often

4=Almost always

1. I feel pleasant.
2. I feel nervous and restless.
3. I feel satisfied with myself.
4. I wish I could be as happy as others seem to be.
5. I feel like a failure.
6. I feel rested.
7. I am "calm, cool, and collected."
8. I feel that difficulties are piling up so that I cannot overcome them.
9. I worry too much over something that really doesn't matter.
10. I am happy.
11. I have disturbing thoughts.
12. I lack self-confidence.
13. I feel secure.
14. I make decisions easily.
15. I feel inadequate.
16. I am content.
17. Some unimportant thought runs through my mind and bothers me.
18. I take disappointments so keenly that I can't put them out of my mind.
19. I am a steady person.
20. I get in a state of tension or turmoil as I think over my recent concerns and interests.

Appendix H
Self Mastery Scale (Pearlin & Schooler, 1978)

Please indicate the extent to which you agree or disagree with the following statements by circling the appropriate response from the following key.

SA=Strongly agree
A=Agree
U=Undecided
D=Disagree
SD=Strongly disagree

<u>M scale</u>
1. There is really no way I can solve some of the problems I have.
2. Sometimes I feel that I'm being pushed around in life.
3. I have little control over the things that happen to me.
4. I can do just about anything I really set my mind to.
5. I often feel helpless in dealing with the problems of life.
6. What depends on me in the future mostly depends on me.
7. There is little I can do to change many of the important things in my life.

Appendix I

Ways of Coping Scale Revised(Folkman & Lazarus)

Please read each item below and indicate, by marking the appropriate category, to what extent you use it to deal with your mother's breast cancer diagnosis and treatment.

0=Does not apply or not used

1=Used somewhat

2=Used quite a lot

3=Used a great deal

1. I went over the situation or event again and again in my mind to try and understand it.
2. I felt that time would make a difference and the only thing to do was to wait.
3. Talked to someone to find out more about the situation.
4. Hoped a miracle would happen.
5. Went along with fate; sometimes I just have bad luck.
6. I went on as if nothing had happened.
7. Looked for the silver lining, so to speak, tried to look for the bright side of things.
8. Tried to seek out sympathy.
9. Tried to do something creative.
10. Tried to forget the whole thing.
11. Tried to make changes in a good way.
12. Decided to wait and see what would happen.
13. Tried to come up with a plan of action.
14. Did not go with my first hunch.
15. Tried to let feelings out.
16. Decided to rediscover life.
17. Asked a friend what s/he thought.
18. Decided to try to change something.
19. Talked to someone about how I was feeling.
20. Drew on past experience.
21. Thought about what could be done.
22. Considered different solutions.
23. Tried to accept the situation.
24. Tried to keep my feelings from interfering with other things too much.
25. Wished that I could change what had happened or how I felt.
26. I daydreamed or imagined a better time.
27. Wished that the situation would go away or somehow be over with.
28. Had fantasies or wished about how things might turn out.
29. I went over in my mind what I would say or do.
30. Tried to see other perspectives.

Appendix J

Adult Attachment Scale

On a 7-point Likert Scale

1=Strongly Agree

2=Agree

3=Somewhat Agree

4=Neither agree nor disagree

5=Somewhat Disagree

6=Disagree

7=Strongly Disagree

1. Being with my mother makes me feel very happy.
2. At times, when I have some trouble or difficulty, my mother's image seems to come to mind.
3. If I am unable to see my mother for a long time, it bothers me a lot.
4. When I have not seen my mother for a while, I feel happy when I see her again.
5. When I feel alone and feel anxious, my mother is the first person I think of.
6. When I am with my mother, I feel very close to her.
7. I feel a sense of joy to be with my mother again when we have been separated for a while.
8. I feel lonely when I don't see my mother often.
9. When I am with my mother, I feel that I am someone I can depend on.
10. If I am in trouble, the first person I want to talk to is my mother.
11. The thought of losing my mother is deeply disturbing to me.
12. When I have been away from my mother for a long time, I feel a sense of security to be with her again.
13. If I feel depressed, my mother is always a source of strength for me.
14. When I am with my mother, I feel that I am someone I can trust completely.
15. After we have been apart for a time, I feel a sense of relief when I see my mother again.
16. It would be very difficult for me to move far away from my mother.

Appendix K

Open ended questions

1. Describe how you felt when you found out that your mother was diagnosed with breast cancer.
2. How has your mother's breast cancer affected your life?
3. What things have you done to cope with your mother's breast cancer that have been the most helpful?
4. Write about anything else that you think might be helpful to tell us about your experience.

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