2000

Women's attitudes toward genetic testing for breast cancer susceptibility as a function of breast cancer screening practices, perceived risk of contracting breast cancer, health locus of control and genetic knowledge

Constance Faye Welebir

WOMEN'S ATTITUDES TOWARD GENETIC TESTING FOR BREAST CANCER SUSCEPTIBILITY AS A FUNCTION OF BREAST CANCER SCREENING PRACTICES, PERCEIVED RISK OF CONTRACTING BREAST CANCER, HEALTH LOCUS OF CONTROL AND GENETIC KNOWLEDGE

A Thesis

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

in

Psychology

---

by

Constance Faye Welebir

September 2000

WOMEN'S ATTITUDES TOWARD GENETIC TESTING FOR BREAST CANCER SUSCEPTIBILITY AS A FUNCTION OF BREAST CANCER SCREENING PRACTICES, PERCEIVED RISK OF CONTRACTING BREAST CANCER, HEALTH LOCUS OF CONTROL AND GENETIC KNOWLEDGE

A Thesis

Presented to the

Faculty of

California State University,

San Bernardino

---

by

Constance Faye Welebir

September 2000

Approved by:

[redacted]

Dr. Joanna Worthley, Chair, Psychology — JUNE 28 2000 Date

[redacted]

Dr. Laura Kamptner

[redacted]

Dr. David Chavez

ABSTRACT

Genetic susceptibility testing for breast and ovarian cancer is an important new tool for assessing cancer risk, one that may facilitate early detection and reduction of cancer risk. Interest in testing among high risk women has been sizeable; however, potential demand for testing may be greatest among women for whom testing is least appropriate. Though interest level in testing is high, studies have found that about one half of women had read or heard almost nothing about genetic susceptibility testing for breast cancer, and most women lacked knowledge about cancer genetics. These findings indicate a clear need for the development of educational and counseling programs for women of every risk status. The present study addressed four hypotheses which assessed the relationship between women's current attitudes toward genetic susceptibility testing for breast cancer (DV) and 1) breast cancer screening practices 2) perceived risk of contracting breast cancer 3) knowledge of genetic susceptibility testing for breast cancer, and 4) health locus of control. The relationship of socio-demographic data and attitude toward genetic susceptibility testing, along with reported sources of genetic susceptibility testing information, and women's

attitudes toward disclosure of genetic susceptibility test results to families and employers were also explored. A sample of 137 women in Southern California, aged 35-70 years, who had not been diagnosed with breast or ovarian cancer, and were awaiting medical appointments, attending women's groups (e.g. book or investment clubs), or employees at local businesses (salesclerks and secretaries), filled out the self-administered "Women's Health Survey" (WHS). Only one hypothesis relating routine breast cancer screening practices and a more positive attitude toward genetic susceptibility testing for breast cancer (in women over 40) was supported. The other three hypotheses were not supported. Thirty-five percent of the sample had never heard of genetic testing for breast cancer risk. Of the remaining participants who had heard of genetic testing, 79% indicated television as a source of genetic susceptibility testing information. Sixty-eight percent of women indicated that no health professional had spoken to them about genetic susceptibility testing for breast cancer. Disclosure concerns included worry to family, affects on daughters/children, and job security. Significant differences were found with exploratory analyses investigating women's perceived risk vs. real risk

of contracting breast cancer during the next five years, with perceived risk higher than real risk. The mean score for overall knowledge was 1.17 (range of -3 to +6), indicating the need for women to become educated about genetics and appropriate use of susceptibility testing.

ACKNOWLEDGMENTS

I wish to thank Dr. Joanna Worthley for her untiring encouragement, direction, and support throughout the completion of this study. It has been inspiring to work with such a gracious and motivating academician. Thank you also to Dr. Laura Kamptner and to Dr. David Chavez for their helpful input and assistance.

TABLE OF CONTENTS

LIST OF TABLES

INTRODUCTION

Breast cancer, the most frequently diagnosed neoplasm in females, is one of the most important diseases affecting women in the United States today, with at least one in eight being diagnosed during her lifetime (Kadison, Pelletier, Mounib, Oppedisano, & Poteat, 1998). Each year, over 186,000 new cases and 46,000 breast cancer deaths are reported in the United States alone. The majority of breast cancer diagnoses occur late in life (postmenopausal) and are probably sporadic (random), in that no strong inherited factors or gene mutations are present. However, an estimated 6-10% of breast cancer is hereditary (Ondrusek, Warner, & Goel, 1999; Neuhausen & Ostrander, 1997).

Familial clustering of breast cancer was first recognized by physicians in ancient Rome, with this phenomenon being described in more recent times by Paul Broca, a French surgeon, who in 1866 reported ten cases of breast cancer in four generations of his wife's family (Weber, 1996). After gender and age, a positive family breast cancer history is the strongest predictive risk factor for breast cancer (Brody & Biesecker, 1998). Women who have a first-degree relative with breast cancer have a

two to three-fold increased risk of developing breast cancer themselves (Schwartz et al., 1998).

Like hypertension, adult-onset diabetes, and asthma, breast cancer can be classified as a "complex disease" at the genetic level, with the emergent phenotype of the disease resulting from interaction of multiple genes and the interplay of genes and environmental factors (e.g., diet, hormones, and behavior). Breast cancer is also a heterogeneous disease whose etiology, for the most part, is unknown. However, in some families, inherited factors clearly are the major component of an individual's cancer risk. It is now known that some of these "cancer families" can be explained by specific mutations (alterations) in single susceptibility genes, with the last decade showing remarkable progress in the understanding of the genes involved in this subset of breast cancer cases (Brody & Biesecker, 1998).

Isolation of the BRCA1 and BRCA2 Susceptibility Genes

In 1988, King and colleagues presented the first quantitative evidence that breast cancer segregated as an autosomal dominant trait in some families. Two years later, after performing a genome-wide linkage scan, they reported a linkage between a region of chromosome 17q21 and

early-onset breast cancer. In succeeding years, the chromosome 17 gene has been cloned, with a second inherited breast cancer susceptibility locus on chromosome 13 also discovered and cloned. The understanding of the two loci defined to date (BRCA1 and BRCA2), associated with an inherited susceptibility to breast and ovarian cancer, is far from complete. However, the cloning of these genes has led to nearly immediate technologic improvements in diagnostics, and the development of tests for carrier identification (Brody & Biesecker, 1998).

Initial studies using genetic linkage analysis estimated that 45% of families with apparent autosomal dominant transmission of breast cancer susceptibility, and approximately 90% of families with dominant inheritance of both breast and ovarian cancer, harbored BRCA1 germline mutations (Weber, 1996). Additionally, The International Breast Cancer Linkage Consortium (1996) showed that female BRCA1 mutation carriers are estimated to have an 85% lifetime risk of developing breast cancer, as well as a 40-60% lifetime risk of developing ovarian cancer. Their report also suggested that the cumulative risk of developing a second breast cancer was 65% for mutation carriers by age 70 (Weber). Moreover, men and women who

carry a mutation of one of these genes have a 50% chance of passing it on to each of their children (Brody & Biesecker, 1998).

Certain ethnic groups (Icelanders, Swedes, Austrians, Dutch, African Americans and Ashkenazi Jews) have been given considerable study, with single BRCA1 and BRCA2 "founder" mutations being identified frequently in these populations (Neuhausen & Ostrander, 1997). Ashkenazim, in particular, have been researched, since frequency estimates of population prevalence of the founder mutation in this group show 1 in 44 carrying a BRCA1 or BRCA2 mutation (Brody & Biesecker, 1998).

Hereditary Breast Cancer

What are the added concerns of women who may be at risk for developing hereditary breast cancer? Familial breast cancer is characterized by young age at diagnosis, an increased risk of bilateral breast cancer, a risk level correlated with increasing numbers of affected family members, and a strong association with ovarian cancer (Weber, 1996). Frank et al. (1998) have shown that in women with breast cancer, mutations in BRCA1 and BRCA2 were associated with a 10-fold increased risk of subsequent ovarian carcinoma ($p=.005$).

Genetic Susceptibility Testing for BRCA1 and BRCA2

Genetic susceptibility testing for breast and ovarian cancer is an important new tool for assessing cancer risk--one that may facilitate early detection and reduce cancer risk. With the identification of BRCA1 and BRCA2, an unprecedented opportunity now exists by which high-risk individuals may learn whether they are genetically predisposed to develop breast or ovarian cancer, and to make subsequent prophylactic decisions (e.g., frequent surveillance, Tamoxifin chemo prevention therapy or double mastectomy). However at present, little is known regarding whether high-risk patients from Hereditary Breast Ovarian Cancer (HBOC) families will want to know their mutation status nor about how they will make decisions about undergoing BRCA1 and BRCA2 testing. Preliminary reports indicate that there is strong interest in genetic susceptibility testing for breast cancer, both in the general population and in high-risk families. However, past experiences with Huntington Disease (HD gene) and Cystic Fibrosis (CF gene), have shown that actual usage of genetic tests may be substantially lower than anticipated based on stated intentions to receive a hypothetical genetic test (Lerman, Narod et al., 1996).

In this study, we address the following questions: Are women currently aware of their risk status and of genetic testing for breast cancer susceptibility, and if so, are they willing to be genetically tested if found to be at high risk? Do socioeconomic factors play a role in women's attitudes toward genetic susceptibility testing for breast cancer? Where are women acquiring information about genetic testing? Do health personnel offer information about genetic susceptibility testing for breast cancer to their patients? Additionally, what are women's attitudes toward disclosing genetic test results to their families and employers? Is a woman's attitude toward genetic susceptibility testing for breast cancer related to her 1) adherence to breast cancer screening practices 2) perceived risk of contracting breast cancer 3) health locus of control, and/or (4) knowledge of genetic susceptibility testing for breast cancer?

The Role of Anxiety in Women's Attitudes toward Genetic Susceptibility Testing for Breast Cancer

Although anxiety is not specifically looked at during this study, it is a variable that is inherently present in any research addressing the subject of breast cancer and genetic susceptibility testing. Previous studies of

individuals at increased risk for cancer inform us about the psychological profile of this target population, with heightened anxiety being cited most widely as a feature of women at increased risk for breast cancer (Lerman & Croyle, 1996). Testing for susceptibility to heritable breast and ovarian cancer has unique psychological costs. If a woman is found to be at high-risk for developing hereditary breast cancer, is informed of the benefits and risks of genetic susceptibility testing, and is confronted with the dilemma of deciding whether to be tested for BRCA1 and BRCA2, she faces many emotional consequences. If she proceeds with testing, negative test results may not be sufficient to relieve anxiety, whereas positive results can cause sufficient distress to compromise patient compliance with surveillance and risk reduction measures (Macdonald, Doan, Kelner, & Taylor, 1996).

Adherence to Screening Practices for Breast Cancer

Studies have shown that usage of screening mammograms, clinical breast examinations and self-breast examinations may be impacted by age level, risk status, cancer worry, and socio-demographic factors (e.g., ethnicity, income, and educational level). Rimer et al. (1991) state that although mammography is a proven technology for diagnosing

early, curable breast cancer, most women do not obtain regular mammograms. Owen and Long (1989) contend that common reasons for noncompliance with established screening guidelines include the following: fear of the carcinogenic effect of radiation, unfamiliarity with the guidelines, belief that mammography is ineffective, or fear that detection will necessitate mastectomy. Additionally, Kash (1998) states that major barriers to mammography include: lack of physician recommendation or referral and cost of procedure, overestimation of risk, fear of finding a lump, fear associated with losing a breast through mastectomy, levels of radiation, amount of physical discomfort from having a mammogram, cancer being a taboo subject in some families, embarrassment about having breasts examined by medical personnel or by themselves, and taking time from other activities.

Age level . Fox et al. (1990) report that only 16% of women over 40 years of age are being screened regularly with mammography. Research examining data on usage of mammograms and clinical breast examinations (CBE) by 1,339 Florida women interviewed during the 1991 Behavioral Risk Factor Surveillance Survey, showed that among women 20 to 40 years old, 87% reported a CBE within the past 3 years,

exceeding the guidelines of the American Cancer Society. Among older women, 70% had experienced a CBE within the past year as recommended; however, when women were assessed for mammography screening, only 50% of those aged 50 years or older had obtained a mammogram during the past year (Vincent, Gradham, Hoercherl, & McTague, 1995).

A further population-based follow-up study assessed 17,811 Greater Lansing, Michigan women in the metropolitan area, who had experienced a mammogram from June 1987 to June 1998. Adherence to mammography screening guidelines was estimated, with findings showing that only 37% of the expected number of women 35 years of age and older had had a mammogram. This study also revealed that adherence to mammography screening guidelines declined with age, with less than 5% (302 of 6700 women aged 55 years and older) reporting annual mammograms (Sienko et al., 1993).

Risk Status. Studies investigating the impact of breast cancer risk information on health screening behavior have provided evidence of adverse psychological reactions in women who have become knowledgeable of risk information, which may impede the process of surveillance and prevention measures (Botkin et al., 1996; Rimer et al., 1996).

Findings of a study of 200 women with one or more first-degree relatives with breast cancer showed that although 94% adhered to regularly scheduled mammograms, only 69% participated in regular clinical breast examinations, and a mere 40% performed monthly breast self-examinations. (Kash, Holland, Halper, & Miller, 1992). Kash et al. report that women who were rated high on perceived risk and had high distress were least likely to use preventive behaviors. Their research reports that the impact of anxiety on detection behavior in high risk women have led some to describe themselves as "walking time bombs" awaiting the inevitable cancer to develop, and avoiding detection behaviors altogether because they fear the possibility of finding cancer.

Cancer worry. There have been contradictory study results as to how cancer worry affects women's surveillance practices. Some studies have related anxiety to a reduced likelihood of adherence to mammography, and to clinical and self-breast examinations (Botkin et al., 1996; Kash, Holland, Halper, & Miller, 1992; Rimer et al., 1996). Rimer et al. (1996) found that over one half of first degree relatives of breast cancer patients reported intrusive thoughts and feelings related to their risk,

along with one third who stated that breast cancer worries interfered with their daily functioning. Researchers contend that these findings have the potential for risk of breast cancer mortality brought on by lack of screening procedures (Lerman & Schwartz, 1993; Rimer et al., 1996).

However, other studies examining predictors of mammography use among women with a family history of breast cancer suggest that moderate levels of cancer worry facilitate, rather than undermine, adherence (Diefenbach, Miller, & Daly, 1999; Fox Chase Cancer Center, 1999; Wilcox & Stefanick, 1999). Wilcox and Stefanick cite McCaul, Bransletter, Schroeder & Glasgow's 1996 research, where mammogram utilization has shown that women who feel more vulnerable to breast cancer and are worried about breast cancer, are more likely to have regular mammograms than are women with lower perceived vulnerability and worry.

Socio-demographic factors. Studies have shown that age, ethnicity, income level and educational level may have an impact on breast cancer screening practices. As mentioned above, research has found that adherence to screening guidelines declines with age (Sienko et al., 1993; Vincent et al., 1995).

Another study examining differences related to breast cancer screening practices of black and white women over age 40 found that black women were more likely to underestimate their cancer risk, to fear radiation, and were less likely to have a doctor advise them to get mammograms. However, black and white women did not differ in terms of self-reported mammography use, with the results of multivariate modeling suggesting that different sets of knowledge and belief variables may explain mammography adherence among black and white women (Glanz, Resch, Lerman, & Rimer, 1996). Another study showed that among women having mammograms, self-referred women were more educated, more affluent, and more likely to be white than were physician-referred women (Vincent, Bradham, Hoercherl, & McTague, 1995).

A further study comparing the adherence to breast cancer screening guidelines among African-American women of differing employment status showed that 63% of all subjects practiced monthly breast self-examinations, and 76% had undergone a yearly physician's breast examination; however, only 20% of all subjects had undergone a mammogram according to the age-related guidelines. Overall, breast cancer screening rates were lower than recommended across

all employment groups, with variables such as age group, previous instruction on mammography, education, marital status, income, social influence, perceived barriers related to mammography, and intrinsic motivation, explaining some of the variance in each of the three screening practices (Phillips & Wilbur, 1995).

Vincent, Bradham, Hoercherl, and McTague (1995) found that annual household income, but not educational level, has been positively associated with adherence to mammography. However, other research has shown that less educated women are less adherent to mammography screening guidelines (Rimer, 1995; Rimer, Lerman, Schwartz et al., 1996). Fox et al. (1990) suggest that poor, urban women are particularly needing education about screening guidelines of the American Cancer Society.

Relationship of Breast Cancer Surveillance and Attitude toward Genetic Susceptibility Testing for Breast Cancer.

It has been shown that women who were younger than 60, and who were white, believed their family would benefit if they had a mammogram, and believed that regular mammograms gave them a feeling of control over their health were more likely to be interested in testing than those who were 60 years or older, African-American or other, and did not

believe that their family would benefit if they had a mammogram or that mammograms gave them a feeling of control over their health (Tambor, Rimer, & Strigo, 1997).

Another study examined predictors of interest in genetic testing for breast cancer risk in four groups of women (307 white, 36 African-American, 87 lesbian/bisexual, and 113 Ashkenazi Jewish). Women in all four groups anticipated using genetic test results to increase the frequency of various breast cancer screening methods (>69% would increase mammogram frequency, >85% would increase clinical exam, and >92% would increase breast self exam) (Durfy et al., 1999).

Other findings from a study in France (Julian-Reynier et al., 1996) showed that 52% of the respondents indicated they would not change their health surveillance habits, even if the outcome of genetic susceptibility testing were negative. Additionally, 96.6% of the women studied (N=209) believed that positive results from genetic susceptibility testing for breast cancer would lead to improved medical surveillance.

Perceived Risk

Many studies have reported that women's perceived risk of developing or dying from breast cancer during their

lifetime has frequently been overestimated (Alexander, Ross, Sumner, et al., 1996; Black, Nease, & Tosteson, 1995; Smith, Gadd, et al., 1996). Additionally, Rimer et al. (1996) contend that a majority of women with a family history of breast cancer have inflated perceptions of their personal risks for this disease.

Wilcox and Stefanick (1999), in a study of middle-aged and older women, found that the majority of Americans, regardless of age, race, education, and income level, lacked knowledge regarding major risk factors for common cancers. They contend that though knowledge has increased over time, certain groups have made substantially less improvement in knowledge, including the less educated and the ethnically diverse. Wilcox and Stefanick further state that though studies of the link between knowledge and behavior change have produced mixed findings, there is increasing evidence that feeling at greater risk for a disease may relate to an increase in preventive health behaviors. They cite McCaul, Bransletter, Schroeder, and Glasgow's (1996) research, where mammogram utilization studies have shown that women who feel more vulnerable to breast cancer and are worried about breast cancer, are more

likely to have regular mammograms than are women with lower perceived vulnerability and worry.

Another study (Aiken, Fenaughty, West, Johnson, & Luckett, 1995), investigating factors believed by women to determine their self-related risk level for breast cancer, found that women held optimistic biases about their own breast cancer risk, often erroneously attributing their relatively lower perceived risk to personal actions, including mammography screening. Perceived susceptibility to breast cancer was related to both family history and breast symptomatology, and early mammography screening was positively related to perceived susceptibility later in time.

A conflicting study (Smith, Gadd et al., 1996) reports that women in their sample (who were attending a breast center and a primary care practice) estimated their personal risk to be even higher than their inflated estimate of general population risk. Women in the youngest and oldest groups were least accurate in estimating risk, and a family history of breast cancer appeared to have little impact on the degree to which women overestimated personal risk.

Relationship of Risk Perception and Attitude toward Genetic Susceptibility Testing for Breast Cancer.

Study findings (Lipkus, Iden, Terrenoire, & Feaganes, 1999) have shown that knowledge of risk factors and attributions of risk are not directly related to interest in genetic susceptibility testing for breast cancer, and that concerns, rather than beliefs about one's risk, are more powerfully related to interest in genetic testing, independent of family history status.

In their study investigating the relationship between perceptions of breast cancer risk and interest in genetic susceptibility testing for breast cancer among African-American women, it was shown that women with a family history of breast cancer reported having greater perceived breast cancer risks and concerns than women without a family history of breast cancer. However, the investigation of 130 and 136 women with and without a family history of breast cancer, respectively, revealed that increasing perceptions of breast cancer risks and concerns were related to a greater interest in genetic testing, and this relationship was not moderated by family history status (Lipkus et al., 1999).

Another study examining decision-making about future susceptibility testing among women at familial risk for breast cancer, found that older age and greater perceived risk (but not empiric risk) were associated with greater readiness (Jacobsen, Valdimarsdottier, Brown, & Offit, 1997). Other studies (Lerman et al., 1994, 1995; Struewing et al., 1995; Tambor et al., 1997) concurred with these findings, reporting no association between actual risk factors, such as having a mother who had been diagnosed with breast cancer, and interest in genetic testing for breast cancer. Rather, the general conclusion has been that perceived risk, which often does not coincide with actual risk, is the more important determinant of interest in testing.

Health Locus of Control (HLC)

Research has evaluated women's internal versus external control of reinforcement, (often referred to as locus of control), in relation to their health status. Rotter (1989) describes internal versus external locus of control as the degree to which persons expect that a reinforcement or an outcome of their behavior is contingent on their own behavior or personal characteristics, versus the degree to which persons expect that the reinforcement

or outcome is a function of chance, luck, or fate, is under the control of powerful others, or is simply unpredictable.

Taylor, Kemeny, Bower, Gruenewald, & Reed (2000), in their research on psychological resources which may influence health in a beneficial direction, suggest that psychological beliefs such as meaning, a sense of personal control, and optimism act as resources which may be protective of physical health. Taylor et al. contend that people who have a positive sense of self-worth, belief in their own control, and optimism about the future may be more likely to practice conscientious health habits and to use services appropriately. Additionally, these characteristics often enable people to have active coping efforts and more social support in the case of stressful events.

Another study which assessed women five years after they had participated in a previous experiment (where locus of control, along with other variables such as stress, hardiness, Type A behavior, and physiological reactivity was measured), evaluated the women's illnesses during the past twelve months. Findings showed that the psychological variable most consistently predictive of subsequent good health in women was having an internal locus of control.

Correlational analyses showed an internal locus of control as being related to both illness frequency and severity (Lawler & Schmied, 1992).

Other research, which focused on Health Locus of Control (HLC) and self-efficacy beliefs in healthy elderly individuals, found that healthy elderly were characterized by an internal health locus of control (IHLC), high generalized self-efficacy, and good health practices. These individuals accepted the responsibility of maintaining their good health status, perceived that they had the ability to do so, and practiced healthy behaviors that led to the expected outcome of good health in the later years (Waller & Bates, 1991).

Findings from another study however, which investigated factors that may influence women to practice an early detection behavior, breast self-examination (BSE), showed that health locus of control had no association with the practice of BSE (Sands, 1981). The hypothesis that women who practice BSE more frequently, as opposed to those who practice it less frequently, would have a higher IHLC was not supported in this research.

In a further study, Thomas and Fick (1995) found that a powerful other locus of control (POLC) was positively

related to engaging in preventive health practices, with women possessing an external locus of control being the most receptive to physician-initiated procedures such as clinical breast examination. This study also showed that women in a low-income group expressed greater belief in the influence of uncontrollable external factors on their health (e.g., will of God, bad luck), than those in a higher income group.

Relationship of HLC and Attitude toward Genetic Susceptibility Testing for Breast Cancer.

Empirical studies on the specific relationship of HLC and women's attitudes toward genetic susceptibility testing were not found. However, it is thought that the potential knowledge acquired through genetic susceptibility testing and the subsequent improvement in decision-making ability, might appeal to individuals who are motivated by a desire to maintain control over their health. Studies have found that interest in genetic testing for breast cancer has been associated with attitudes and behaviors concerning mammography (Chaliki et al., 1995; Tambor et al., 1997).

Tambor et al. (1997) found that a number of variables related to health care behaviors and intentions (e.g., recency of clinical breast exam and plans for future

mammograms) were associated with interest in testing in bivariate analysis, but were not significant predictors in regression analyses. Attitudes toward mammography, however, were important predictors of interest in testing. Specifically, women who reported that having regular mammograms gave them a feeling of control over their health, were more likely to be interested in genetic susceptibility testing than those who did not believe that mammograms gave them a feeling of control. Thus, women who have an internal locus of control may be more likely to be interested in another breast cancer screening procedure --genetic susceptibility testing for breast cancer--if found to be at high risk.

Knowledge of Genetic Susceptibility Testing for Breast Cancer

In their study, Ludman, Curry, Hoffman, & Taplin (1999) found that despite increasing media attention, almost half of the women they surveyed while visiting a primary care clinic, had read or heard almost nothing about genetic testing for breast cancer susceptibility. Furthermore, not surprisingly, most women did not have accurate information about breast cancer genetics (e.g., only 40% knew that a woman who does not have an altered

BRCA1 gene can still get breast cancer). And although few women gave incorrect answers, most responded that they did not know the answer to the questions asked about breast cancer genetics. A further study (Lerman, Narod et al., 1996) concurred with these findings, showing their subjects as giving correct responses for only about 55% of the items presented.

Ludman et al. (1999) found that though women who had heard or read about genetic susceptibility testing for breast cancer were more likely to agree that genetic testing should be offered only to people who have a reason to think that they have an altered gene, many of the women in their study believed it should be offered to everyone. The researchers concluded that although most women knew little about genetic susceptibility testing, many expressed interest in being tested; thus, primary care providers may be asked to educate women about cancer genetics and appropriate use of susceptibility testing.

Women's interest in genetic susceptibility testing may be instigated by many factors. Studies have shown that socio-demographic variables (e.g., age, education, income and ethnicity) are strongly related to women's knowledge of genetic susceptibility testing for breast cancer.

Mogilner, Otten, Cunningham & Brower (1998), surveying a total of 354 women who completed a questionnaire concerning the breast cancer genes BRCA1 and BRCA2, showed that the very young, the very old, and African-Americans, were the least informed in terms of awareness of the genes and the availability of testing for the breast cancer susceptibility genes. Jewish people, people with a college education or beyond, people earning more than $30,000 a year, and Caucasians, were more aware of the genes and of testing for these genes.

These findings concurred with Tambor et al. (1997), who also found that women who described themselves as comfortable financially, had at least some college education, and were pre-menopausal, were more likely to have heard of the gene discovery than women who were not financially comfortable, had no more than a high-school education, and were post-menopausal.

Lipkus et al.'s (1999) research with African-American women with and without a family history of breast cancer, showed that knowledge of breast cancer risk factors was very poor and correlated weakly with perceptions of risk and concern. In this study, women with a family history of breast cancer expressed greater interest in genetic testing

for breast cancer susceptibility than women without a family history, although interest in testing was high overall--a finding which concurs with Ludman et al.'s conclusion that women need to be educated about the appropriateness of genetic susceptibility testing.

Relationship of Knowledge of Genetic Testing for Breast Cancer Susceptibility and Attitude toward Genetic Testing for Breast Cancer Susceptibility.

Little empirical data to date could be found regarding the relationship between women's knowledge of genetic susceptibility testing for breast cancer and their attitude toward genetic testing. Ludman et al. (1999) did find that despite limited knowledge about genetic testing, most women believed that genetic testing for breast cancer susceptibility should be offered to everyone, with many women in this study stating that they planned to undergo such testing themselves. However, women who were more informed about genetic susceptibility testing were more likely to believe that genetic testing should be offered only to people who have a reason to think that they have an altered gene.

Prior Research on Attitude toward Genetic Testing for Breast Cancer Susceptibility

The readiness of many women to seek breast cancer susceptibility testing can be attributed, in large part, to their perceptions that the advantages outweigh the disadvantages (Jacobsen et al., 1997). Preliminary studies have found that women are interested in proceeding with genetic testing. Braczkowski et al. (1998) reported that 77% of women in their study (N=200), accepted genetic tests for breast cancer. Additionally, Julian-Reynier et al. (1996), in their preliminary investigation, found that 87.7% of their sample (N=209), stated that they would ask for breast cancer gene testing if this test became available. Ludman et al. (1999) found that more than three quarters of the 91 respondents in their study reported believing that once genetic testing is available, it should be offered to everyone. And, despite limited knowledge about genetic testing, many women said that they plan to undergo such testing themselves. Seventy-one percent of the respondents indicated they would proceed with testing if insurance covered the cost, and 44% would do so even if they had to pay out of pocket.

Tambor et al. (1997) reported that 69% of the 473 women aged 50 and over who were surveyed (almost all of whom did not have an increased risk of breast cancer based on family history), responded that they would be interested in being tested to find out if they had a breast cancer gene. Tambor et al. found that variables significantly associated with interest in testing included age, race, working status, and adherence to surveillance practices for breast cancer. In their study, women younger than 60 were almost three times as likely to be interested in the test as women aged 60 and over, and white women were over twice as likely to be interested as African American or other ethnicities. Their sample of working women showed 68% as being interested in testing, with only 32% of non-working women being interested. Additionally, women who believed that having a mammogram would benefit their families, were twice as likely to be interested as those who did not believe their family would benefit. And women who believed that having regular mammograms gave them a feeling of control over their health were almost three times as likely to be interested in genetic testing as those who did not have this belief.

Mogilner, Otten, Cunnigham & Brower (1998) found that most groups in their study expressed interest in testing for the breast cancer susceptibility genes, with the exception of those above 60 and those with only an elementary school education. Additionally, a family history of breast cancer did not seem to correlate to a significantly higher interest in genetic testing for hereditary breast cancer.

Durfy et al. (1999) listed significant predictors of interest in genetic testing for breast and ovarian cancer susceptibility, as cancer worry, perceived risk, and beliefs about access to testing. Women thought the decision to be tested should be a personal choice, favored ready access to testing, and believed that genetic test results should stay confidential. Lerman, Narod et al. (1996) further report that rates of test use may be higher in persons of a higher socioeconomic status and those with more relatives affected with breast cancer.

Disclosure of Genetic Test Results for Breast Cancer Susceptibility to Family Members and Employers or Insurance Providers

Family members. Genetic information is distinctive in that an individual's test result can be informative about the potential genetic characteristics of parents, siblings,

and children. Disclosure of test results to family members may be a very complex issue for women. While interviewing women one month after receipt of genetic test results, Williams and Schutte (1997) found that some carriers experienced difficulty disclosing results to selected family members. Lerman and Croyle (1996) state that family issues promise to be a very complicated consideration in genetic testing, stressing the need for professionals to discuss family relationship issues and the impact of genetic information on the family before and after the communication of test results. They additionally contend that the spouse can be a "forgotten person" in genetic counseling, with the strain of the test process exacerbating problems in marital relationships.

However, in a previous study on cancer survivors, Cella and Tross (1986) state that the majority of cancer survivors reported that their marital relationship was satisfactory or better after the diagnosis than pre-diagnosis, and this may also prove to be true for family relationships of women receiving positive test results from genetic screening.

In their study of 200 Polish women's (of different age, education and professional status) attitudes and

possible acceptance of genetic tests for breast cancer susceptibility, Braczkowski et al. (1998) found that 48% of the women accepted informing their close relatives of the genetic test results. Another study (Julian-Reynier et al., 1996) showed 90% of participants indicating that they would inform the family members at risk about the availability of predictive testing. The main reason given for not informing the relatives was difficult family relationships. Other reasons included: lack of perceived usefulness, the unpleasantness of the message, the disturbance it would cause, and the likelihood that the message would be rejected. Among the 161 cases in this study, 16% of the participants stated that they would prefer their relatives be contacted directly by the oncologist.

Employers or insurance providers. Questions regarding insurance companies' access to and use of genetic test results and genetic information have been raised since the beginning of the Human Genome Project (Zimmerman, 1998). Insurance companies maintain that the ability to place applicants of similar risks in groups (underwriting) is critical to the availability and affordability of individually underwritten life, disability income, and

long-term care insurance. However, how life insurance companies use medical information and particularly genetic test results and other genetic information in the risk assessment process is a matter of concern.

Although at present 26 states have enacted laws prohibiting the insurance industries in those states from using genetic information/testing in setting rates or denying coverage, Young, Brooks, Edwards, and Smith (1998) state that there are still no national regulations prohibiting the use of genetic information by the insurance industry in a discriminatory manner. And until this occurs, it is mandatory to discuss these possibilities with the patient.

A substantial portion of medical insurance in the U.S. is provided by employers' group policies. While there are no medical risks with genetic testing, one of the psychosocial consequences of testing is fear of being at risk of genetic discrimination (Kodish et al., 1998). It has been shown that women who have been identified as carriers have expressed concerns regarding disclosure of testing to insurance providers (Williams & Schutte, 1997). Kadison et al. (1998) found in a telephone-based breast cancer risk assessment study, that although women at a

greater genetic risk tended to call the survey, these same women were reluctant to furnish a name and address to receive additional information. The researchers contend that it is possible that women with a genetic risk may not reveal this information given a fear that it will be obtained by their company or insurance carrier.

Mann and Borgen (1998) found that in people being tested for inherited metabolic diseases, 25% believed they were refused life insurance, 22% health insurance, and 13% believed they were refused or let go from a job as a result of the condition. The researchers further state that fear of similar discrimination after genetic testing for cancer susceptibility is a major reason given for not being tested when the indications appear clear. Another study (Lerman, Narod et al., 1996) found that the possibility of losing health insurance was rated as a somewhat or very important limitation or risk of genetic testing by 34% of their sample.

Summary and Purpose of Study

Genetic testing for breast cancer susceptibility is becoming widely available and is being promoted by for-profit laboratories. Prior studies show that around half of all women surveyed have heard almost nothing about

genetic testing and do not know the answers to basic questions about breast cancer genetics. However, despite this lack of knowledge, most women thought that every woman should be offered testing. Studies also reveal poor breast cancer screening practices by many women today, pointing to the roles of cancer worry, women's perceived risk of contracting breast cancer, and socio-demographic factors, as either promoting or deterring routine screening practices. Women's internal health locus of control has been linked to the practice of routine mammography; however, studies were not found linking health locus of control to women's attitudes toward genetic susceptibility testing for breast cancer.

Additionally, studies show that most women are interested in learning more about cancer genetics and testing and are seeking information about hereditary breast cancer (HBC) and genetic susceptibility testing from a variety of sources, including: family physicians or other medical personnel, television, the print media, or the Internet. As women assimilate this information, their attitudes and beliefs will be shaped, with fears and anxieties being either increased or allayed, along with

potentially increasing or decreasing surveillance practices and prophylactic measures.

Health care systems must be prepared to address the demand for genetic counseling services, not only among women at high risk for carrying genetic mutations, but also among women who are at average risk, since potential demand for testing may be greatest among women for whom testing is least appropriate. With previous studies showing a high level of initial interest in genetic testing for breast cancer, it is important to ensure that women who express an interest in being tested are made fully aware of testing criteria, along with the limitations and possible consequences of testing (e.g., future fertility intentions, potential apprehension for other relatives following positive test results of a family member, psycho-social implications if a woman were to elect prophylactic surgery, or genetic discrimination at the workplace, etc.).

Genetic susceptibility testing for breast cancer is a relatively new subject in the area of women's health. In order for health care systems to implement optimal educational and counseling protocol for women of every risk and socio-demographic status, there is a need for further investigative studies to assess what and where women are

learning about genetic susceptibility testing, and how they are reacting to a screening option that can be highly psychologically charged. Lerman and Croyle (1996) contend that an implicit assumption of cancer genetic testing programs, is that the communication of information concerning one's risk of cancer will motivate individuals to modify their behavior (e.g., diet, exercise, utilization of screening services, self-examination) in ways that will reduce their risk of premature death from the disease. Therefore, it is essential that clinical protocols be informed by behavioral science theory and research.

The present study explores these issues by investigating women's (35-70 years who have not been diagnosed with breast or ovarian cancer) attitudes toward genetic testing for breast cancer susceptibility. The study is in the form of a questionnaire (Women's Health Survey--see Appendix B), and will assess women's and their family's health histories, along with women's surveillance practices for breast cancer, perceived risk of contracting breast cancer, health locus of control, and knowledge of genetic susceptibility testing for breast cancer.

Additionally, the relationship of socio-demographic data (age, race/ethnicity, education, marital status, and

income level) and women's attitudes toward genetic susceptibility testing for breast cancer will be studied. Exploratory information will also be collected on women's reported sources of information (including health personnel sources of information) of genetic testing for breast cancer susceptibility. Further exploratory questions will assess women's attitudes toward disclosure of genetic test results to their families and employers. This investigative study is intended to broaden the scope of knowledge regarding women's attitudes toward genetic susceptibility testing for breast cancer in order to facilitate the implementation of optimal counseling and educational programs for all women.

Specifically, the study addresses the following four research questions: What is the relationship between women's: 1) breast cancer surveillance practices 2) perceived risk of contracting breast cancer 3) health locus of control, and 4) knowledge of genetic susceptibility testing for breast cancer, and their attitude toward genetic susceptibility testing for breast cancer?

Rationale for Hypotheses.

Adherence to Routine Surveillance for Breast Cancer.

Although there have been contradictory study results as to how anxiety and cancer worry affects women's surveillance practices, research has shown that women who believed their families would benefit if they had a mammogram and who believed that regular mammograms gave them a feeling of control over their health, were more likely to be interested in genetic testing for breast cancer susceptibility than those who did not (Tambor, Rimer, & Strigo, 1997). Therefore, the hypothesis regarding adherence to routine screening practices for breast cancer is as follows:

1) Women aged 35 to 70 years (who have not been diagnosed with breast or ovarian cancer), who practice routine screening for breast cancer, are more likely to have positive attitudes toward genetic testing for breast cancer susceptibility, than those who do not practice routine screening for breast cancer.

Perceived Risk.

Research (Wilcox & Stefanick, 1999) provides increasing evidence that feeling at greater risk for a

disease relates to an increase in preventive health behaviors. Lipkus et al. (1999) and Durfy et al. (1999), revealed that increased levels of perceived breast cancer risk and concerns were related to a greater interest in genetic testing. Further research also reported no association between actual risk factors and women's readiness for future susceptibility testing, but concluded that perceived risk is the more important factor in determining interest in genetic screening (Jacobsen et al., 1997; Lerman et al., 1994, 1995; Struewing et al., 1995; Tambor et al., 1997). Therefore, the following hypothesis is made:

2) The higher a woman's perceived risk of contracting breast cancer during the next five years (for women aged 35 to 70 years who have not been diagnosed with breast or ovarian cancer), the more positive her attitude will be toward genetic testing for breast cancer susceptibility.

Health Locus of Control (HLC).

In their research, Tambor et al. (1997) found that attitudes toward mammography were important predictors of interest in genetic testing. Specifically, women who reported that having regular mammograms gave them a feeling of control over their health, were more likely to be

interested in genetic susceptibility testing than those who did not believe that mammograms gave them a feeling of control. Although empirical studies on the specific relationship of HLC and women's attitudes toward genetic susceptibility testing for breast cancer were not found, Tambor's research would suggest that women with an internal health locus of control may possess a similar attitude toward genetic susceptibility testing for breast cancer (a screening process for high risk women) and traditional breast cancer screening procedures, such as mammography. Additionally, it is thought that the potential knowledge acquired through genetic susceptibility testing and the subsequent improvement in decision-making ability, might appeal to individuals who are motivated by a desire to maintain control over their health. Therefore, the following hypothesis is suggested:

3) Women aged 35 to 70 years (who have not been diagnosed with breast or ovarian cancer) who exhibit an internal health locus of control, are more likely to show more positive attitudes toward genetic testing for breast cancer susceptibility than those who exhibit an external health locus of control.

Knowledge of Genetic Susceptibility Testing for Breast Cancer.

As mentioned above, studies have found that most women know very little about genetic testing for breast cancer susceptibility and hereditary breast cancer (Lerman, Narod et al., 1996; Ludman et al., 1999). Ludman et al. did find that women who were more informed about genetic susceptibility testing were likely to agree that genetic testing should be offered only to people who have a reason to think that they have an altered gene. However, empirical studies were not found regarding the specific relationship of women's current knowledge of genetic susceptibility testing and their attitudes toward testing. In order to investigate this issue in the present study, the following hypothesis is suggested:

4) Women aged 35 to 70 years (who have not been diagnosed with breast or ovarian cancer), who are more knowledgeable of genetic susceptibility testing for breast cancer, are more likely to have positive attitudes toward genetic testing for breast cancer susceptibility than those who are less knowledgeable.

METHOD

Participants

One hundred and thirty-seven women between the ages of 35 and 70 years, who had not been diagnosed with breast or ovarian cancer, were recruited from the general population in Southern California. Women were attending appointments with their physicians or dentists at various medical practices (dermatology, opthamology, family practice or dental), or attending women's groups (book or investment clubs). Additionally, a sample of women employees (salesclerks and secretaries) at several local businesses were recruited.

Materials and Procedures

Overview. Prior to the distribution of the instrument used in this study, the "Women's Health Survey" (See Appendix B), an appointment was made with each office involved, to discuss the format of the questionnaire. Consent by the physician/dentist and/or the office personnel to distribute the questionnaire to appropriate participants for the study, was also verified.

After responding to an "informed consent" form (see Appendix A), women in the study population participated in the research by filling out a questionnaire (Women's Health

Survey) (WHS) that had been adapted from six sources--the Breast Cancer Gail Model Risk Assessment Tool, the 1999 Behavioral Risk Factor Surveillance System Questionnaire used by the Center for Disease Control (Section 11—Women's Health), the University of California, Los Angeles' Familial Cancer Registry and Genetic Evaluation Program's Family History Screening Information Form, the U.S. Department of Health and Human Services, Center for Disease Control's preliminary draft of the National Health Interview Survey (NHIS) Year 2000 questions on genetic testing for cancer genes in the United States population, the Breast Cancer and Hereditary Knowledge Scale (Ondrusek, Warner, & Goel, 1999), and the Multidimensional Health Locus of Control Scales (MHLC) (Wallston, Wallston, & DeVellis, 1978). Participants were told that the survey would take approximately 15-30 minutes to complete.

Women's Health Survey (WHS). The questionnaire (WHS) included questions regarding the participant's health history, family health history (number of first degree "blood" relatives of participant diagnosed with breast, ovarian, or other cancers), and the participant's routine screening practices for breast cancer. Further questions assessed the participant's perceived risk of developing

breast cancer, both during her lifetime, and during the next five years, knowledge possessed of hereditary breast cancer and genetic testing for breast cancer susceptibility, and attitude toward responsibility of her health.

Additional questions assessed the participant's attitude toward electing to proceed with genetic testing for breast cancer susceptibility (the DV in this study), if her health history were to suggest genetic screening. Socio-demographic questions were also asked, along with questions exploring women's sources of information regarding genetic susceptibility testing for breast cancer (including health personnel who had offered genetic susceptibility testing information to participants). Questions were also asked exploring women's attitudes toward disclosing genetic test results to their families and employers.

Data in the Women's Health Survey was categorized into five sections:

1. Socio-Demographic Information: Age, race/ethnicity, education, marital status and income level were assessed.

2. Family History Screening Information: Questions were asked regarding first degree relatives who had been diagnosed with cancer. Since genetic information refers to biological relatives only, special instructions were given to participants in order to avoid the use of step or adoptive parents, sisters, or children in their responses. One example: "How many FULL sisters do you have? (These are siblings that have the same mother and father as you do)."

Perceived Risk.

At the end of the "Family History Screening Section", participants were asked to estimate their perceived risk of contracting breast cancer during their lifetime and during the next five years. The questions read, "Looking back over the last nine questions (in the Family History Screening Section), what do you feel your chances are of developing breast cancer during your lifetime", and "What do you feel your chances are of developing breast cancer during the next five years?" Perceived risk was evaluated with percentage levels, and was treated as a continuous variable (range=0 to 100).

Participants were asked to estimate lifetime risk first, in order to "prepare" them for estimating their

chances of contracting breast cancer within the next five years, which may be a more difficult percentage to estimate for many women. The hypothesis which was made regarding women's perceived risk of contracting breast cancer within the next five years and their attitude toward genetic testing for breast cancer susceptibility, was done so in order to facilitate the use of the Breast Cancer Gail Model Risk Assessment Tool, which determines the participant's five year actual (empiric) risk.

Relationship between Perceived Risk and Actual (Empiric) Risk of Contracting Breast Cancer during the Next Five Years.

In exploring the correlation between women's perceived and actual (empiric) risk of contracting breast cancer within the next five years, empiric risk was evaluated using the Breast Cancer Gail Model Risk Assessment Tool, which utilizes personal histories regarding risk factors.[1] Six risk factors were included--age, race, number of first degree relatives with breast cancer (mother, sister or

---

[1]The Breast Cancer Gail Model Risk Assessment Tool is widely known to the medical and biostatistical communities, and is being used increasingly to determine individual breast cancer risk, and to tailor preventive health recommendations accordingly.

daughter), age at first menses (11 years or younger, 12 - 13 years, or 14 years or more), age at first live birth or nulliparity, and number of past breast biopsies. Scoring is done using the Gail Model (a mathematical model which produces a risk "index" based on the six factors), where a score of 1.7 or above, indicates a high-risk status.

Perceived risk (reported originally as percentages) of the participant was converted into relative risk (since relative risk is calculated by the Gail Model). Relative risk reported by the participant was then compared with statistical analyses with the relative risk calculated directly by the Gail model.

3. Health and Breast Screening Information: The 1999 Behavioral Risk Factor Surveillance System Questionnaire used by the Center for Disease Control (Section 11--Women's Health) was used to assess participants' routine screening practices for breast cancer (mammograms, clinical breast exams and self-breast exams). Reliability coefficients on this measure for behavioral risk factors are above 0.70 (Stein, Lederman, & Shea, 1996). Questions included a description of the procedure, e.g: "A clinical breast exam is when a doctor, nurse, or

other health professional feels the breast for lumps. Have you ever had a clinical breast exam?"

Adherence to routine screening practices for breast cancer was assessed by scoring a woman's adherence in three categories: 1) routine mammograms 2) yearly clinical breast examinations, and 3) monthly self-breast examinations. For women 40 years of age and over, total screening scores were calculated with 0 being the lowest score possible and 3 being the highest. Women received one point if they practiced routine screening in the recommended amount of time, and a zero if they did not practice routine screening in the recommended amount of time (for each of the three categories).

Since screening recommendations for mammograms differ for women under 40 years of age, mammography screening scores were left out for this age group. Therefore, women in this category could score from 0 to 2 in screening for yearly clinical breast exams and self-breast exams, with a high score of 2 and a low score of 0.

In this section of the questionnaire ("Health and Breast Screening Information"), additional questions regarding history of pregnancies, age at first live birth, age at menarche, and history of breast biopsies were asked,

to provide required data for the Breast Cancer Gail Model Risk Assessment Tool.

4. Genetic Screening Information: The University of California, Los Angeles' Familial Cancer Registry and Genetic Evaluation Program's Family History Screening Information Form was utilized in assessing the participants' awareness of genetic susceptibility testing. One question was asked to assess women's current awareness of genetic susceptibility testing for breast cancer: "Have you ever heard of genetic testing to determine if a person is at greater risk of developing breast cancer?"

For women who indicated an awareness of genetic testing, additional questions were asked regarding sources of genetic susceptibility testing information. Further questions assessed women's knowledge of hereditary breast cancer and genetic testing for breast cancer susceptibility, and their attitude toward proceeding with genetic testing for breast cancer risk, if their health history were to suggest testing (the DV in this study). Exploratory issues of disclosure of genetic test results to family or employer were investigated with open-ended questions.

Sources of Information for Genetic Testing for Breast Cancer Susceptibility.

Two questions assessed women's sources of genetic testing information. The first question asked the participants to indicate where they had learned about genetic susceptibility testing for breast cancer (a list of possible sources, e.g. television, magazine, or the Internet, was provided--See Appendix M), and to further indicate from which source they had received the most information. The second question asked the participants to indicate which health professional had spoken to them (if any) about genetic susceptibility testing for breast cancer. A list of possible health professional sources (e.g. nurse, gynecologist, or family practice physician) was also provided (See Appendix O).

Knowledge of Hereditary Breast Cancer and Genetic Testing for Breast Cancer Susceptibility.

Knowledge of hereditary breast cancer and genetic susceptibility testing for breast cancer was assessed using the U. S. Department of Health and Human Services, Center for Disease Control's preliminary draft of the National Health Interview Survey (NHIS) Year 2000 (section on genetic testing for cancer genes in the United States population). Additionally, questions from the Knowledge

Scale about Breast Cancer and Heredity (BCHK) developed by Ondrusek, Warner and Goel (1999) for women at low to moderate risk for hereditary breast cancer, was used. This measure was developed recently (1999), and presently test-retest reliability of the BCHK is at 0.81 (Ondrusek, Warner & Goel). Criterion validity was not determined at the initial development of the BCHK because no comparable previously validated scale existed. Construct validity was not examined because the test population was too heterogenous to look for trends in the scores; however, construct validity will be examined in studies planned for women scheduled for counseling at familial breast clinics.

The BCHK scale is formatted as a series of statements to which respondents are asked to "strongly agree", "agree", "disagree", or "strongly disagree", with a middle category for "unsure". A statement regarding women's knowledge of genetics and hereditary breast cancer was as follows: "A woman whose mother was diagnosed with breast cancer at age 69 is considered to be at high risk for breast cancer." A correct response to a statement, whether "strongly agree" or "strongly disagree" was assigned a value of 2. A less certain response of "agree" or "disagree" was assigned a value of 1. Incorrect responses

were given a negative value (-1), and "unsure " responses were assigned a value of 0. An overall score was used in the analysis of knowledge, with a possible range of -4 to +8.

Attitude toward Genetic Susceptibility Testing for Breast Cancer (DV).

Women's attitude toward genetic susceptibility testing was assessed by one question: "If your health history were to suggest that genetic testing for breast cancer risk would be advisable, would you be inclined to proceed with genetic testing?" A 5-point Likert scale ranging from "Absolutely Not" to "Absolutely Yes", was used, with 1=Absolutely Not; 2=Probably Not; 3=Unsure; 4=Probably Yes; 5=Absolutely Yes.

Disclosure of Genetic Test Results for Breast Cancer Susceptibility to Family and Employer.

Women's attitudes toward disclosure of genetic test results to their families or employers were also explored, with the open-ended questions, "If your health history were to suggest that genetic testing for breast cancer risk would be advisable, and you decided to proceed with genetic testing, what would be your primary concerns about discussing the genetic test results with your family", and "what would be your primary concerns about discussing the

genetic test results with your employer?" Participants were asked to fill in the blank, and responses were evaluated individually. Closely related responses were classified in order to generate clear descriptive categories (see Appendixes P and Q).

5. Current Health Status and Health Locus of Control (HLC) Information: Participants were asked to rate their present health (very poor, poor, good, very good, or excellent), and were then assessed for internal or external health locus of control (HLC). The Multidimensional Health Locus of Control Scale (MHLC), an 18-item self-rating measure of the locus of control of health-related behavior (Wallston, Wallston, & DeVellis, 1978), was used in this study. The MHLC Scale is divided into three sub-scales of 6 items each which assess three dimensions of health locus of control: Internal HLC (IHLC), powerful others HLC (POLC), and chance HLC (CHLC). All items are arranged on 6-point Likert scales ranging from 1="strongly disagree" to 6="strongly agree". Each subscale has a range of 6 to 36 with a median score of 21. Respondents scoring above 21 on a subscale are classified as being high internal (if scoring the IHLC subscale), or low internal, if scoring 21 or below. Likewise, participants scoring above 21 in POLC

or CHLC subscales are classified as high external (POLC or CHLC), with respondents scoring 21 or below classifed as low external (POLC or CHLC).

Scores for each subscale are the sums of the following items: IHLC—1, 6, 8, 12, 13, & 17; POHLC—3, 5, 7, 10, 14, & 18; CHLC—2, 4, 9, 11, 15, & 16 (see Appendix B, WHS, Section: Current Health Status). Reliablities of the subscales, using Chronbach's alpha range from .81, .79, and .79, respectively (Wall, Hinrichsen, & Pollack, 1989), to .62, .64, and .60, respectively (Goldsteen, Counte, & Goldsteen, 1994).

The following questions are examples of the questions that were asked regarding the participant's locus of control: "I am directly responsible for my health getting better or worse" (IHLC), "If I see my doctor regularly, I am less likely to have problems with my health" (POHLC), or "Luck plays a big part in determining how my health improves" (CHLC).

RESULTS

Descriptive Statistics

A total of 137 women between the ages of 35 and 70 years, who had not been diagnosed with breast or ovarian cancer, returned the Women's Health Survey. The mean age was 49.38 years (see Appendix C) with predominantly white women (65%) participating. Hispanic or Latino women (16.9%) were the next highest ethnic group of participants with African American, Mexican American, and Asian women making up smaller percentages (see Appendix D). The mean education level of the respondents was 14.64 years (see Appendix E), and the majority (75.9%) of the participants were married, with 15.3% being divorced, 2.2% widowed and 2.2% separated (see Appendix F). Forty-one percent of the participants indicated an annual income of $75,000 or above and 18.7% of the respondents reported an annual income of $50,001 to $75,000 (see Appendix G).[2]

Analyses of the Four Predictor Variables

For convenience purposes, the DV in this study (women's attitude toward electing to proceed with genetic

---

[2]Note: Not all study participants responded to every question. Please consult Tables for missing values for individual questions.

susceptibility testing for breast cancer, if their health history were to suggest that testing would be advisable), will be abbreviated throughout the following sections as ATGT (attitude toward genetic testing). Additionally, due to the small number of respondents answering "Probably Not", "Absolutely Not" and "Unsure", compared with those responding in the 2 positive categories "Probably Yes", and "Absolutely Yes", the 5 categories for the DV were collapsed into 3 categories. This generated more comparable groups while producing results that were still meaningful. The three categories were abbreviated as follows: "Absolutely Not", "Probably Not", and "Unsure" became one category (N/U), with "Probably yes" (PY) and "Absolutely Yes" (AY) each becoming a category. A total of 26 study participants responded in the three categories which became one category (N/U), whereas 50 participants responded with PY and 60 participants responded with AY.

The relationships between each of the IV's and the DV (ATGT) were analyzed with the recoded DV (3 categories); thus while discussing results, references made to the differences between the "three groups" of the DV throughout the following sections refer to women responding "No", "Probably", or "Yes", when asked if they would proceed with

genetic susceptibility testing for breast cancer, if their health history were to suggest testing. The level of significance has been set at .05 for all statistical tests.

Predictor Variable 1--Women's Screening Practices

Question: Is there a significant correlation between favorability toward genetic susceptibility testing for breast cancer and a woman's breast cancer screening practices?

Hypothesis 1. It was hypothesized that women aged 35 to 70 years (who had not been diagnosed with breast or ovarian cancer), who practiced routine screening for breast cancer, would be more likely to have positive attitudes toward genetic testing for breast cancer susceptibility, than those who did not practice routine screening for breast cancer.

This hypothesis was supported with women aged 40 years or older, but not supported with women under 40 years of age. Since women under 40 years of age follow different breast cancer screening recommendations for mammography than women over 40 years of age, these two age groups were looked at separately.

Women 40 Years of Age and Older. There were 113 women aged 40 years or over who answered all three

questions regarding screening (mammography, clinical breast exam, and self-breast exam). For this age group, total screening scores were calculated with 0 being the lowest score possible and 3 being the highest (1 point for each screening procedure done during the recommended time period). The highest number of women (30.7%) scored 2 for routine surveillance, with 20 women scoring zero.

The non parametric Spearman's correlation coefficient was calculated to investigate the correlation between breast screening practices (IV) and ATGT (DV), since both variables were ordinal. The correlation coefficient was statistically significant, indicating that women who screened at the correct time in more categories were more likely to answer that they would participate in genetic susceptibility testing for breast cancer if necessary (see Table 1).

Table 1

Correlation of Routine Screening for Breast Cancer and ATGT in Women 40 Years of Age and Over

Correlations

			Genetic testing (3 cat)	Final score on exams for those >40
Spearman's rho	Genetic testing (3 cat)	Correlation Coefficient	1.000	.240*
		Sig. (2-tailed)	.	.010
		N	136	113
	Final score on exams for those >40	Correlation Coefficient	.240*	1.000
		Sig. (2-tailed)	.010	.
		N	113	114

*. Correlation is significant at the .05 level (2-tailed).

In order to investigate if there were a difference (in the distribution of screening scores) between the three groups of the DV, "Absolutely Not, Probably Not, or Unsure" (N/U), "Probably Yes" (PY), or "Absolutely Yes (AY), and breast screening surveillance scores, a Kruskal Wallis test was performed, with findings showing a statistically significant difference between the three groups ($H=.019$, $p<.05$). This result indicated a difference between at least 2 of the groups in their screening practices.

Further analyses investigated which groups in the DV differed in relation to women's breast cancer screening

scores. One-Way ANOVA on the ranks was performed and multiple comparisons were computed. Two of 3 multiple comparison tests (LSD and Duncan) showed statistically significant differences between those in the N/U category vs. both those who answered PY and those who answered AY. Results were as expected with those individuals who stated N/U scoring lower on the overall screening index than those answering either PY or AY. One of the 3 multiple comparisons (Tukey) resulted in a difference only between those who answered N/U and AY (the difference in this result may have been due to the lower sensitivity of the Tukey test).

Women under 40 Years of Age. There were 20 women who were under 40 years of age in this sample. For these women, mammography screening scores were left out. Therefore the overall screening index for women in this category ranged from 0 to 2. Spearman's correlation coefficients did not show a statistically significant relationship between favorability toward genetic susceptibility testing and screening practices in women under 40 years of age (r_s= -.170, p>.05). Note however that this sample was very small and may not have been a representative sample of women under 40 years of age.

Predictor Variable 2--Perceived Risk of Contracting Breast Cancer

Question: Is self-reported probability of contracting cancer during the next five years associated with higher or lower favorability toward genetic susceptibility testing for breast cancer?

Hypothesis 2. It was hypothesized that the higher a woman's perceived risk of contracting breast cancer during the next five years (for women aged 35 to 70 years who had not been diagnosed with breast or ovarian cancer), the more positive her attitude would be toward genetic testing for breast cancer susceptibility.

This hypothesis which was analyzed using Spearman correlation coefficients was not supported (r_s=.051, p>.05). Although participants were asked to indicate their perceived risk of contracting breast cancer both during their lifetime and during the next five years, the hypothesis was made only in regard to perceived risk of contracting breast cancer during the next five years. Five year perceived risk was asked in order to compare perceived risk and actual risk, with the use of the Breast Cancer Gail Model Risk Assessment Tool, which estimates the participant's actual "relative" risk of contracting breast

cancer during the next five years. (Findings for "lifetime perceived risk" and ATGT are reported in the Overview of WHS: Section: "Correlation of Perceived Risk of Contracting Breast Cancer within Lifetime and ATGT").

Predictor Variable 3--Health Locus of Control

Question: Do women who exhibit an internal health locus of control (HLC) look more favorably on genetic susceptibility testing for breast cancer than those who exhibit an external health locus of control (HLC)?

Hypothesis 3. It was hypothesized that women aged 35 to 70 years (who had not been diagnosed with breast or ovarian cancer) who exhibit an internal health locus of control, are more likely to show more positive attitudes toward genetic testing for breast cancer susceptibility than those who exhibit an external health locus of control.

With 101 participants scoring as having an internal HLC (IHLC), 69 scoring with an external HLC, powerful other (POLC), and 15 scoring with an external HLC, chance (CHLC), it was evident that some of the same participants scored above 21 in both the IHLC and POLC subscales (see Table 2 for the means, medians and standard deviations for the three subscales of HLC).

Table 2
Means, Medians and Standard Deviations of HLC as a Continuous Variable

Statistics

		Internal locus of control score	Chance score-health locus of control	Powerful others score-Health locus of control
N	Valid	133	130	133
	Missing	4	7	4
Mean		24.83	14.26	21.72
Median		25.00	13.00	22.00
Std. Deviation		5.03	5.37	4.37
Minimum		11	6	6
Maximum		35	29	33

Therefore, two analyses were used in determining the relationship of HLC and ATGT, since a participant could have overlap in the classifications of internal and external HLC.

In the first analysis, respondents were coded into either an internal HLC or an external HLC. Since a very low number of the respondents in this study were categorized as CHLC (n=15), external POLC and external CHLC were as treated one category. Individuals who scored above 21 on the IHLC subscale and 21 or less on both the POLC and CHLC subscales were categorized as having an internal HLC. Individuals scoring above 21 on at least one of the two

external subscale measurements and 21 or less on the IHLC subscale, were categorized as having an external HLC. If the individual scored above 21 on the IHLC subscale and scored above 21 on either of the two external subscales, they were excluded from the analysis.

From the frequency table (see Table 3), it can be seen that a total of 83 participants were excluded from the analysis, leaving a total of 49 participants for inclusion in this analysis. Thirty-one of the participants were ranked as internal only, and 18 ranked as external only.

Table 3

Frequency Table for HLC Subscales

Health Locus of Control

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Neither or both	83	60.6	62.9	62.9
	Internal only	31	22.6	23.5	86.4
	External only	18	13.1	13.6	100.0
	Total	132	96.4	100.0	
Missing	System	5	3.6		
Total		137	100.0		

A Mann Whitney test was used to test the null hypothesis that there was no difference in the distribution of attitude scores between respondents classified as having an internal HLC and those classified as having an external HLC. Results of the test were not significant (U= -.889, p>.05), and failed to reject the null hypothesis.

For the second analysis, only the IHLC subscale was utilized in determining the respondent's status to be either internal or not. A particpant scoring above 21 was classified as having an internal HLC. Those who scored at 21 or below were classified as not having an internal HLC. The Mann-Whitney Test was used to discover if there were a difference in the distribution of ATGT on the basis of the respondents having an internal or "not internal" HLC. There was no statistically significant difference in ATGT between those who had an internal HLC when compared to those who did not (U=.980, p>.05).

Further investigation using the Spearman Correlation Coefficient to see if there were a correlation between higher scores on internal HLC and a higher score in ATGT did not find a significant correlation between these two variables (r_s=.014, p>.05). A higher internal HLC did not

correlate with a more favorable outlook on genetic testing for breast cancer susceptibility.

With each of these anaylses showing no significant findings, the hypothesis regarding health locus of control and ATGT was not supported.

Predictor Variable 4--Knowledge of Genetic Susceptibility Testing for Breast Cancer

Question: Is there a correlation between women who have a higher degree of knowledge about genetic susceptibility testing for breast cancer and their likelihood of reporting that they would be inclined to proceed with genetic testing for breast cancer susceptibility if their health history would suggest that testing would be advisable?

Hypothesis 4. It was hypothesized that women (aged 35 to 70 years who had not been diagnosed with breast or ovarian cancer) who were more knowledgeable of genetic susceptibility testing for breast cancer would be more likely to have positive attitudes toward genetic testing for breast cancer susceptibility than those who were less knowledgeable.

The current study did not support this hypothesis. Spearman's correlation coefficients did not show a

statistically significant correlation coefficient for the association between the two variables (r_s=.012, p>.05).

Overview of Women's Health Survey

Exploratory Issue: Relationship of ATGT and Socio-Demographic Variables.

Age.

Since the assumptions of normality and equal variance held for the variable *age*, an ANOVA test was run, with results showing no statistically significant results (F[2,130]=.083, p>.05). There appeared to be no difference due to *age* among the 3 response groups (N/U, PY or AY) on ATGT.

Education.

The data for *education* was not normally distributed within each of the 3 dependent variable (ATGT) categories, thus the non parametric Kruskal Wallis test was used for the analysis to see if the distribution of *education* differed for the N/U groups compared with the PY and AY groups. There was not a statistically significant difference between the three groups (H=.812, p>.05) indicating that level of *education* did not influence ATGT.

Annual Income.

The distribution of *annual income* was heavily skewed and transformation did not result in a normal distribution. Therefore, the Kruskal Wallis test was used to investigate possible differences between the response categories based on income levels. Results showed no statistical difference ($H=.614$, $p>.05$) associated with *annual income* for the three response levels (N/U, PY, or AY) on ATGT.

Analyses for Race and Marital Status.

Due to the concentration of most observations in one category, these variables were recoded in order to create groups that were comparable numerically. These two demographic variables were grouped into two categories; then non-parametric Mann-Whitney statistical analyses were used to assess whether or not there were a difference between the two categories (e.g., *race* = white vs. other, *marital status* = married vs. not married) in attitude toward genetic testing for breast cancer susceptibility.

The findings for *race* were not significant ($U=.243$, $p>.05$) with no statistical difference in attitude toward genetic testing for breast cancer susceptibility between the two *race* categories. Findings for *marital status* (married vs. other) were also non-significant

(U=.917, p>.05) showing that there was no difference in the distribution of attitude scores between married and unmarried persons in this sample.

Family History Screening Information: Descriptive Statistics

To assess the participants' genetic risk, questions were asked regarding cancer diagnoses of first degree relatives (mother, sister and daughter). Since the criteria for participating in the study included women who had not been diagnosed with breast or ovarian cancer themselves, questions were included for self diagnosis of any cancers, to validate this criteria. None of the participants reported a previous diagnosis of breast or ovarian cancer; however, five of the participants reported cancer diagnoses other than breast or ovarian cancer.

Only one participant reported having a daughter who had been diagnosed with cancer, of which breast cancer was not the primary site. Thirty-six of the participants reported a diagnosis of cancer in their mothers. Of these, 14 indicated their mothers as being diagnosed with breast cancer as a primary source (see Appendix H). One participant reported their mother's age at diagnosis as 39 years, with two other participant's mothers being diagnosed

with breast cancer at the ages of 42 and 43 years (see Appendix I).

Eleven participants reported having a sister who had been diagnosed with cancer, with five of these diagnoses reporting breast cancer as the primary site. Since hereditary breast cancer is characterized by early onset, the ages of the sisters at breast cancer diagnoses were noted. The reported ages were 43, 47, 55, 57, and 66 years.

Health and Breast Screening Information: Descriptive Statistics

Age at First Full Term Birth or Nulliparity.

The majority of the participants, 121 women (89%), reported a pregnancy, with 15 women never experiencing pregnancy (nulliparity). Sixteen women indicated that they had experienced a miscarriage before full term. Of the participants who did not experience a miscarriage before full term, the mean age of women at the time of their first full-term birth was 24.07 years (see Appendix J).

Age at Menarche.

Of the 137 participants, 56.2% reported age of menarche between the ages of 12 to 13 years, with 25.5% indicating the age of 11 years or younger at menarche.

Within the 14 years or older age category, 18.2% of the participants reported menarche.

Number of Breast Biopsies.

Twenty (14.6%) of the 137 women in the study had experienced a breast biopsy with two respondents declining to indicate the number of biopsies they had experienced. Twelve women reported having had one biopsy, and 6 women reported two or more past breast biopsies.

Routine Surveillance for Breast Cancer.

Mammogram.

The majority of the participants (80.3%) reported having a mammogram in the past; however, only 58.3%of the respondents had had a mammogram within the last year (see Table 4).

Clinical Breast Exam.

All of the participants indicated that they had experienced a clinical breast exam, with 65.7% reporting a clinical exam within the past year, and 16.8% reporting an exam within the past two years (see Table 5).

Table 4

Time of Last Mammogram

How long has it been since you had your last mammogram?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within the past year	67	48.9	58.3	58.3
	Within the past 2 years	23	16.8	20.0	78.3
	Within the past 3 years	7	5.1	6.1	84.3
	Within the past 5 years	7	5.1	6.1	90.4
	5 or more years ago	9	6.6	7.8	98.3
	Don't know/not sure	2	1.5	1.7	100.0
	Total	115	83.9	100.0	
Missing	System	22	16.1		
Total		137	100.0		

Table 5

Time of Last Clinical Breast Exam

How long has it been since you last had a clinical breast exam?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within the past year	90	65.7	65.7	65.7
	Within the past 2 years	23	16.8	16.8	82.5
	Within the past 3 years	8	5.8	5.8	88.3
	Within the past 5 years	11	8.0	8.0	96.4
	5 or more years ago	5	3.6	3.6	100.0
	Total	137	100.0	100.0	

Self-Breast Exam.

One hundred and thirty women reported that they had done a self-breast exam in the past, with 7 women indicating that they had never conducted a self-breast exam. Of the 130 participants, 47.3% reported that they had done a self-breast exam during the past month (1 to 30 days), with 22.1% indicating a self-breast exam within the past 3 months (30 to 90 days) (see Table 6).

Table 6

Time of Last Self-Breast Exam

How long has it been since you last did a self-breast exam?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within the past month	62	22.5	47.3	47.3
	Within the past 3 months	29	10.5	22.1	69.5
	Within the past 3 to 6 months	15	5.4	11.5	80.9
	Within the past 6 months to one year	13	4.7	9.9	90.8
	One or more years ago	7	2.5	5.3	96.2
	Don't know/ Not sure	5	1.8	3.8	100.0
	Total	131	47.5	100.0	
Missing	System	145	52.5		
Total		276	100.0		

Perceived Risk of Contracting Breast Cancer Within Next Five Years

The mean percentage of self-reported probability of contracting breast cancer over the next five years was 16.9%. The largest number of participants (n=37) reported a 10% probability, and 16 respondents indicated a 50% probability, with 16 respondents also indicating a 0% probability of contracting breast cancer within the next five years. Three participants (2.5%) reported a high percentage (80%) of contracting breast cancer within the next five years (see Appendix K).

Perceived Risk of Contracting Breast Cancer Within Lifetime

The mean percentage of participants' self-reported risk of contracting breast cancer during their lifetime was 21.5%. The largest number of participants (n=31) reported a 10% probability of contracting breast cancer during their lifetime, with 17 respondents indicating a 50% perceived risk of contracting breast cancer during their lifetime (see Appendix L).

Lifetime perceived risk of contracting breast cancer was analyzed with a Spearman Correlation Coefficient Test which showed no statistical reason to believe that as self reported risk (within lifetime) increases, the propensity

to undergo genetic susceptibility testing for breast cancer also increases (r_s=.046, p>.05).

Genetic Screening Information

All of the 137 participants responded to the question "Have you ever heard of genetic testing to determine if a person is at greater risk of developing breast cancer?" Eighty-four of the respondents answered "Yes", with forty-eight participants responding "No" (see Table 7).

Table 7

Awareness of Genetic Susceptibility Testing for Breast Cancer

Have you ever heard of genetic testing for breast cancer risk?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	84	61.3	61.3	61.3
	No	48	35.0	35.0	96.4
	Don't know/Not sure	5	3.6	3.6	100.0
	Total	137	100.0	100.0	

Knowledge of Genetic Testing for Breast Cancer Susceptibility.

Although 84 participants responded that they had heard of genetic testing for breast cancer susceptibility, women

revealed a low knowledge level of genetics and hereditary breast cancer. On the Knowledge Scale (Ondrusek, Warner & Goel, 1999), a high score of 8 and low score of -4 were possible; however the participants' scores ranged from a high score of 6 to a low score of -3. The mean overall score for knowledge was 1.17. The largest percentage of participants (28.6%) scored zero, which indicated an "unsure" response. Table 8 shows the overall scores for the knowledge scale.

Table 8

Overall Knowledge Scores

Overall score for knowledge

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	-3	2	1.5	1.5	1.5
	-1	12	8.8	9.0	10.5
	0	38	27.7	28.6	39.1
	1	33	24.1	24.8	63.9
	2	20	14.6	15.0	78.9
	3	17	12.4	12.8	91.7
	4	7	5.1	5.3	97.0
	5	2	1.5	1.5	98.5
	6	2	1.5	1.5	100.0
	Total	133	97.1	100.0	
Missing	System	4	2.9		
Total		137	100.0		

Attitude toward Genetic Susceptibility Testing for Breast Cancer.

When participants were asked to respond to the question, "If your health history were to suggest that genetic testing for breast cancer risk would be advisable, would you be inclined to proceed with genetic testing?" (the DV in this study), the majority of the participants responded that they would either "probably" or "absolutely" be inclined to proceed with testing if their health history would advise testing (see Table 9).

Table 9

Attitude toward Genetic Susceptibility Testing for Breast Cancer

Would you be inclined to proceed with genetic testing?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Absolutely not	5	3.6	3.7	3.7
	Probably not	4	2.9	2.9	6.6
	Unsure	17	12.4	12.5	19.1
	Probably yes	50	36.5	36.8	55.9
	Absolutely yes	60	43.8	44.1	100.0
	Total	136	99.3	100.0	
Missing	System	1	.7		
Total		137	100.0		

Exploratory Issue: Sources of Information for Genetic Susceptibility Testing for Breast Cancer.

Of the participants who had heard of genetic susceptibility testing for breast cancer, the majority of women (78.6%) indicated television as a source of information, with 46.4% listing magazines, and 38.1% indicating newspapers as a source of information (see Appendix M).

In responding to the question, "Where have you received the most information about genetic testing to determine if a person is at greater risk of developing breast cancer", television was again indicated by 35.7% of the participants (see Appendix N).

When participants were asked if a health professional had spoken with them about genetic testing for breast cancer susceptibility, 67.9% responded that no one had spoken to them, with 8.3% indicating that they had learned about genetic testing from their family practice physician. Some participants (6%) also listed their gynecologist as a source of information (see Appendix O).

Exploratory Issue: Disclosure of Genetic Test Results to Family and Employer.

Family.

Open-ended questions were asked in the Women's Health Survey in an effort to investigate women's concerns regarding disclosure of genetic susceptibility test results to their families. The greatest percentage (38.1%) of respondents indicated that they had "No concerns". Some participants (11.5%) listed concerns about test results being a worry to their family, with other women (7.1%) listing as a concern the effect that test results may have on their daughters/children (see Appendix P)

Employer.

The largest percentage (29.5%) of participants indicated that genetic test results were none of their employer's business, or that they would not reveal test results to their employer. Some of the participants (11.4%) were concerned about job security, and 2% of the respondents indicated that they had no concerns (see Appendix Q).

Exploratory Issue: The Relationship of Women's Perceived Risk and their Actual (Empiric) Risk of Contracting Breast Cancer during the next Five Years

Respondents were asked to estimate their percentage of perceived risk of developing breast cancer over the next five years and their lifetime. An exploratory question of interest was how close the respondent's perceived risk was to their actual risk. Calculations were made of the relative risk of developing breast cancer at the point in time that the respondent's answered the questionnaire by using the Breast Cancer Gail Model Risk Assessment Tool. Comparisons were made between the relative risk of developing breast cancer at the time of the questionnaire and the relative risk reported by the respondent over the next five years. The question of interest was whether or not the distribution of answers supplied by the respondent for their perceived five-year risk was statistically different from the distribution of answers provided for risk by the Gail Model. This was assessed using both non-parametric (Wilcoxin Signed Ranks Test) and parametric measures (Paired t-test) since the data was questionably normal.

The null hypothesis for the non-parametric test was as follows: There is no difference in the distribution of

relative risk reported by respondents and the distribution of scores calculated by the Breast Cancer Gail Model Risk Assessment Tool. The results of the Wilcoxin Signed Ranks Test lead to rejection of the null hypothesis (T= -9.104, p=.000) (See Appendix R). Statistically there was a highly significant difference (p<.000) between the distributions of risk reported by the respondent and those calculated by the Gail Model Risk Assessment Tool. The risk reported by the respondent was higher than the risk reported by the Gail Model.

The null hypothesis for the parametric test was as follows: There is no difference in the mean relative risk reported by the respondents and the mean relative risk calculated by the Breast Cancer Gail Model Risk Assessment Tool. The results of the paired samples t-test resulted in rejection of the null hypothesis (Paired sample means and standard deviations, and Paired t-test for difference of reported relative risk and actual risk within next five years are reported in Appendix S). The means of the relative risk reported by the respondents were statistically different from the mean relative risk calculated by the Breast Cancer Gail Model Risk Assessment Tool (t= -37.397, p=.000). The relative risk calculated by

the Gail Model was lower than the relative risk reported by the respondent.

DISCUSSION

Genetic susceptibility testing for breast cancer is a powerful new technology which may save lives. This study was conducted in an effort to determine what women currently know about this new technology, and what their attitudes are toward genetic testing. The present study examined the relationship between women's 1) surveillance practices for breast cancer 2) perceived risk of contracting breast cancer 3) health locus of control, and 4) knowledge of genetic susceptibility testing for breast cancer, and their attitudes toward genetic testing for breast cancer susceptibility (ATGT). The study also explored the relationships of socio-demographic factors and women's attitudes toward genetic susceptibility testing, and identified the informational sources where women may be learning about genetic susceptibility testing for breast cancer. Further exploration looked at women's attitudes toward the disclosure of genetic test results for breast cancer susceptibility to their families and employers. Finally, the relationship of women's perceived risk and their actual (empiric) risk of contracting breast cancer during the next five years was examined.

This study (which included 137 women between the ages of 35 and 70, who had not been diagnosed with breast or ovarian cancer) was conducted to assist in exploring the following vital issue which underlies these research questions: How can we expedite the development of the most useful educational and counseling protocols for cancer genetic testing that will reach women of every risk status and in all socio-demographic groups?

Hypotheses

Hypothesis 1: Routine Surveillance.

The hypothesis that women, aged 35 to 70 years (who had not been diagnosed with breast or ovarian cancer) who practiced routine screening for breast cancer (routine mammograms, yearly clinical breast exams by their physicians, and monthly self-breast exams) were more likely to have a positive attitude toward genetic susceptibility testing for breast cancer than those who did not practice routine screening for breast cancer, was the only hypothesis which was supported in this study. These findings concurred with previous study results (Chaliki et al., 1995; Tambor, Rimer, & Strigo, 1997) which showed that women who believed their family would benefit if they had a mammogram and that regular mammograms gave them a feeling

of control over their health were more likely to be interested in genetic susceptibility testing.

This hypothesis, however, was supported only among 40 to 70 year old women in the study. In 35 to 40 year old women, the hypothesis was not statistically supported. As noted earlier, this finding for younger women may not have been representative because of a small sample size (n=20), which will be discussed below under "Methodological Issues".

Hypothesis 2: Perceived Risk.

The hypothesis that the higher a woman's perceived risk of contracting breast cancer during the next five years (for women aged 35 to 70 years who had not been diagnosed with breast or ovarian cancer), the more positive her attitude would be toward genetic testing for breast cancer susceptibility, was not supported in this study. These findings did not coincide with some past research (Jacobsen, Valdimarsdottier, Brown & Offit, 1997; Lerman et al., 1994, 1995; Lipkus et al., 1999; Tambor et al., 1997) which has suggested that greater perceived risk was associated with greater readiness for genetic susceptibility testing for breast cancer.

Past study results also show mixed findings regarding traditional screening procedures (e.g. mammograms, clinical and self-breast exams) when women perceive their cancer risk to be high, with some increasing their routine screening, and others neglecting to do so because of fear of cancer detection (Botkin et al., 1996; Kash, Holland, Halper, & Miller, 1992; Rimer et al., 1996). Even though Hypothesis 1 was supported in the 40 to 70 year old women who practiced routine screening procedures for breast cancer, this study showed that with a higher perceived risk of contracting breast cancer, women were unsure of their desire to seek further screening if recommended. Possibly, this is because women in this study had a very low knowledge level of genetic screening for breast cancer susceptibility, reflecting the need for education and counseling. Even though many women in this study were found to practice traditional methods of routine screening for breast cancer, they may simply not be aware of the benefits of genetic screening for breast cancer susceptibility for high risk women.

Hypothesis 3: Health Locus of Control.

The hypothesis that women who have an internal HLC exhibit a more positive attitude toward genetic testing for

breast cancer susceptibility than women who exhibit an external HLC (powerful other or chance), was not supported in this study.

These findings did not coincide with past studies, which have shown that women who exhibit an internal HLC have utilized mammography more routinely than those who do not exhibit an internal HLC (Tambor, Rimer, & Strigo, 1997), and that women who believe in their own control may be more likely to practice conscientious health habits and to use services appropriately (Taylor, Kemeny, Bower, Gruenwald, & Reed, 2000). The results of the current study may again be due to lack of knowledge, in that women who exhibit an internal HLC and practice traditional breast screening practices, may not realize that genetic susceptibility testing is another form of screening to detect breast cancer susceptibility in high risk women.

Hypothesis 4: Knowledge of Genetic Testing for Breast Cancer Susceptibility.

The hypothesis that women who were more knowledgeable about genetic testing for breast cancer susceptibility would have a more positive attitude toward genetic susceptibility testing for breast cancer than women who were less knowledgeable, was also not supported by this

study. However, with 29% of the participants scoring 0 on the knowledge index, and the mean score for knowledge only 1.17, the restriction of range caused by low levels of knowledge made it impossible to tell if well-informed women might be more positive regarding genetic susceptibility testing.

Overview of Women's Health Survey

Exploratory Issue: Relationship of ATGT and Socio-Demographic Variables.

Preliminary analyses were completed in an effort to determine if women's attitudes toward genetic susceptibility testing for breast cancer were related to their age, race, education, annual income, or marital status. Analyses revealed no statistically significant differences between the DV in this study (ATGT), and any of the socio-demographic variables. These variables did not appear to make a difference in the participants' attitude toward genetic susceptibility testing for breast cancer.

Although no past research was found regarding the correlation of marital status with ATGT, the current study's findings were not consistent with past research (Tambor, Rimer & Strigo, 1997) which reported that women who were younger than 60 years of age and white were more

likely to be interested in testing than those who were over 60 years and were African American or other ethnicities. Additionally, results from this study did not coincide with Mogilner et al. (1998), who found that most groups in their study expressed interest in genetic susceptibility testing with the exception of those above 60 years of age and those with only an elementary school education, or with Lerman, Narod et al. (1996) who reported that rates of test use may increase with increases in socioeconomic status.

Family History Screening Information.

Hereditary breast cancer is characterized by early onset (age 40 or younger). It was of interest in this study to note the number of participant's mothers who had been diagnosed with an early onset of breast cancer. Of the 137 participants in this study, 14 indicated their mothers as being diagnosed with breast cancer, with one respondent reporting an onset earlier than age 40 years (mother's age of 39). Two participants reported their mother's breast cancer onset at ages 42 and 43 respectively. Although only three participants reported a fairly early onset of breast cancer in their mothers, the descriptive statistics emphasize the necessity of every woman becoming cognizant of risk factors.

Health and Breast Screening Information.

Risk factors which were assessed in this study included: number of first degree relatives (mother, daughter or sister) with breast cancer (risk increases as number of first degree relatives with breast cancer increases), age at first full term birth or nulliparity (risk increases with increasing age or nulliparity), age at menarche (risk increases with early onset--11 years or younger), and number of breast biopsies (risk increases with increasing number of biopsies), in addition to race (risk is higher for caucasian and non-black women) and age (risk increases with age).

Some of the participants in the study sample reported various factors which possibly could assign them a high risk status (e.g., 26% of the participants reported menarche at age 11 years or earlier, 20 of respondents had experienced a breast biopsy, with 6 of these women reporting two or more past breast biopsies, and one participant reported her mother's onset of breast cancer at the age of 39). These reported frequencies indicate the necessity for women to be knowledgeable of all risk factors when considering their breast cancer risk status.

Routine Surveillance for Breast Cancer.

Previous literature has reported poor breast screening habits among many women (Fox et al., 1990; Sienko et al., 1993; Vincent, Gradham, Hoercherl & McTague, 1995). While analyzing the surveillance habits of the participants in this study, the study sample appeared to fit a similar pattern of non-optimal breast cancer screening habits. Only 58.3% of the 137 respondents (four of these being under the age of 40) had had a mammogram within the last year, and 20% reported a mammogram during the last two years. With all 137 participants indicating that they had experienced a clinical breast exam, only 65.7% reported an exam within the past year, with 16.8% reporting an exam within the past two years.

Additionally, with 130 women responding that they had conducted a self-breast exam at sometime in the past, only 47.3% indicated a self-breast exam during the past month (1 to 30 days), with 22.1% reporting a self-breast exam within the past 3 months (30 to 90 days).

Perceived Risk.

Exploratory Issue: Relationship of Women's Perceived Risk and Actual (Empiric) Risk of Contracting Breast Cancer Within the Next Five Years.

Earlier studies (Alexander, Ross, Sumner et al., 1996; Black, Nease, & Tosteson, 1995; Botkin et al., 1996; Kash, Holland, Halper, & Miller, 1992; Rimer et al., 1996; Smith, Gadd et al., 1996) have indicated that women's perceived risk of contracting breast cancer during their lifetime has frequently been overestimated. The participants in this study responded similarly, with an inflated estimate, when asked to assess the probability of contracting breast cancer during their lifetime and during the next five years.

While estimating their probability of contracting breast cancer within their lifetime, 14.3% of the participants indicated a 50% chance. Previous research has estimated the risk of contracting breast cancer during a lifetime as one in eight women, or 12.5% (Kadison, Pelletier, Mounib, Oppedisan, & Poteat, 1998).

While estimating their five-year probability, 30.8% of the participants reported a 10% probability, and 13.3% of respondents indicated a 50% chance of contracting breast cancer. With the exploratory question of interest being

the relationship of the respondent's perceived risk with their actual risk of contracting breast cancer during the next five years, the Breast Cancer Gail Model Risk Assessment Tool was utilized in determining the participants actual risk at the time they completed the WHS.

Analyses showed a statistically significant difference between the distributions of risk reported by the respondent and those calculated by the Gail Model Risk Assessment Tool, with the risk reported by the respondent being higher than the risk reported by the Gail Model. The Paired Samples t-test showed the mean of the participants' five year perceived risk of contracting breast cancer as 1.1736; whereas results of the five year relative risk calculated by the Breast Cancer Gail Model Risk Assessment Tool showed a mean of -.1749. These findings were not surprising, with past studies (listed above) of women's perceived risk of contracting breast cancer showing a highly inflated perceived risk level for many women.

Genetic Screening Information.

Results of questions which assessed women's awareness of genetic susceptibility testing for breast cancer indicated that women are learning about genetic testing

from a variety of sources. Of the 137 participants in this study, 84 women (61.3%) reported that they had heard of genetic susceptibility testing for breast cancer. With the majority (78.6%) of these 84 participants indicating television as the primary source of information on genetic susceptibility testing for breast cancer, the importance of the media as an educational source was highlighted.

However, with for-profit sources being ever present in the media, it would seem that the objectives of the informational source should be carefully analyzed. Information regarding genetic susceptibility testing should necessarily encompass impartial factual information, in order for women to obtain the full knowledge which is needed in decision-making processes about genetic susceptibility testing. Moreover, benefits and limitations of genetic susceptibility testing should be understood before women attempt to make genetic testing decisions.

Of the 84 participants in this study who indicated an awareness of genetic susceptibility testing for breast cancer, the majority of women (67.9%), when asked to indicate which health professional had spoken with them about genetic testing, reported that no one had spoken to them. Family physicians were named by 8.3% of the

respondents and 6% of the sample reported their gynecologist as a source of information.

These results indicate a need for physicians of all specialties to become vigilant in their initial assessment of female patients. If a women appears to be a possible high risk candidate for breast cancer during a general health screening process, it would be prudent for the attending physician to refer the patient to a genetic counseling center for further evaluation.

The current study highlighted the low level of knowledge among women regarding hereditary breast cancer and genetic susceptibility testing for breast cancer, which has been reported in previous literature (Lerman, Narod et al., 1996; Lipkus et al., 1999; Ludman, Curry, Hoffman & Taplin, 1999). As noted earlier, the mean overall score for knowledge was 1.17 (with a high score of 6 and low score of -3), with the largest percentage of participants (28.6%) in this study scoring zero (indicating an "unsure" response). This low knowledge level underlines the necessity of developing educational programs to keep women informed, who may be at high or moderate risk of contracting breast cancer. Additionally, women who are at low risk require genetic testing information, since many

women believe that all women should be tested, even those who may not be at high risk.

Attitude Toward Genetic Susceptibility Testing for Breast Cancer (DV).

The majority of the study participants responded "Absolutely Yes" (44.1%), or "Probably Yes" (36.8%), when asked if they would undergo genetic susceptibility testing if their health history would suggest that testing would be advisable. Thus, respondents appeared to have a positive attitude toward genetic testing, which concurred with previous research (Braczkowski et al., 1998; Julian-Reynier et al., 1996; Ludman et al., 1999; Mogilner, Otten, Cunnigham & Brower, 1998; Tambor et al, 1997).

Disclosure of Test Results to Family and Employer.

Family.

Several exploratory questions examined the areas of concern that women are experiencing regarding disclosure of genetic susceptibility test results to their families or employers. Given the low level of knowledge about genetic susceptibility testing for breast cancer which was evidenced by a large percentage of the participants in this study, it would seem that many women may also not be knowledgeable of the possible complications which may

emerge within their families, once test results are revealed.

Although some participants did express disclosure concerns, such as worry to their families, or the effect test results may have on their daughters or children, the greatest percentage (38.1%) of participants responded that they had no concerns. With a previous study (Williams & Schutte, 1997) finding that carriers experienced difficulty disclosing results to some family members, and other researchers (Lerman & Croyle, 1996) contending that family issues promise to be a very complicated consideration in genetic testing, findings from the present study suggest the need for more education and counseling in this area, since many women may not be aware of family implications following positive test results.

Employer.

When women were asked an open-ended question regarding their concerns in disclosing genetic susceptibility test results to their employers, issues of job security, insurance, confidentiality and workplace exposure were listed. The largest percentage (29.5%) of participants stated that disclosing genetic test results to their employers would be "None of their business". These

findings coincided with previous research (Kadison et al., 1998; Kodish et al., 1998; Williams & Schutte, 1997) where women have expressed concerns regarding disclosure of test results for fear of genetic discrimination.

Twenty percent of the respondents indicated they had no concerns regarding disclosure of test results to their employers, which again appears to be indicative of the need for education and counseling in this area. Previous research (Mann & Borgen, 1998) has shown that people with inherited diseases have beliefs that they were refused life or health insurance, or let go from a job, because of genetic discrimination. A further study (Lerman, Narod et al., 1996) found the possibility of losing health insurance was rated as an important limitation or risk of genetic testing by 34% of their sample.

Limitations of Research and Methodological Issues

This study was conducted in an effort to determine what women from all socio-demographic groups currently know about genetic susceptibility testing for breast cancer, and what their attitudes are toward testing, in order to further assess the educational and counseling needs of all women. Interpretation of the findings was somewhat limited however, in that the sample was not as diverse as

anticipated. Additionally, if the sample size had been larger, the study may have had more power to detect the hypothesized relationships.

However, the results of this study were unexpected in that even though the sample was small, and predominately white (65.4%), well educated (mean level of 14.6 years of education), and had a high income level (41% reported a yearly income of over $75,000), only one of the hypotheses was supported. Previous research had found that women who were white, more educated and were more affluent scored higher on ATGT (Vincent, Bradham, Hoercherl, & McTague, 1995). Nonetheless, even in light of the unexpected results of this study, a larger and more diverse (socio-demographically) sample should be a goal in further research.

Secondly, in assessing breast cancer surveillance habits, it was necessary to break the age level into two groups for scoring (women 40 years of age and older and those under 40 years), since recommendations differ for these two age levels. With the sample in the age category of under 40 years being small ($\underline{n}$=20), the findings for this group may not be representative of 35 to 40 year old women. Additionally, with this group analyzed separately, the

overall sample size was reduced which induced more limited statistical power.

Third, past research has shown that many women have an extremely inflated perceived risk of contracting breast cancer within their lifetime, or over a number of years, which may not coincide with their actual (empiric) risk (Alexander, Ross, Sumner, et al., 1996; Black, Nease, & Tosteson, 1995; Smith, Gadd, et al., 1996). Although questions regarding perceived risk of contracting breast cancer are frequently used to assess women's perceived risk, it seems that women would possibly have a difficult time calculating what their risk may be, particularly during a short period of time (e.g. within the next five years). With 120 of the participants responding in this study, 13.3% indicated a 50% chance, and 2.5% indicated an 80% chance of contracting breast cancer within the next five years. This issue did not appear to affect the results of the current study, in that a higher perceived risk was not found to be correlated with women's ATGT. However, for accuracy reasons, this issue may need to be addressed in future research on women's perceived risk of contracting breast cancer.

Additionally, in this study when women were asked to estimate their perceived risk of contracting breast cancer during their lifetime and during the next five years (while completing the WHS), an example of a percentage level was given with the directions to the question. The example which was given stated the arbitrary percentage of 10% (to ensure a thorough understanding of the question). Findings may have been coincidental; however, 30.8% (the largest percentage of the respondents), listed their chances of contracting breast cancer within the next five years as 10%. Since calculations may have been difficult for some of the participants, and 10% is quite an inflated percentage of the chance of contracting breast cancer during the next five years (for most women), it may be possible that some respondents listed 10% because they had seen it used in the example. To promote further accuracy, the wording in the directions may need some revisions for future research.

Fourth, an attempt was made to assess where women are receiving the most information about genetic susceptibility testing for breast cancer. Directions were given to participants, which included checking boxes indicating various sources from which they had learned about genetic

testing, and then secondly to circle the one source which they felt had offered the most information. Of a total of 84 respondents (some participants had previously indicated that they had never heard of genetic susceptibility testing for breast cancer, and therefore could not answer questions regarding sources of information), 25 participants who had indicated the sources of information, did not mark the source they felt had offered the most information. Possibly, a separate question asking for the source offering the most information would have secured a better response.

Fifth, the question included in the Women's health Survey (See Appendix B, question 9, under "Health and Breast Screening Information") regarding age of menarche, was categorized into "Eleven years old or younger", "Twelve to thirteen years old", and "Fourteen years old or older". Some participants were confused with the second age category. Possibly, stating "Twelve up to fourteen years of age" for the second category would increase accuracy in reporting this risk factor.

Significance and Implications for Future Research

BRCA1 and BRCA2 are genetic mutations responsible for approximately 5% to 10% of cases of breast cancer and

ovarian cancer (Ford & Easton, 1995; Ludman et al., 1999). Testing for these mutations has recently become more widely available and is being promoted by for-profit laboratories, which are marketing the test directly to women (Ludman et al., 1999). Ondrusek, Warner, and Goel (1999) contend that media coverage has led many women with a family history of breast cancer to wonder whether they should be tested, with women seeking information about hereditary breast cancer (HBC) from a variety of sources, including family physicians, television and print media, and the Internet.

Interest in genetic testing for breast cancer susceptibility among high risk women has been sizable (Lerman, Daly et al., 1995; Lerman, Seay, et al., 1995; Struewing et al., 1995). However, potential demand for testing may be greatest among women for whom testing is least appropriate (Ludman et al. 1999; Tambor, Rimer & Strigo, 1997). Furthermore, even though interest level is high among women, studies have found that about one half of women had read or heard almost nothing about genetic susceptibility testing for breast cancer, and most women lacked knowledge about cancer genetics (Ludman et al.) These findings indicate a clear need for the development of

educational and counseling programs for women of every risk status.

Julian-Reynier et al. (1996) contend that the way in which information about the efficacy of preventive strategies is presented in the future will be one of the keys to ensuring that cancer genetic testing becomes widely accepted. Health care systems must be prepared to address the demand for genetic counseling services, not only among women at high risk for carrying genetic mutations, but also among women who are at average risk. Ludman et al. (1999) state that although health care organizations are developing screening algorithms and guidelines for appropriate testing, they may not provide general patient education about these guidelines (e.g., about appropriate identification of high-risk individuals) or about the risks, benefits, and limitations of testing.

With the high level of interest in genetic susceptibility testing for breast cancer (Tambor, Rimer & Strigo, 1997), it is important to ensure that women who express an interest in being tested are made fully aware of the limitations and possible consequences of testing (e.g., psycho-social effects of testing, family concerns for first degree relatives, and genetic discrimination at the

workplace). Furthermore, with studies showing that women at higher socioeconomic levels tend to be more aware of genetic discoveries than those at lower socioeconomic levels (Tambor et al., 1997) an effort should be made to provide testing information and access to testing to all women who might be interested in testing and may benefit from testing.

Educational and counseling criteria for genetic testing for cancer susceptibility are complex, in that young women may have different concerns than older women, and women with children may have concerns that do not apply to those without children (and women without children have additional fertility decisions). Furthermore, African American women may have concerns unique to white women, and Ashkenazi Jewish women need additional information that is relevant to a specific ethnic/demographic group.

Tambor et al. (1997) suggest that strategies to augment traditional genetic counseling approaches should be pursued, with printed educational materials being distributed prior to genetic counseling sessions, that are tailored for each participant based on her responses to a baseline survey (e.g., only women who have or are planning to have children would receive detailed information about

the implications of testing for one's children, etc.) Tambor et al. contend that tailored messages will also highlight individual knowledge deficits and concerns about testing, and that by providing personalized informational materials, women will become more engaged in the decision-making process at an early stage, thereby enhancing the overall education and counseling process.

In some cases, cancer may be potentially preventable and can be treated effectively if detected early. Comprehensive cancer-risk counseling programs must educate patients to facilitate informed decisions and promote long-term changes in risk-related health behaviors and surveillance patterns. Any educational approaches will potentially affect large numbers of women, and should be evaluated carefully. Therefore, women's current attitudes toward genetic testing must be ascertained, in order to design and implement appropriate counseling and educational protocols.

There were several possible implications of the findings from the present study. One significant finding, that women over 40 years who practice routine screening for breast cancer showed a more positive attitude toward genetic testing for breast cancer susceptibility, would

suggest that women who are alert to screening practices may be more open to accepting further screening if their risk status were to suggest testing.

Furthermore, there are implications from this study for health care personnel to become more vigilant with general assessment of their patients, considering that 67.9% of the participants in this study (n=84) indicated that no one had spoken to them about genetic testing for breast cancer susceptibility. Additionally, the extremely low level of knowledge which women currently possess regarding genetic susceptibility testing for breast cancer should also serve as a signal for health personnel to carefully evaluate female patients in initial assessments of their health. Genetic and counseling centers are becoming available and should be utilized by health care personnel in their referrals for potential high risk patients.

Future research is suggested to further assess women's attitudes toward genetic susceptibility testing for breast cancer, and to test their knowledge about genetic testing. Specific studies focusing on a target age population (e.g., pre-menopausal women who may be at greatest risk of contracting breast cancer at an early age, if carrying a

BRCA1 or BRCA2 gene mutation) are also suggested, in an effort to educate this important sector of the population.

Additionally, future studies are needed which address all levels of socio-economic groups in an effort to evaluate the needs of all women and to instigate optimal educational and counseling programs at appropriate levels of understanding. As all women assimilate genetic susceptibility testing information, hopefully they will become motivated to seek further counseling if necessary, and to modify their behavior in ways that will reduce their risk of premature death from breast cancer.

This study, which assessed women's attitudes toward genetic susceptibility testing for breast cancer, is expected to add to the growing pool of knowledge regarding women's current attitudes toward this new technology, in an effort to develop optimal educational and counseling programs, and to potentially save lives.

APPENDIX A: Informed Consent

Women's Health Survey: Informed Consent

Women's Health Survey
Informed Consent

The study in which you are about to participate is designed to investigate women's attitudes toward genetic testing for breast cancer susceptibility. The survey will assess women's health and their practices regarding routine screening for breast cancer, their perceived risk of contracting breast cancer, their health locus of control, and their current knowledge of genetic susceptibility testing for breast cancer. The study is being conducted by Connie Welebir, B.S.N., R.N., under the supervision of Dr. Joanna S. Worthley, Associate Professor of Psychology. This research has been approved by the Department of Psychology Human Subjects Review Board, California State University, San Bernardino. The University requires that you give your consent before participating in this study.

You will be asked to answer questions regarding known relatives who have been diagnosed with cancer, your own background and health screening habits, what you feel your risk is of contracting breast cancer, how you feel about your present health, what you have heard about hereditary breast cancer and genetic testing for breast cancer susceptibility and how you feel about genetic susceptibility testing. The survey should take around 15-30 minutes to complete. All of your responses will be kept in strictest confidence by the researcher. You will not be required to provide your name or to answer any questions that you would prefer not to answer. All data will be reported in group form only. The group results will be available in June, 2000.

Your participation in this study is completely voluntary. You are free to withdraw at any time without penalty. When you give your completed survey to the receptionist at the front desk, you will receive a debriefing statement describing the study in more detail.

If you have any questions regarding this study, please feel free to contact Professor Joanna S. Worthley at (909) 880-5595.

By placing an "X" in the box below, I acknowledge that I have been informed of, and that I understand the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place an "X" here ☐ Today's Date:_____

WOMEN'S HEALTH SURVEY

AGE

(*Please fill in blank*)

What is your age? _____

RACE/ETHNICITY

Which of the following do you consider yourself to be?

(*Check all that apply*)

- ☐ American Indian or Alaskan Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Mexican-American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Other: (**specify**) _____
- ☐ Don't know/Not sure

EDUCATION

What is the highest grade or year of regular school you ever completed?

☐ Never attended or kindergarten only

(*Please circle number of years completed*)

Elementary	1	2	3	4	5	6	7	8
High School	1	2	3	4				
College	1	2	3	4				
Graduate School	1	2	3	4	5+			

CURRENT MARITAL STATUS

☐ Married

☐ Divorced

☐ Widowed

☐ Separated

☐ Never been married

or

☐ A member of an unmarried couple

ANNUAL INCOME

Is your annual household income from all sources:

☐ Less than $10,000

☐ $10,001 to $20,000

☐ $20,001 to $30,000

☐ $30,001 to $40,000

☐ $40,001 to $50,000

☐ $50,001 to $75,000

☐ More than $75,000

FAMILY HISTORY SCREENING INFORMATION

We would like to ask you some questions about your family history of cancer in your "blood" (biological) relatives. Do not include any step or adoptive parents, sisters, or children.

(*Please check appropriate box*)

1. Have you ever been diagnosed with cancer?

☐ Yes (go to question 2)

☐ No (go to question 4)

2. What was the primary site for your cancer (for example, uterine or colon cancer?) _____

3. How old were you when you were diagnosed? Age at diagnosis _____

4. Do you have any daughters?

☐ Yes Number of daughters _____ (go to question 5)

☐ No (go to question 7)

5. Do your daughters all have the same mother and father?

☐ Yes

☐ No, please explain _____

☐ Don't Know/Not Sure

6. Have any of your daughters been diagnosed with cancer?

☐ Yes Number of daughters diagnosed with cancer _____ (please fill in box below)

☐ No (go to question 7)

☐ Don't Know/Not Sure (go to question 7)

(if you checked yes, please fill in box below)

Daughter	Date of Birth	Type of Cancer	Age at Diagnosis	Age at Death Or Not Applicable
Daughter				
Daughter				
Daughter				
Daughter				

7. Did your mother have cancer?

☐ Yes (please fill in box below)

☐ No (go to question 8)

☐ Don't know/Not sure (go to question 8)

(*if you checked yes, please fill in box below*)

Mother's Date of Birth	Type of Cancer	Age at Diagnosis	Age at Death or Not Applicable

8. Do you have any FULL sisters? (These are siblings that have the same mother and father as you do).

☐ Yes Number of full sisters _____ (go to question 9)

☐ No (go to question 10)

☐ Don't know/Not sure (go to question 10)

9. Have any of your full sisters been diagnosed with cancer?

☐ Yes Number of sisters diagnosed with cancer _____(please fill in box below)

☐ No (go to question 10)

☐ Don't know/Not sure (go to question 10)

(if you checked yes, please fill in box below)

Sister	Date of Birth (Year)	Type of Cancer	Age at Diagnosis	Age at Death Or Not Applicable
Sister				
Sister				
Sister				
Sister				

10. Looking back over the last nine questions (in the Family History Screening Information Section), what do you feel your chances are of developing breast cancer during your lifetime?

(Please fill in the blank with a percentage level rounded off to the nearest whole percentage, for example, a 10% chance)

_____

11. What do you feel your chances are of developing breast cancer during the next five years?

(Please fill in the blank with a percentage level rounded off to the nearest whole percentage, for example, a 10% chance)

_____

HEALTH AND BREAST SCREENING INFORMATION

1. A mammogram is an x-ray of each breast to look for breast cancer. Have you ever had a mammogram?

☐ Yes (go to question 2)

☐ No (go to question 3)

2. How long has it been since you had your last mammogram?

(*Please check appropriate box*)

☐ Within the past year (1 to 12 months ago)

☐ Within the past 2 years (1 to 2 years ago)

☐ Within the past 3 years (2 to 3 years ago)

☐ Within the past 5 years (3 to 5 years ago)

☐ 5 or more years ago

☐ A mammogram is not recommended for my age group

☐ Don't know/Not sure

3. A clinical breast examination is when a doctor, nurse, or other health professional feels the breast for lumps. Have you ever had a clinical breast examination?

☐ Yes (go to question 4)

☐ No (go to question 5)

☐ Don't know/Not sure (go to question 5)

4. How long has it been since your last clinical breast examination by a doctor, nurse, or other health professional?

☐ Within the past year (1 to 12 months ago)

☐ Within the past 2 years (1 to 2 years ago)

☐ Within the past 3 years (2 to 3 years ago)

☐ Within the past 5 years (3 to 5 years ago)

☐ 5 or more years ago

☐ Don't know/Not sure

5. A self-breast examination is when you feel your breasts for lumps. Have you ever done a **self-breast examination**?

☐ Yes (go to question 6)

☐ No (go to question 7)

☐ Don't know/Not sure (go to question 7)

6. How long has it been since you last did a **self-breast examination**?

☐ Within the past month (1 to 30 days)

☐ Within the past 3 months (30 to 90 days)

☐ Within the past 3 to 6 months (90 to 180 days)

☐ Within the past 6 months to one year

☐ One or more years ago

☐ Don't know/Not sure

7. Have you ever been pregnant?

☐ Yes (go to question 8)

☐ No (go to question 9)

☐ Don't know/Not sure (go to question 9)

8. If answered yes to previous question (question 7), at what age were you when your first child was born?

(Please fill in the blank) _____

☐ Experienced a miscarriage before full term

9. Menarche is the first time a woman menstruates or has her "period". At what age were you when you experienced menarche (your first menstrual period?)

☐ Eleven years old or younger

☐ Twelve to thirteen years old

☐ Fourteen years old or older

☐ Don't know/Not sure

10. A breast biopsy is when a small specimen is surgically removed from the breast for further evaluation. Have you ever had a breast biopsy?

☐ Yes (go to question 11)

☐ No (go to question one on next page in the Genetic Screening Information Section)

☐ Don't know/Not sure (go to question one on next page in the Genetic Screening Information Section)

11. If answered yes to the previous question (question 10), how many breast biopsies have you had?

☐ One

☐ Two or more

☐ Don't know/Not sure

GENETIC SCREENING INFORMATION

(Please read the following)

Genes contain biological information that is passed from parents to their children. The following questions refer to "genetic testing for cancer risk." That is, testing your blood to see if you carry genes which may predict a greater chance of developing cancer at some point in your life.

1. Have you ever heard of genetic testing to determine if a person is at greater risk of developing breast cancer?

☐ Yes (go to question 2)

☐ No (go to question 4)

☐ Don't know/Not sure (go to question 4)

2. If answered yes to previous question (question 1), please indicate where you learned about genetic testing to determine if a person is at greater risk of developing breast cancer, and from which source you have received the most information.

Please read directions carefully

Step 1 (***Please check all that apply***)

Step 2 (***Please circle the source from which you have received the most information***)

☐ Newspaper

☐ Magazine

☐ Periodical or Journal (for example, a scientific or medical journal)

☐ Health Newsletter

☐ Television

☐ Radio

☐ Internet

☐ Friend

☐ Your Physician

☐ Other (please specify) _____

3. If a **health professional** has spoken with you about genetic testing to determine if a person is at greater risk of developing breast cancer, please indicate which person of the following spoke with you:

(Please check all that apply)

☐ Nurse

☐ Surgeon

☐ Gynecologist

☐ Internist

☐ Family Practice Physician

☐ Genetic Counselor

☐ Oncologist

☐ A Doctor, but don't know what specialty

☐ Other (please specify)_____

☐ No one has spoken with me

4. If your health history were to suggest that genetic testing for breast cancer risk would be advisable, would you be inclined to proceed with genetic testing?

(*Please circle the number of your response*)

1	2	3	4	5
Absolutely Not	Probably Not	Unsure	Probably Yes	Absolutely Yes

5. If your health history were to suggest that genetic testing for breast cancer risk would be advisable, and you decided to proceed with genetic testing, what would be your primary concerns about discussing the genetic test results with your

Family?

(*Please fill in the blank*)

_____

What would be your primary concerns about discussing the genetic test results with your

Employer?

(*Please fill in the blank*)

_____

The following statements are items concerning genetics and hereditary breast cancer. Please indicate to what degree you are in agreement (or disagreement) with each statement.

(Please circle the number of your response)

6. A woman whose mother was diagnosed with breast cancer at age 69 is considered to be at high risk for breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree

7. Ovarian cancer and breast cancer in the same family can be a sign of hereditary breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree

8. Testing for breast cancer gene mutations can tell a woman if she has breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree

9. Men cannot inherit breast cancer gene mutations.

1	2	3	4	5
Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree

CURRENT HEALTH STATUS

The following questions are about your health status today.

How would you rate your present health?

(Please circle your response)

Very Poor	Poor	Good	Very Good	Excellent

Think about the most significant health problem you cope with in your life currently or have coped with in the recent past (for example, arthritis, depression, high blood pressure, cold, or flu).

Write the health problem here:

(*Please circle the number that would most closely correspond with your feelings for each question*)

Example: If I have good health, I am lucky.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

(Circling five means that I agree with the statement almost completely).

1. If my health worsens, it is my own behavior that determines how soon I feel better again.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

2. As far as my health is concerned, what will be will be.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

3. If I see my doctor regularly, I am less likely to have problems with my health.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

4. Most things that affect my health happen to me by chance.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

5. Whenever my health worsens, I should consult a medically trained professional.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

6. I am directly responsible for my health getting better or worse.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

7. Other people play a big role in whether my health improves, stays the same same, or gets worse.

Strongly Disagree **Strongly Agree**

1 2 3 4 5 6

8. Whatever goes wrong with my health is my own fault.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

9. Luck plays a big part in determining how my health improves.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

10. In order for my health to improve, it is up to other people to see that the right things happen.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

11. Whatever improvement occurs in my health is largely a matter of good fortune.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

12. The main things that affect my health are what I do for myself.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

13. I deserve the credit when my health improves and the blame when it gets worse.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

14. Following doctor's orders to the letter is the best way to keep my health from getting any worse.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

15. If my health worsens, it's a matter of fate.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

16. If I am lucky, my health will get better.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

17. If my health takes a turn for the worse, it is because I have not been taking proper care of myself.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

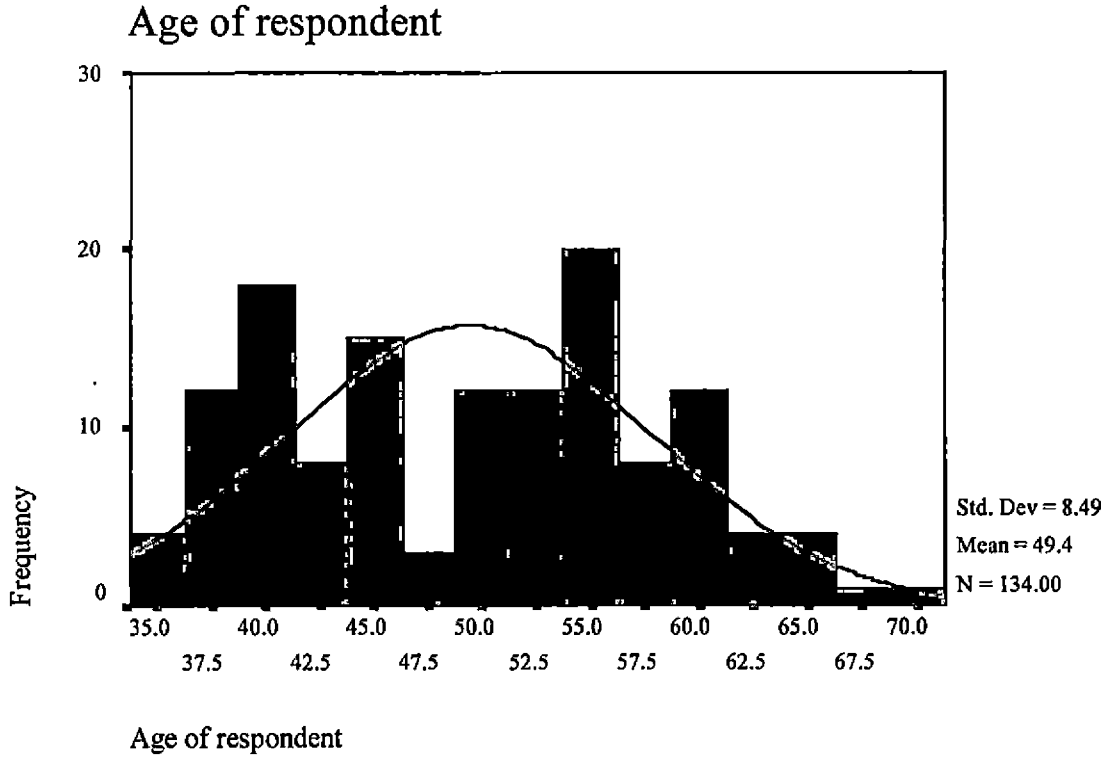
18. The type of help I receive from other people determines how soon my health improves.

Strongly Disagree					**Strongly Agree**
1	2	3	4	5	6

THANK YOU FOR TAKING YOUR TIME TO COMPLETE THIS SURVEY

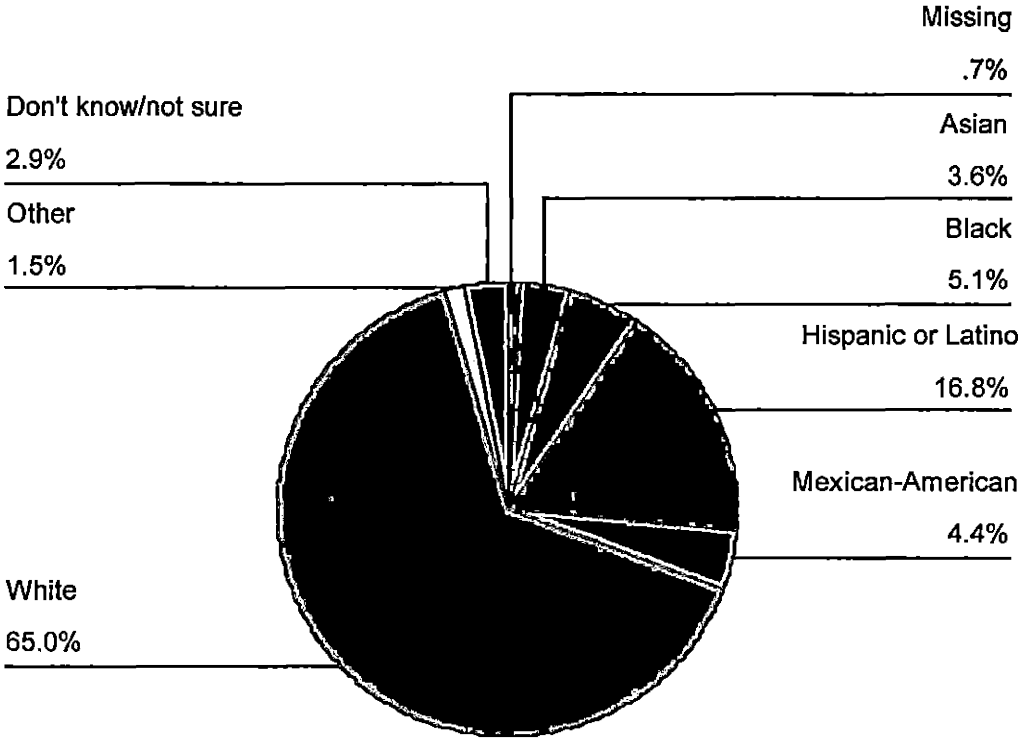
APPENDIX C: Age of Study Participants

Age of Study Participants



APPENDIX D: Race of Study Participants

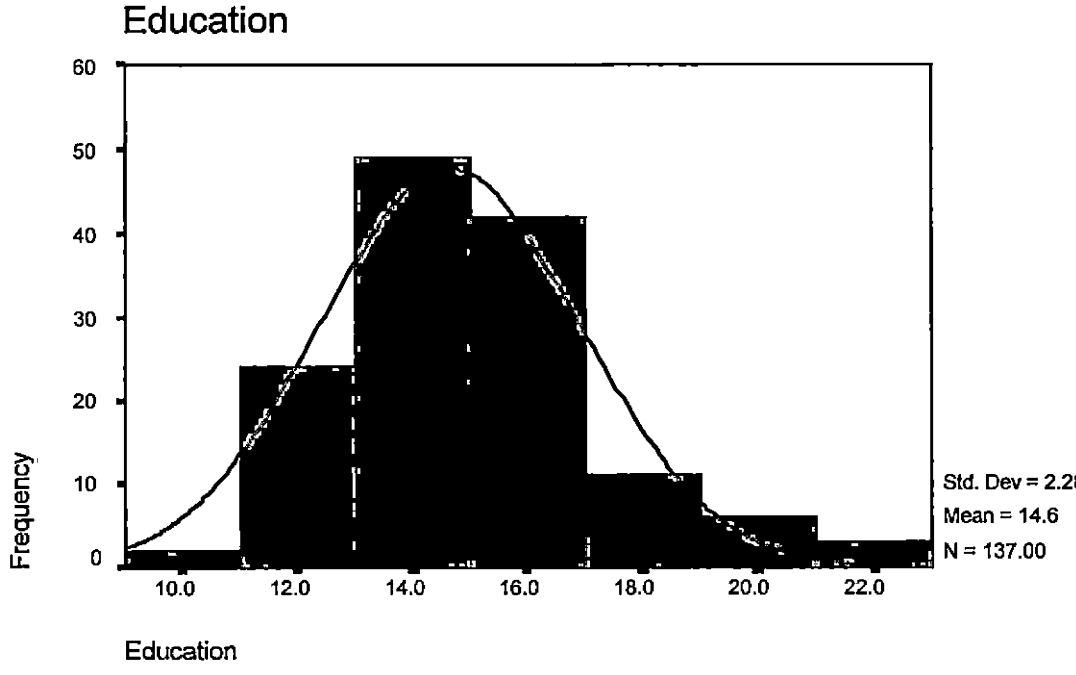
Race of Study Participants



Note: Participants reporting more than one ethnicity were classified as "Don't Know/Not Sure"

APPENDIX E: Education of Study Participants

Education of Study Participants



APPENDIX F: Marital Status of Study Participants

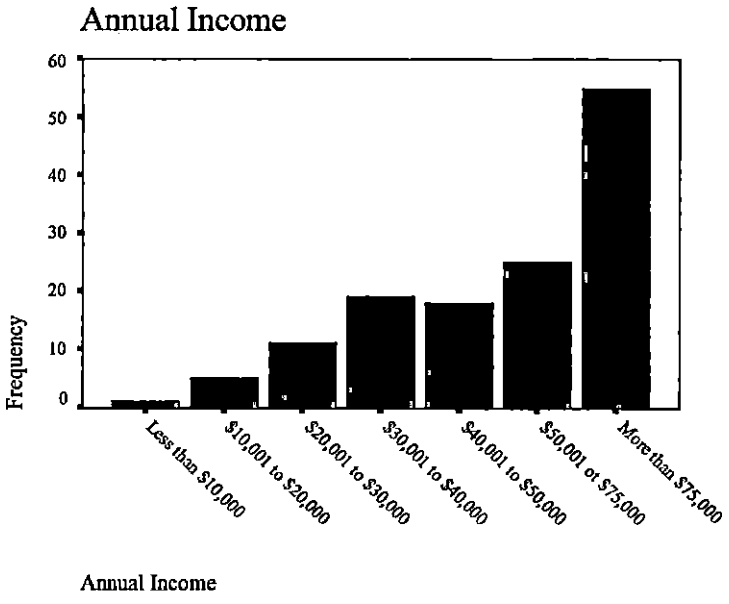
Marital Status of Study Participants

Marital Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Married	104	75.9	75.9	75.9
	Divorced	21	15.3	15.3	91.2
	Widowed	3	2.2	2.2	93.4
	Separated	3	2.2	2.2	95.6
	Never been married	5	3.6	3.6	99.3
	A member of an unmarried couple	1	.7	.7	100.0
	Total	137	100.0	100.0	

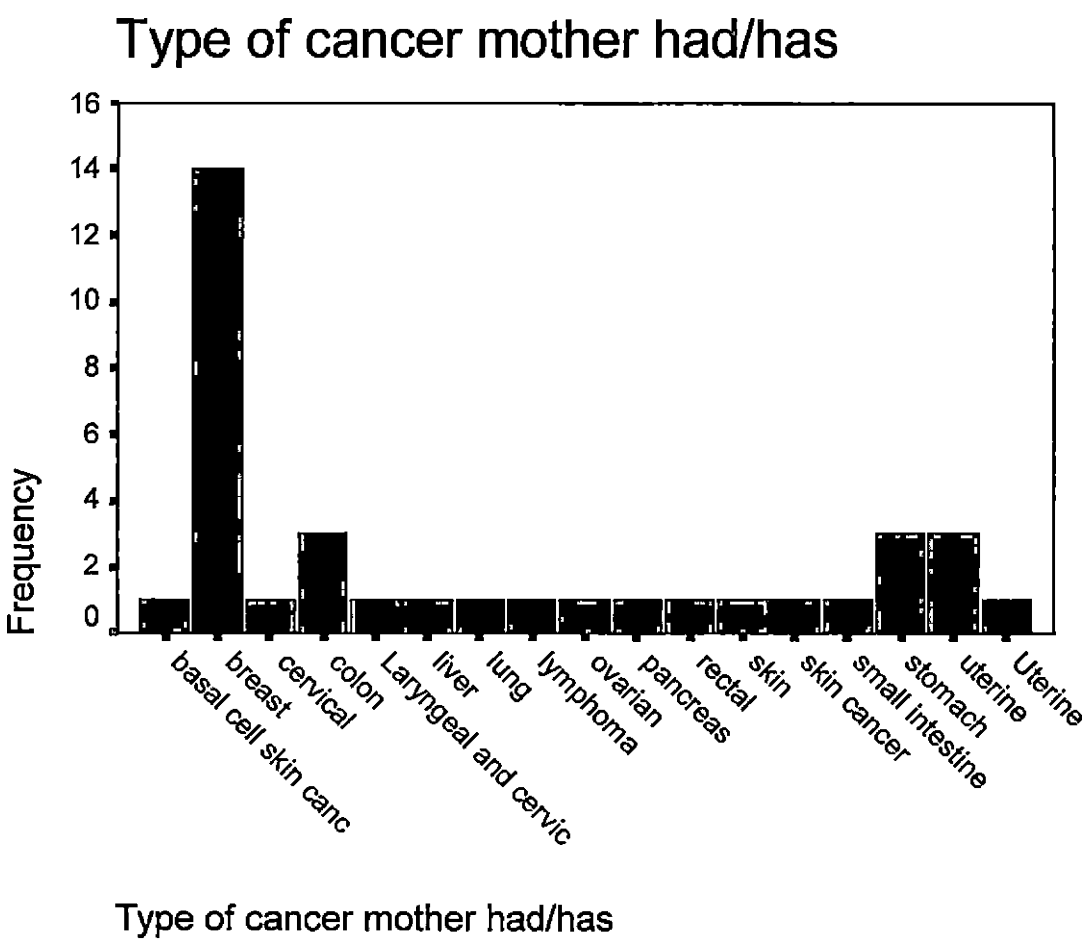
APPENDIX G: Annual Income of Study Participants

Annual Income of Study Participants



APPENDIX H: Breast Cancer as Primary Site in Participant's Mother

Breast Cancer as Primary Site in Participant's Mother



APPENDIX I: Age of Participant's Mother at Breast Cancer Diagnosis

Age of Participant's Mother at Breast Cancer Diagnosis

Mother's age at diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	39	1	7.1	7.7	7.7
	42	1	7.1	7.7	15.4
	43	1	7.1	7.7	23.1
	50	1	7.1	7.7	30.8
	52	1	7.1	7.7	38.5
	58	1	7.1	7.7	46.2
	59	1	7.1	7.7	53.8
	62	1	7.1	7.7	61.5
	63	1	7.1	7.7	69.2
	70	1	7.1	7.7	76.9
	75	1	7.1	7.7	84.6
	78	1	7.1	7.7	92.3
	81	1	7.1	7.7	100.0
	Total	13	92.9	100.0	
Missing	System	1	7.1		
Total		14	100.0		

APPENDIX J: Participant's Age at First Live Birth

Participant's Age at First Live Birth

Age when first child was born

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	14	1	.8	.8	.8
	16	2	1.7	1.7	2.5
	17	2	1.7	1.7	4.2
	18	6	5.0	5.1	9.3
	19	11	9.1	9.3	18.6
	20	9	7.4	7.6	26.3
	21	17	14.0	14.4	40.7
	22	9	7.4	7.6	48.3
	23	5	4.1	4.2	52.5
	24	6	5.0	5.1	57.6
	25	9	7.4	7.6	65.3
	26	6	5.0	5.1	70.3
	27	7	5.8	5.9	76.3
	28	7	5.8	5.9	82.2
	29	4	3.3	3.4	85.6
	30	5	4.1	4.2	89.8
	31	1	.8	.8	90.7
	32	4	3.3	3.4	94.1
	35	3	2.5	2.5	96.6
	36	1	.8	.8	97.5
	38	2	1.7	1.7	99.2
	41	1	.8	.8	100.0
	Total	118	97.5	100.0	
Missing	System	3	2.5		
Total		121	100.0		

APPENDIX K: Perceived Five Year Risk

Perceived Risk of Contracting Breast Cancer Within the Next Five Years

Self reported probability of breast cancer within next 5 yrs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	16	11.7	13.3	13.3
	1	11	8.0	9.2	22.5
	2	2	1.5	1.7	24.2
	3	1	.7	.8	25.0
	5	14	10.2	11.7	36.7
	10	37	27.0	30.8	67.5
	15	1	.7	.8	68.3
	20	6	4.4	5.0	73.3
	25	4	2.9	3.3	76.7
	30	6	4.4	5.0	81.7
	40	3	2.2	2.5	84.2
	50	16	11.7	13.3	97.5
	80	3	2.2	2.5	100.0
	Total	120	87.6	100.0	
Missing	System	17	12.4		
Total		137	100.0		

APPENDIX L: Perceived Lifetime Risk

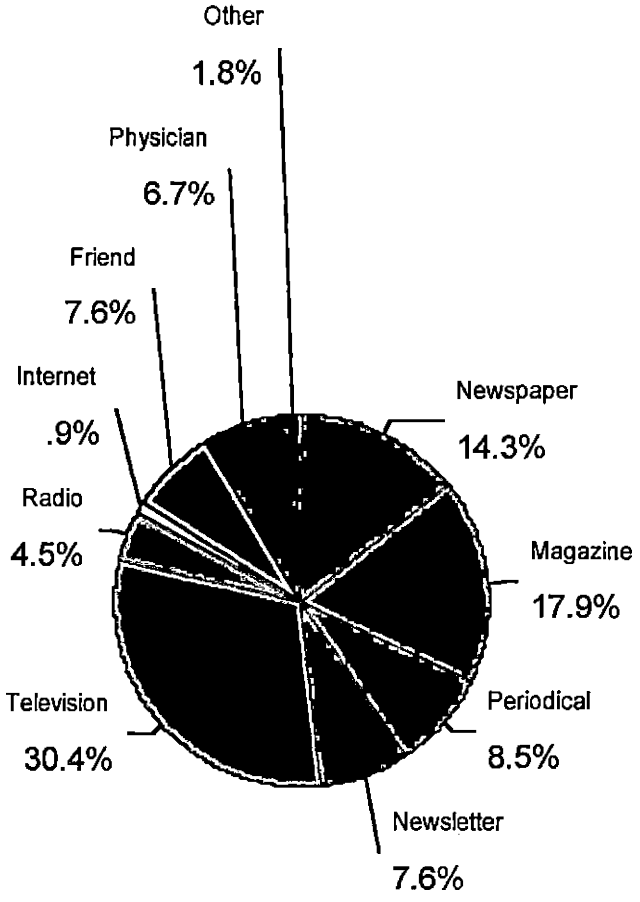
Perceived Lifetime Risk of Contracting Breast Cancer

Self reported probability of breast cancer within lifetime

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	6	4.4	5.0	5.0
	1	13	9.5	10.9	16.0
	2	1	.7	.8	16.8
	4	1	.7	.8	17.6
	5	13	9.5	10.9	28.6
	10	31	22.6	26.1	54.6
	15	3	2.2	2.5	57.1
	20	8	5.8	6.7	63.9
	25	6	4.4	5.0	68.9
	30	11	8.0	9.2	78.2
	40	2	1.5	1.7	79.8
	50	17	12.4	14.3	94.1
	70	2	1.5	1.7	95.8
	80	4	2.9	3.4	99.2
	90	1	.7	.8	100.0
	Total	119	86.9	100.0	
Missing	System	18	13.1		
Total		137	100.0		

APPENDIX M: Sources of Information Regarding Genetic Testing

Sources of Information Regarding Genetic Susceptibility Testing for Breast Cancer



APPENDIX N: Sources Giving the Most Information about Genetic Testing

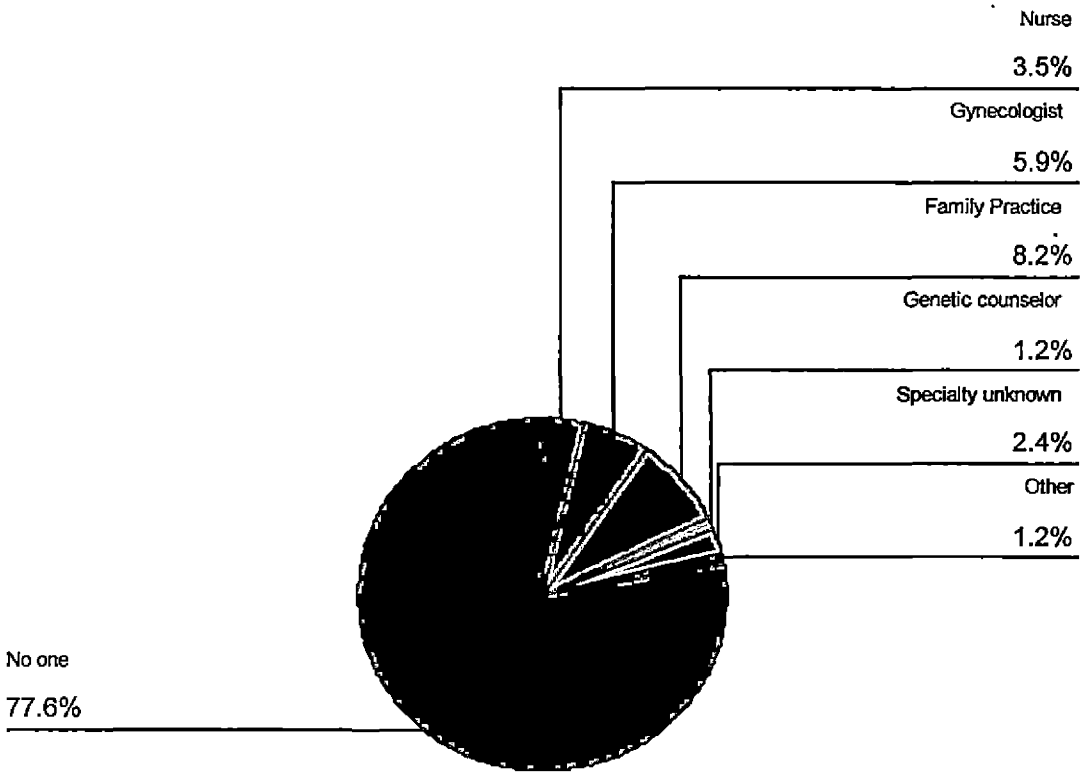
Sources Indicated as Giving the Most Information about Genetic Testing for Breast Cancer Susceptibility

Where did you receive the most information?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Newspaper	2	2.4	3.4	3.4
	Magazine	7	8.3	11.9	15.3
	Periodical or journal	8	9.5	13.6	28.8
	Health Newsletter	1	1.2	1.7	30.5
	Television	30	35.7	50.8	81.4
	Internet	1	1.2	1.7	83.1
	Friend	4	4.8	6.8	89.8
	Your physician	3	3.6	5.1	94.9
	Other	3	3.6	5.1	100.0
	Total	59	70.2	100.0	
Missing	System	25	29.8		
Total		84	100.0		

APPENDIX O: Health Personnel Sources of Information

Health Personnel Sources of Information for Genetic Susceptibility Testing for Breast Cancer



APPENDIX P: Disclosure of Test Results to Family

Concerns Regarding Disclosure of Genetic Susceptibility Test Results to Family

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Worry family	13	9.5	11.5	11.5
	Affect on daughters/children	8	5.8	7.1	18.6
	Don't know	3	2.2	2.7	21.2
	Unknown family history	2	1.5	1.8	23.0
	Awareness for family	2	1.5	1.8	24.8
	No concerns	43	31.4	38.1	62.8
	Depends on situation	1	.7	.9	63.7
	* Future	8	5.8	7.1	70.8
	Meaning of results	4	2.9	3.5	74.3
	Husband	2	1.5	1.8	76.1
	Insurance	2	1.5	1.8	77.9
	Other	21	15.3	18.6	96.5
	Testing other family members	4	2.9	3.5	100.0
	Total	113	82.5	100.0	
Missing	-1	24	17.5		
Total		137	100.0		

*Answers that did not apply to the categories listed were noted as "Other".

APPENDIX Q: Disclosure of Test Results to Employer

Concerns Regarding Genetic Susceptibility Test Results to Employer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None of their business/wouldn't tell	31	22.6	29.5	29.5
	Insurance	3	2.2	2.9	32.4
	Job security	12	8.8	11.4	43.8
	No concerns	21	15.3	20.0	63.8
	Not employed	8	5.8	7.6	71.4
	Don't know	6	4.4	5.7	77.1
	Loose insurance & loss of job	4	2.9	3.8	81.0
	Confidentiality	3	2.2	2.9	83.8
	Time off	5	3.6	4.8	88.6
	Workplace exposure	2	1.5	1.9	90.5
	Other	10	7.3	9.5	100.0
	Total	105	76.6	100.0	
Missing	-1	32	23.4		
Total		137	100.0		

APPENDIX R: Wilcoxin Signed Ranks Test for Perceived vs Actual Risk

Wilcoxin Signed Ranks Test for Difference of Reported Relative Risk and Actual Risk Within the Next Five Years

Test Statistics [b]

	5yr RR reported by respondent - Risk calculated by Gail Model
Z	-9.104*
Asymp. Sig. (2-tailed)	.000

a. Based on negative ranks.

b. Wilcoxon Signed Ranks Test

*Perceived risk percentage has been recalculated as relative risk.

APPENDIX S: Paired Samples Statistics for Perceived and Actual Risk

Paired Samples Means and Standard Deviations for Perceived Risk and Actual Risk

Paired Samples Statistics

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Risk calculated by Gail Model	-.1749	110	.3657	3.487E-02
	5yr RR reported by respondent	1.1736	110	.1988	1.896E-02

Paired t-test for Difference of Reported Relative Risk and Actual Risk Within Next Five Years

T	Df	Sig. (2-tailed)
-37.397	109	.000

REFERENCES

Aiken, L. S., Fenaughty, A. M., West, S. G., Johnson, J.J., & Luckett, T. L. (1995, spring). Perceived determinants of risk for breast cancer and the relations among objective risk, perceived risk, and screening behavior over time. Women's Health, 1 (1), 27-50.

Alexander, N.E., Ross, J., Sumner, W., Nease, R. F., & Littenberg, B. (1996). The effect of an educational intervention on the perceived risk of breast cancer. Journal of General Internal Medicine, 11, 92-97.

Black, W. C., Nease, R. F., & Tosteson, A. N. A. (1995). Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. Journal of the National Cancer Institute, 87, 720-731.

Botkin, J. R., Croyle, R. T., Smith, K. R., Baty, B. J., Lerman, C., Goldgar, D. E., Ward, J. M., Flick, B. J. & Nash, J. E. (1996). A model protocol for evaluating the behavioral and psychosocial effects of BRCA1 testing. Journal of the National Cancer Institute, 88 (13), 872-882.

Braczkowski, E., Nowakowska-Zajdel, B., Zubelewicz, M., Muc-Wierzgon, M., & Romanowski, W. (1998). Journal of Experimental Clinical Cancer Research, 17 (3), 299-302.

Brody, L. C., & Biesecker, B. B. (1998). Breast cancer susceptibility genes BRCA1 and BRCA2. Medicine, 77, 208-26.

Cella, D., & Tross, S. (1986). Psychological adjustment to survival from Hodgkins disease. Journal of Consultants in Clinical Psychology, 54, (5), 616-622.

Center for Disease Control, Behavioral Risk Factor Surveillance System Questionnaire, Section 11—Women's Health Survey (1999).

Chaliki, H., Loader, S., Levenkron, J. C., Logan-Young, W., Hall, W. J., Rowley, P. T. (1995). Women's receptivity to testing for a genetic susceptibility to breast cancer. American Journal of Public Health, 85, 1133-1135.

Diefenbach, M. A., Miller, S. M., & Daly, M. B. (1999). Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. Health Psychology, 18 (5), 532-6.

Durfy, S. J., Bowen, D. J., McTiernan, A., Sporleder, J. & Burke, W. (1999). Attitudes and interest in genetic testing for breast and ovarian cancer susceptibility in diverse groups of women in western Washington. Cancer Epidemiology, Biomarkers and Prevention, 8 (4 Pt 2), 369-75.

Ford, D., & Easton, D. F. (1995). The genetics of breast and ovarian cancer. British Journal of Cancer, 72, 805-12.

Fox Chase Cancer Center, Division of Population Science, Cheltenham, Pennsylvania, 19012, USA (Diefenbach).

Fox, S. A., Klos, D. S., Worthen, N. J., Pennington, E., Bassett, L. W., & Gold, R. H. (1990). Improving the adherence of urban women to mammography guidelines: strategies for radiologists. Radiology, 174 (1), 203-6.

Frank, T. S., Manley, S. A., Olopade, O. I., Cummings, S., Garber, J. E., Bernhardt, B., Antman, K. Russo, D., Wood, M. E., Mullineau, L., Isaacs, C., Peshkin, B., Buys, S., Venne, V., Rowley, P. T., Loader, S., Offit, K., Robson, M., Hampel, H., Brener, D., Winer, E. P., Clark, S., Weber, B., Strong, L. C., Rieger, P., McClure, M., Ward, B. E., Shattuck-Eidens, D., Oliphant, A., Skolnick, M. H. & Thomas, A. (1998). Sequence analysis of BRCA1 and BRCA2: Correlation of mutations with family history and ovarian cancer risk. Journal of Clinical Oncology, 16 (7), 2417-2425.

Gail Model Breast Cancer Risk Assessment Tool: Correspondence to: Dr. Mitchell H. Gail, Executive Plaza North, Room 403, National Institutes of Health, Rockville, MD 20892.

Glanz, K., Resch, N., Lerman, C., & Rimer, B. K. (1996). Black-white differences in factors influencing mammography use among employed female health maintenance organization members. Ethnicity and Health, 1 (3), 207-20.

Goldsteen, R. L., Counte, M. A., & Goldsteen, K. (1994, August). Examining the relationship between health locus of control and the use of medical care services. Journal of Aging and Health, 6 (3), 314-335.

Jacobsen, P. B., Valdimarsdottier, H. B., Brown, K. L., & Offit, K. (1997). Decision making about genetic testing among women at familial risk for breast cancer. Psychosomatic Medicine, 59 (5), 459-66.

Julian-Reynier, C., Eisinger, F., Vennin, P., Chabal, F., Aurren, Y., Nogues, C., Bignon, Y-J., Machelard-Roumagnac, M., Maugard-Louboutin, C., Serin, D., Blanc, B., Orsoni, P., & Sobol, H. (1996). Journal of Medical Genetics, 33 (9), 731-6.

Kadison, P., Pelletier, B. A., Mounib, E. L., Oppedisano, P., & Poteat, H. T. (1998). Improved screening for breast cancer associated with a telephone-based risk assessment. Preventive Medicine, 27, 493-501.

Kash, K. M. (1999). Psychosocial and ethical implications of defining genetic risk for cancers. Annals of the New York Academy of Sciences, 41-52.

Kash, K. M., Holland, J. C., Halper, M. S., & Miller, D. G. (1992, January). Psychological distress and surveillance behaviors of women with a family history of breast cancer. Journal of the National Cancer Institute, 84 (1), 24-30.

Kodish, E., Wiesner, G. L., Mehlman, M., & Murray, T. (1998). Genetic testing for cancer risk: how to reconcile the conflicts. Journal of the American Medical Association, 279 (3), 179-181.

Lawler, K. A., & Schmied, L. A. (1992). A prospective study of women's health: The effects of stress, hardiness, locus of control, type A behavior, and physiological reactivity. Women and Health, 19 (1), 27-41.

Lerman, C., & Croyle, R. T. (1996, February). Emotional and behavioral responses to genetic testing for susceptibility to cancer. Oncology, 10 (2), 191-202.

Lerman, C., Daly, M., Masny, A., Balshem, A. (1994b). Attitudes about genetic testing for breast ovarian cancer susceptibility. Journal of Clinical Oncology 12, 843-850.

Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., Gold, K., Trock, B., Main, D., Lynch, J., Fulmore, C., Snyder, C., Lemon, S. J., Conway, T., Tonin, P., Lenoir, G. & Lynch, H. (1996). BRCA1 testing in families with hereditary breast-ovarian cancer: A prospective study of patient decision making and outcomes. Journal of the American Medical Association, 275 (24), 1885-1892.

Lerman, C., Seay, J., Balshem, A., Audrain, J. (1995). Interest in genetic testing among first-degree relatives of breast cancer patients. American Journal of Medical Genetics, 57, 385-392.

Lerman, C., & Schwartz, M. (1993). Adherence and psychological adjustment among women at high risk for breast cancer. Breast cancer Research and Treatment, 28, 145-155.

Lipkus, I. M., Iden, D., Terrenoire, J., & Feaganes, J. R. (1999). Relationships among breast cancer concern, risk perceptions, and interest in genetic testing for breast cancer susceptibility among African-American women with and without a family history of breast cancer. Cancer Epidemiological Biomarkers Prevention, 8 (6), 533-9.

Ludman, E. J., Curry, S. J., Hoffman, E., & Taplin, S. (1999). Women's knowledge and attitudes about genetic testing for breast cancer susceptibility. Effective Clinical Practice, 2 (4), 158-162.

Mann, G. B., & Borgen, P. I. (1998). Breast cancer genes and the surgeon. Journal of Surgical Oncology, 67, 267-274.

McCaul, K. D., Schroeder, D. M., & Reid, P. A. (1996). Breast cancer worry and screening: Some prospective data. Health Psychology, 15 (6), 430-433.

McDonald, K. G., Doan, B., Kelner, M., & Taylor, K. M. (1996). A sociobehavioural perspective on genetic testing and counselling for heritable breast, ovarian and colon cancer. Canadian Medical Association Journal, 154 (4), 457-64.

Mogilner, A., Otten, M., Cunningham, J. D., & Brower, S. T. (1998). Awareness and attitudes concerning BRCA gene testing. Annals of Surgical Oncology, 5 (7), 607-12.

Neuhausen, S. L., & Ostrander, E. A. (1997). Mutation testing of early-onset breast cancer genes BRCA1 and BRCA2. Genetic Testing, 1 (2), 75-83.

Ondrusek, N., Warner, E., & Goel, V. (1999). Development of a knowledge scale about breast cancer and heredity (BCHK). Breast Cancer Research and Treatment, 53, 69-75.

Owen, P., & Long, P. (1989). Facilitating adherence to ACS and NCI guidelines for breast cancer screening. American Association of Occupational Health Nurses, 37 (5), 153-7.

Phillips, J. M., & Wilbur, J. (1995). Adherence to breast cancer screening guidelines among African-American women of differing employment status. Cancer Nursing, 18 (4), 258-69.

Rimer, B. K. (1995). Mammography use in the U.S: Trends and the impact of interventions. Annals of Behavioral Medicine, 16, 317-326.

Rimer, B. K., Lerman, C., Schwartz, M. D., Miller, S. M., Daly, M., & Sands, C. (1996). A randomized trial of breast cancer risk counseling: Interacting effects of counseling, educational level, and coping style. Health Psychology, 15 (2), 75-83.

Rimer, B. K., Trock, B., Engstrom, P. F., Lerman, C., & King, E. (1991). Why do some women get regular mammograms? American Journal of Preventive Medicine, 7 (2), 69-74.

Rotter, J. B. (1989). Internal versus external control of reinforcement. American Psychologist, 45 (4), 489-493.

Sands, D. W. (1982, July). The role of health locus of control, cancer health beliefs, and body image in breast self-examination. Dissertation Abstracts International, 43 (1), 84-A.

Schwartz, M. D., Lerman, C., Audrain, J., Cella, D., Rimer, B., Stefanek, M., Garber, J., Lin, T. H., & Vogel, V. (1998). The impact of a brief problem-solving training intervention for relatives of recently diagnosed breast cancer patients. Annals of Behavioral Medicine, 20 (1), 7-12.

Sienko, D. G., Hahn, R. A., Mills, E. M., Yoon-DeLong, V., Ciesielski, C. A., Williamson, G. D., Teutsch, S. M., Klenn, P. J., & Berkelman, R. L. (1993). Mammography use and outcomes in a community. The Greater Lansing Area Mammography Study. Cancer, 71 (5), 1801-9.

Smith, B. L., Gadd, M. A., Lawler, C., MacDonald, D. J., Grudberg, S. C., Chi, F. S., Carlson, K., Comegno, A., & Souba, W. W. (1996). Perceptions of breast cancer risk among women in breast center and primary care settings: Correlation with age and family history of breast cancer. Surgery, 120, 297-303.

Stein, A. D., Lederman, R. I., & Shea, S. (1993). The behavioral risk factor surveillance system questionnaire: Its reliability in a statewide sample. American Journal of Public Health, 83 (12), 1768-72.

Struewing, J. P., Lerman, C., Kase, R. G., Giambarresi, T.R., & Tucker, M. A. (1995). Anticipated uptake and impact of genetic testing in hereditary breast and ovarian cancer families. Cancer Epidemiology, Biomarkers Prevention, 4, 169-173.

Tambor, E. S., Rimer, B. K., & Strigo, T. S. (1997). Genetic testing for breast cancer susceptibility: awareness and interest among women in the general population. American Journal of Medical Genetics, 68 (1), 43-9.

Taylor, S. E., Kemeny, M. E., Bower, J. E., Gruenewald, T. L., & Reed, G. M. (2000, January). Psychological resources, positive illusions, and health. American Psychologist, 55 (1), 1-16.

Thomas, S. M., & Fick, A. C. (1995). Women's health. Part II: Individual, environmental and economic factors affecting adherence to recommended screening practices for breast cancer. Journal of Louisiana State Medical society, 147, (4), 149-155.

University of California, Los Angeles, Familial Cancer Registry and Genetic Evaluation Program, Family History Screening Information Form.

U. S. Department of Health and Human Services, Center for Disease Control, Preliminary Draft of the National Health Interview Survey (NHIS) Year 2000 (to be used by the National Cancer Institute).

Vincent, A. L., Bradham, D., Hoercherl, S., & McTague, D. (1995). Survey of clinical breast examinations and use of screening mammography in Florida. Southern Medical Journal, 88 (7), 731-6.

Wall, R. E., Pollack, S., & Hinrichsen, G. A. (1989, January). Psychometric characteristics of the multidimensional health locus of control scales among psychiatric patients. Journal of Clinical Psychology 45, (1), 94-98.

Waller, K. V., & Bates, R. C. (1991). Health locus of control and self-efficacy beliefs in a healthy elderly sample. American Journal of health promotion, 6 (4), 302-309.

Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scales. Health Education Monographs, 6 (2), 160-170 (as adapted by Loma Linda University School of Medicine, Department of Family Medicine, Medical Care Preferences Survey, 7-9).

Weber, B. L. (1996, January/February). Genetic testing for breast cancer. Scientific American,12-21.

Wilcox, S., & Stefanik, M. (1999). Knowledge and perceived risk of major diseases in middle-aged and older women. Health Psychology, 18 (4), 346-353.

Williams, J. K., & Schutte, D. L. (1997). Benefits and burdens of genetic carrier identification. Western Journal of Nursing Research, 19 (1), 71-81.

Young, S. R., Brooks, K. A., Edwards, J. G., & Smith, S. T. (1998). Basic principles of cancer genetics. The Journal of the South Carolina Medical Association, 94 (7), 299- 305.

Zimmerman, S. E. (1998). The use of genetic tests and genetic information by life insurance companies: does this differ from the use of routine medical information? Genetic Testing, 2 (1), 3-8.