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The Impact of a Didactic Group Experience on Young Women with a Maternal History of Breast Cancer

Bonnie M. Taylor
Loyola University Chicago

LOYOLA UNIVERSITY OF CHICAGO

THE IMPACT OF A DIDACTIC GROUP EXPERIENCE ON YOUNG WOMEN WITH A MATERNAL HISTORY OF BREAST CANCER

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BONNIE M. TAYLOR

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INTRODUCTION

Breast cancer is the second leading cause of cancer death in women in the United States. An estimated 182,000 new cases of breast cancer will occur during 1993 (ACS, Facts & Figures, 1993). This disease is the most prominent cause of death for women 35-54 years of age (Goodman, 1987). Breast cancer is slowly increasing in incidence and prevalence. (Incidence is the number of new cases of disease in a particular time period. Prevalence is the number of existing cases of disease in a particular time period). In 1963 the incidence of breast cancer was 1 in every 18 women with an estimated life span of 72 years (Shimkin, 1963). Breast cancer incidence rates have increased about 3% a year since 1980, going from 84.8 per 100,000 in 1980 to 109.5 per 100,000 in 1988. Some of the increase is believed to be due to screening programs detecting tumors before they become clinically apparent. Other reasons for the increase are not fully understood at this time. Based on the number of new cases of breast cancer in 1993, it is estimated that 46,300 deaths (46,000 women; 300 men) will occur. Only lung cancer leads as a cause of death in women.

Overview of Breast Cancer

When discussing breast cancer, it is important to understand the common statistics used in relation to risk factors and breast cancer research. There are three types of risk: absolute risk, relative risk and attributable risk (Love, 1991).

Absolute risk is the rate cancer occurs in the general population. It is usually reported as a number per 100,000 in a given time period, or is reported as a cumulative risk up to a particular age. This is a number that can not be applied to any one individual. The risk for breast cancer is often explained as a cumulative risk. For example, approximately one of every 9 (and possibly one of every 8) women will develop breast cancer during a lifetime. This number is figured on a lifetime cumulative risk, based on risk in a given population from age 20-30 plus age 30-40, and so on. With a lifetime cumulative risk, the longer a person lives, the higher the risk. With most cancers, this risk increases with age (Kelly, 1987). These numbers do not mean that if there is a room of nine women, one of these women will develop breast cancer.

According to the American Cancer Society (ACS) calculations, the average Caucasian woman in the U.S. in 1988 had a 10 percent risk of developing breast cancer. This 10 percent risk is the lifetime cumulative risk for all white

women, which means a risk from the time of a woman's birth until she reaches 110 years of age. So only if a woman were to live to age 110 would her risk be 10 percent.

The second type of risk when discussing breast cancer is relative risk. This is the comparison of the incidence of breast cancer among people with a particular risk factor to people without that factor.

Risk Factors

The term "risk factor" refers to identifiable factors that make some people more susceptible than others to a particular disease, for example, smoking is a "risk factor" in lung cancer, and high cholesterol is a risk factor in heart disease (Love, 1991).

In general the principle risk factors for breast cancer include age, family history and menstrual and reproductive history (Harris, Hellman, Cannellos & Fisher, 1985). Specifically, the most important factors influencing a woman's likelihood of developing breast cancer include: advancing age, history of a previous breast cancer and a history of breast cancer in a mother or sister diagnosed before menapause (Stoll, 1991).

Age: woman's risk at any one time depends on the extent of the woman's age. For the average Caucasian woman, it is approximately 1/1000/year at age 40, or 0.1 percent. This number increases with age, because breast cancer becomes more

common as women get older. For example, at age 50 the average Caucasian woman has a 1/500/year, or 0.2 percent risk of developing breast cancer (Love, 1991). Table 1 and Table 2 contains the specific details.

Table 1.

The Average Risk of Developing Breast Cancer in a Given Year in White Women *

Age	Risk Per Year
30	1 in 5,900
35	1 in 2,300
40	1 in 1,200
50	1 in 590
60	1 in 420
70	1 in 330
80	1 in 290

*Adapted from P.C. Stomper, R.S. Gelman, J.E. Meyer and G.S. Gross, "New England Mammography Survey 1988: Public Misconceptions of Breast Cancer Incidence," Breast Disease, May, 1990. Reprinted with permission.

Table 2.

Probability of a Woman Developing Breast Cancer by age 75 *

Ethnic Group	%	Number
Caucasian	8.2	1 in 12
African-American	7.0	1 in 14
Chinese- American	6.1	1 in 16
Japanese-American	5.4	1 in 19
New-Mexican Hispanic	4.8	1 in 21
American Indian	2.5	1 in 40

* J.W. Berg, (1984) "Clinical Implications of Risk Factors for Breast Cancer," Cancer 53, 589. Reprinted with permission.

The highest incidence of breast cancer occurs in women between the ages of 50-59 (Sakamoto & Sugano, 1981). The second peak incidence occurs in women between 65-69 years of age (Goodman, 1987).

Family History: in addition to advancing age, heredity (family history) is considered another major risk factor. Women who have a first-degree relative (mother or sister) with breast cancer have a risk two or three times that of the general population. This risk is further increased if the relative is diagnosed at an early age or had bilateral disease. The risk of breast cancer in women with both an affected mother and sister is about 6.5 times greater and significantly different ($p < .005$) than that in women with either an affected mother or sister alone (Sattin, Rubin, Webster, Huezo et al, 1985).

This risk translates into a 50 percent probability of developing breast cancer by age 65 for women with an affected mother and sister (Swartz, 1982). These numbers however must be kept in perspective.

Genetically, we divide breast cancer occurrences into three groups. According to Love (1991), the first and most common type is sporadic. This group includes the 70 percent of women who have no known family history of the disease. The second group of breast cancer occurrences is genetic, where there is one dominant cancer gene that is passed on to every generation. This type of pure hereditary breast cancer is rare, but does occur. Only between 5 and 7 percent of all breast cancers fall into this category (Love, 1991).

Love (1991) reports that "most people assume that these are the only two kinds of breast cancer: the kind that is inherited and the kind that is not" (Love, 1991, p. 146). However there is a third group that is much more common than the genetic group. This is the "polygenic" category, in which there is a family history of breast cancer that is not directly passed on to each generation through one dominant gene, but will affect some members of the family and not affect others (Love, 1991).

Even though most breast cancers occur in women with no known history, it is clear that a family history is still considered a major risk factor for developing the disease.

Menstrual and Reproductive History: The third major risk factor for developing breast cancer is hormonal. Hormones play a key factor in breast cancer because it is a common cancer in women and rare in men. At this point in time, there is not a full understanding of how the hormonal factor plays out, but there are some interesting clues. There is an association between age and menstrual cyclying. The younger a woman is when she begins menstruating, and the older she is when she begins menopause, the more likely she is to develop breast cancer. It appears that the more periods a woman has over her lifetime, the more prone she is to develop breast cancer (Love, 1991). Castration either by surgery or radiotherapy, substantially reduces a woman's risk of getting breast cancer (MacMahon, Cole & Brown, 1973; Tuchopoulos, MacMahon & Cole, 1968). If the castration occurs early (prior to 35 years of age) with removal of the ovaries, the risk of cancer is reduced to one third of that experienced by women who have a natural menopause (Harris, Hellman, Cannelos & Fisher, 1985).

A strong association exists between breast cancer and pregnancy. Nulliparous women (those who have never had children) appear to be more at risk than women who have had children. Women who have their first child before the age of 18 have only one third the breast cancer risk of those whose

first child is born after 30 years of age (Harris et al, 1985). However, this does not appear to apply to pregnancies that are terminated because of miscarriage or abortion (Rosenberg, Palmer, Kaufman, Strom, Schottenfeld & Shapiro (1988). Women who have their first child after age 30 actually have significantly higher risk than do women who remain nulliparous (Henderson, Pike & Gray, 1981).

Early Detection

The 5-year survival rate for localized breast cancer has risen from 78 percent in the 1940's to 92 percent today (ACS, Facts & Figures, 1992). The survival rate is directly related to the size of the breast lesion. The larger the tumor, the greater the chance that metastases have occurred. Once breast cancer occurs or spreads beyond the breast it is a lethal disease. Therefore, early detection of breast cancer remains a vital key to increased cure rates and survival.

There are three established methods of early detection of breast cancer: physical examination, breast self-examination, (BSE) and mammography. Mammography is a radiographic technique to detect non-palpable cancers. Eighty-five percent of breast cancers will be detected by mammography and up to 50 percent of these will be nonpalpable (Beahrs, Shapiro & Smart, 1979).

However routine screening with mammography has not been recommended for women under age 40 for several reasons. First, mammography has less diagnostic accuracy in this age

group because of increased density of the normal breast tissue. Second, concern still exists over repeated low dose radiation exposure over many years. Further the incidence of breast cancer below age 40 is low compared to the cost of the procedure. Therefore, physical examination by experienced medical personel and BSE is advised especially in younger women.

Breast self-examination (BSE) is recommended by the American Cancer Society (ACS) on a monthly basis for all women over age 20. BSE is a simple and safe procedure without cost to women who practice it. In a study of over 2000 women Huguley and Brown (1981) found that the more frequently women performed BSE, the more likely BSE was successful as being the first method to detect cancer. When cancer was discovered by BSE it was at an earlier stage than after all other methods of detection except mammography. This finding indicates that the practice of BSE can play an important role in early diagnosis of breast cancer. Improvements in the practice of BSE may reasonably be expected to impact on survival of women with breast cancer.

This limited background on the subject of breast cancer serves as a foundation for this study. With a better understanding of this disease, health psychologists can play a major role in designing better methods to educate all women about risk factors, to promote the importance of early

detection in this disease and to identify high-risk individuals who need increased awareness and education about their risk.

As a way of narrowing the focus of such a broad and complex problem, this research will examine a group of women toward whom little attention has been directed, that is toward daughters who have a maternal history of breast cancer.

Theoretical Rationale

A theoretical model which best addresses the health behavior of this population is the Health Belief Model (HBM). This model was devised in the early 1950's by Levanthal and colleagues (a group of social psychologists at the United States Public Health Service) in an attempt to understand the "widespread failure of people to accept disease preventives or screening tests for the early detection of asymptomatic disease" (Rosenstock, 1974, p. 328). It was later applied to patients' responses to symptoms (Kirscht, 1974) and to compliance with prescribed medical regimens (Becker, 1974).

Since 1974, the HBM has continued to be an organizing framework for explaining and predicting acceptance of health and medical care recommendations. It has been applied to a wide range of health behaviors including smoking, dietary changes and cervical and breast cancer screening compliance.

Specifically the HBM consists of three dimensions. It predicts that preventive health actions will more likely be

performed by individuals who (1) perceive susceptibility to a disease and (2) perceive the severity of the disease; and (3) perceive the benefits of the preventive health actions to outweigh the cost of doing such action. Thus, "The combined levels of susceptibility and severity provide the energy or force to act and the perception of benefits (minus the barriers) provide a preferred path of action" (Rosenstock, 1974, p. 332).

In 1977 Bandura introduced the concept of self-efficacy as a distinct outcome expectation (Bandura, 1977a, 1977b,1986), which, based on present health behavior research, needs to be included in the HBM in order to increase its explanatory power (Rosenstock, Strecher & Becker, 1988). Self-efficacy is defined as "the conviction that one can successfully execute the behavior required to produce the outcomes (Bandura, 1977a, p. 79). Therefore, for behavior change to succeed, individuals must (as the original HBM theorizes) feel threatened by their current behavioral patterns (perceived susceptibility and severity) and believe that a change in action will be beneficial (outweigh the cost), but they must also feel competent (self-efficacious) to implement the change (Rosenstock, 1990).

Several recurrent critiques continue to surface against the utility and validity of the HBM. The major criticism is that the notion of a belief-behavior relationship has never

been uniformily established. Rosenstock (1990) argues "what would seem to be needed is further research to specify the conditions under which specific beliefs and behaviors are causally related and the conditions under which they are not" (Rosenstock, 1990, p. 48).

A second criticism is that the HBM does not address strategies for change in behaviors. However, the originators of this model argue that this was not its purpose. Rosenstock (1990) comments that "overenthusiastic proponents of the HBM may on occasion have attempted to explain more than such a model could possibly explain" (p. 49). It has been pointed out that "the HBM is a psychosocial model and as such, it is limited to accounting for as much of the varience in individuals' health-related behaviors as can be explained by their attitudes and beliefs. It is clear that other forces influence health actions as well" (Janz and Becker, 1984, p. 44).

Table 3.

Key Components of the Health Belief Model

I.	Threat
	A. Perceived susceptibility to an ill-health condition (or acceptance of a diagnosis)
	B. Perceived severity of the condition
II.	Outcome expectations
	A. Perceived benefits of specified action
	B. Perceived barriers to taking that action
III.	Efficacy expectations
	A. Conviction about one's ability to perform the recommended action (self-efficacy)

Note: Sociodemographic factors such as education, age, gender, ethnicity and income are believed to influence behavior directly by affecting perceived threat, outcome expectations and efficacy expectations. Used with permission. Rosenstock (1990).

Kasl and Cobb (1966) define health behaviors as "any activity undertaken by a person believing himself to be healthy, for the purpose of preventing disease or detecting it in an asymptomatic state". Harris and Guten (1979) have expanded this definition to include health-promoting and health maintaining behaviors as well as disease-preventing behaviors and have labeled these "health-protective behaviors". Attempts to predict the performance of these health-protective behaviors have relied on the Health Belief Model.

Perception of Risk

In health psychology one of the primary concerns is the way individuals respond to and cope with threats and stresses posed by sickness and health care (Stone, 1979). Current concepts of illness behavior and health protective behaviors place an emphasis on cognitive factors. An example of these factors can be seen in the continued expansion of the Health Belief Model to include the concept of the "at risk role" described by Baric (1969). The individual at risk is somewhere in the middle of a state of health and the state of experiencing symptoms. People "at risk" include those who perform certain activities (i.e. smoking) which increases their risk of illness to a much higher degree than that of the general population. The risk however must be perceived as such for it to have an impact on the decision-making of the individual at risk (Stone, 1979).

This perception of risk is discussed by Wallston and Wallston, (1982) as the "readiness to take a health action". This "readiness" is determined by (1) the person's perceived likelihood of susceptibility to a disease (such as having a mother with breast cancer) and (2) by the individual perceiving the severity and the consequences of developing a particular illness, (such as having a mother who has gone through treatment for breast cancer). These two factors, the susceptibility and severity comprise the perceived threat of

the disease. Once an individual identifies the threat, then health behaviors (such as BSE and mammography) are likely to be evaluated both for their potential benefit and for whether performing these health behaviors outweigh the costs. A cue to action, (such as a health education message) will enhance the likelihood of performing these health behaviors.

The Health Belief Model has been applied to several studies looking at health beliefs and attitudes, and breast cancer screening. Lermer, Rimer & Engstrom (1989) review several studies that relate to the HBM and breast cancer screening. For example, Slenker and Grant (1989) found that the more strongly a woman believed in the benefits of mammography, and the less concern she reported toward the "barriers" or costs, the more likely she was to have had a mammogram or to say that she intended to have a mammogram. In another study, Calnan (1984), identified beliefs in the efficacy of mammography and the potential curability of breast cancer as factors that related to obtaining mammograms. In addition, an earlier study by Fink, Shapiro & Roester (1972) found that regular participation for breast cancer screening was associated with increased perceptions of susceptibility to breast cancer. However, Rimer and colleagues (1988) have reported opposite findings. In addition, another study that looked at beliefs and breast cancer screening also identified "barriers" or costs which women report as reasons for not

obtaining mammography, such as financial constraints, fear of radiation exposure and inconvenience (Fox, Baum, Klos & Tsou, 1985).

Although the Health Belief Model attempts to explain factors which influence individuals to take action so as to prevent, detect and diagnose disease, there is the option of reacting to the threat of breast cancer, for example, with the use of negative coping mechanisms. These might include, for example, the use of denial in which case women with a maternal history of breast cancer may not perceive an increased risk to themselves, and may not take part in any health-protective behaviors such as BSE and mammography (Disch, 1987; Taylor, 1987). Secondly, individuals may feel terrified at the thought of getting breast cancer and may take on obsessive-compulsive behaviors or become extremely anxious and phobic about the disease.

Significance of the Study

Breast cancer is the most common cancer in women. The emotional, social and medical needs of women with breast cancer have been increasingly recognized and studied in the last few years. Patients with breast cancer are so profoundly affected by their disease, it is not surprising that their families are also deeply affected. However, few articles exist which address specific family members. Given the limited amount of investigation, it seems timely to look at

the daughters of women with breast cancer. Since little is known concerning their awareness of risk, their knowledge of breast cancer, their psychological issues and whether or not they practice health-protective behaviors, a randomized, controlled study was needed to address these issues more objectively. Using the Health Belief Model as a theory base and recognizing the potential severity and chronicity of breast cancer, it was appropriate to specifically address the issues of awareness of risk, knowledge of breast cancer, psychological factors that may be affecting the daughters and the practice of health behaviors in young women with a maternal history of breast cancer. With an increased understanding of breast cancer and these issues, health psychologists will be better able to address the issues of education and promotion of health to women in general and to those at a higher risk of breast cancer.

Purpose of the Study

This study identified a high risk population of women in developing breast cancer (those with a maternal history of breast cancer). With breast cancer specifically, it is likely that daughters will be emotionally affected by the chronicity of the disease of their mothers. However, despite their sensitization, they may or may not develop a sense of being at risk themselves. Extending the Health Belief Model to such women, one would assume that daughters of women with breast

cancer would (1) have an accurate sense of their own risk for breast cancer, (2) have an accurate knowledge base about the disease and (3) pratice health-protective behaviors to minimize the risk. However these hypotheses have not been tested. The purpose of this randomized, controlled, intervention study was to identify in women with a maternal history of breast cancer (1) their knowledge base about breast cancer, (2) an awareness of the risk to self, (3) identify psychological factors that may or may not be affecting these women, (4) to identify any behaviors that might minimize their risk and (5) to investigate the impact of a didactic group experience on these women who potentially have a high risk of developing breast cancer.

Summary

Chapter One highlights information about breast cancer including incidence, risk factors, early detection and screening for breast cancer. This background served as a foundation for the theoretical framework consisting of the Health Belief Model. This framework included a discussion of current concepts related to illness and health behaviors and how these relate to the "at risk" role. The significance and purpose of the study are then presented.

Chapter Two will be a review of selected literature concerning the psychosocial impact of breast cancer on women with a maternal history of disease.

Chapter Three will include the methodology including the design, subject selection, instrumentation, procedural details and treatment of the data from the questionnaires, pre and posttests and standardized measures.

Chapter Four will describe the analysis of data and discussion of those results.

Chapter Five will include the limitations of the study, the summary, discussion, conclusion and implications for health psychology and future research.

CHAPTER II

REVIEW OF THE LITERATURE

Psychosocial Impact of Breast Cancer on Daughters

Women with a first-degree relative (a mother or sister) who have had breast cancer have a risk for breast cancer two to three times the risk of the general population (Sattin and colleagues, 1985; Byrne, Brinton, Haile and Schairer, 1991). Over the last twenty years, the literature has addressed the biological and psychological components related to the individual with breast cancer. Because women with breast cancer are significantly affected by the disease, it would be surprising if their family members were not also affected (Kelly, 1980). In the past the literature regarding the impact of breast cancer on the family has been limited to a very general focus. Specific family members, such as daughters, have received insufficient attention by researchers. Given the potential identification and closeness of mothers and daughters, the impact of breast cancer may be significant for the daughters. This chapter will review the literature on the the impact of breast cancer on the daughters whose mothers have breast cancer.

Several early studies have addressed the impact of breast cancer on the family in a very descriptive and general fashion.

One of the earliest studies in the literature to report on the impact of breast cancer on family members is by Grandstaff (1976). The author conducted interviews and counseled patients recently diagnosed with breast cancer and their families pre and post surgery. The author reported that teen-aged or older daughters "usually identify quite closely with their mother" and because of this shared experience, the daughters may assume the major "support role" (p. 153). The author concludes from the interviews that many of the patients express feelings of guilt regarding the potential development of breast cancer in their daughters. And the daughters reported a "considerable amount of fear toward develping breast cancer" (Grandstaff, 1976). This study, although methodologically weak, represents one of the first reports of the emotional impact that breast cancer might inflict upon daughters.

Lewis, Ellison and Woods (1985) discussed selected concepts that characterize the impact of breast cancer on the family, primarily as the illness relates to the day-to-day operations of family life; for example: the family's adaptation style, characterized with such themes as

powerlessness, uncertainty, interdependence, ambivalence, role restructuring and resiliency (Lewis, Ellison and Woods, 1985).

The second half of this research reported on a longitudinal study looking at 126 families whose mothers had nonmetastatic breast cancer. Discussion focused on initial at-home interviews with the mother, her partner and school-aged children. The authors examined the data for differences in responses according to the children's stage of psychosocial development. The adolescent group (14-19 years of age) provided some of the "most provocative interviews" (p. 209), illustrating significant conflict for the adolescents. For example, "they spoke of being torn between wanting to spend time with their mother and wanting to 'do their own thing'" (Lewis, Ellison and Woods, 1985, p. 209).

Wellisch, Mosher and Van Scoy (1978) have also reported on observations of children, although the study did not focus specifically on breast cancer. The authors observed that children who have a parent with cancer have frequently attended their family therapy group sessions. They found that the children are very reactive to cancer in a parent but are far less verbal than adults.

This study was a retrospective clinical account of six adolescents and their need for psychological interventions because of problems which occurred due to the dianosis of

cancer in a parent. The authors hypothesized that as a reaction to the cancer in a parent, the adolescents acted out in maladaptive ways. Some developed problems in school or became disciplinary problems in an unconscious attempt to refocus the attention of family from the cancer onto their own problems.

Overall, the stresses for adolescents whose parents have cancer can be extremely intense. The authors discussed the developmental phase of adolescence, specifially the normal processes of "gradual emotional withdrawal and intensification of relationships outside the family system that should occur. Cancer in a parent will disturb or reverse this process" (p. 230).

The authors also discussed observations seen in children in their late teens and early twenties who found themselves "placed in the role of emotionally parenting their frightened and regressed parents before they felt adequately prepared to do so" (Wellisch, Mosher and Van Scoy, 1978, p. 230).

Berman, Cragg and Kuenzig (1988) assessed the reactions of ten adolescents and their reactions to the death of a parent from cancer, again, not specifically for breast cancer. The adolescents and their surviving parent were evaluated using a semi-structured questionnaire looking at communication

patterns and support systems for the adolescents. The authors reported that all ten families kept the adolescents well informed about the parent's illness from the time of diagnosis to death. Similiar reporting of important events like diagnosis, death and funeral were found between adolescent and parent. However, there was disagreement between parents and adolescents on identified sources of support. Parents identified physicians and school personnel as their greatest sources of support, while adolescents identified family friends, relatives and peers as their greatest sources of support. The adolescents reported little or no help or support from health care professionals and reported feeling isolated especially when the parent with cancer was in a terminal phase of the illness (Berman, Cragg and Kuenzig, 1988).

Rosenfeld and colleagues (1983) addressed the issues of adolescents specific to the impact of breast cancer. The authors reported on a pilot retrospective, exploratory study from Israel of eight adolescent daughters whose mothers had breast cancer. A structured interview format conducted by a clinical psychologist and a pediatrician trained in child psychiatry was used in obtaining information from the adolescent girls. The authors reported that "most girls were significantly upset, felt inadequately supported and lacked

information during periods of peak stress caused by the illness and its treatment" (p. 244). The authors observed no maladaptive behaviors in this group of adolescents.

A dissertation by Lamb (1984) also addressed problems and concerns of adolescent girls' responses to their mothers' breast cancer. An open-ended, semi-structured interview was conducted with 10 adolescent girls between 13 and 17 years of age. The purpose of this study was to identify the impact of a mother's breast cancer in several areas including: perceived changes in the family system, somatic concerns, relationship issues and coping styles. A case study format was used to report findings. The major theme expressed by all daughters was that of anxiety about a possible recurrence of cancer in their mother, as well as concerns about developing breast cancer themselves. In addition, a large number of somatic concerns were reported by many of the girls. The author reports that the overall coping style was one of denial and avoidance, which appeared to be successful adaptations to control the anxiety about their mothers' illness. No major mood disorders or acting out behaviors were observed, however one subject demonstrated a depressed affect (Lamb, 1984).

This next study to be reviewed addressed relationship

issues between women with breast cancer and their daughters and sons. Lichtman and colleagues (1984) describe a study in which 78 patients with breast cancer were interviewed and completed standardized measures to assess psychological adjustment and to document perceptions of changes in their relationships with their children. Although the majority of mother-child relationships were reported to be strong or to have become stronger, twelve percent of those studied had a deterioration in their relationship. Mothers who had a poor prognosis, more severe surgery, poorer psychological adjustment, and to a lesser degree had more difficulty with chemotherapy or radiation therapy were more likely to have problems with their children. The authors report that:

> The mothers' relationship with their daughters were at significantly greater risk than were the relationships with their sons. Seventeen percent of the patients studied reported that their daughters were withdrawn, fearful, hostile or rejecting; only eight percent of women reported having problems with their sons (p. 1).

Several contributing factors to the difficulties with adolescents or post-adolescent daughters included: fear of inheriting breast cancer and mothers' demands on the daughters for support (Lichtman and colleagues, 1984).

Several studies have been reported that address more specific issues of women with a maternal history of breast cancer. Kelly (1980) used a semistructured interview designed to elicit what thirty-nine women with a maternal history of breast cancer thought, felt and did about breast cancer and health practices specific to breast cancer. Each woman reported they were profoundly affected by their mother's illness. They expressed "feelings of guilt and anxiety which came about after their mother's diagnosis. Many felt chronically threatened by breast cancer. Although the women were concerned about risk, they had only vague and sometimes incorrect information about the significance of the risk" (Kelly, 1980, p. 118).

Although these studies represent some of the first to specifically address daughters of women with breast cancer, there are significant methodological weaknesses including: very small sample size, absence of control groups, and little or no use of standardized measures. The conclusions drawn strongly emphasize the anxiety issues and lack of accurate information and support that these women experience.

Based on previous research (Kelly, 1980), Kelly embarked on a new approach and reported on experiences of risk counseling for relatives of individuals with cancer (Kelly,

1987). The process of risk counseling presents various aspects of cancer risk analysis, which provides information about the social, scientific and medical factors that can affect individuals who have a family member with cancer. The premise of the service is that accurate information increases a sense of empowerment. The service provides individuals with the opportunity to explore their own and other family members' risks of developing cancer. The author reports specific accounts of women seeking cancer risk analysis whose mother or sister has breast cancer. Kelly advises that the information be given as part of an ongoing process, not in a hurried single visit. When people are anxious and confused, they need more information, not less. The expected outcome is that information will relieve anxiety and help relatives of persons with cancer to function more effectively (Kelly, 1987).

Kash, Holland, Halper and Miller (1992) investigated the beliefs of women at high risk for breast cancer regarding their own breast cancer risk and the impact of this information on their psychological distress and the health behaviors they practice. Two hundred seventeen women were evaluated based on multiple instruments measuring anxiety, coping styles, social support, social desirability and health behaviors practiced. The results of their study found that women who perceived (1) a high risk for breast cancer, (2) had

high anxiety levels and (3) felt they could do little about developing breast cancer were less compliant with health behaviors such as BSE and mammography screening. Another major finding in this study was that mean levels of psychological distress (based on Brief Symptom Inventory) among these women exceeded normal ranges by almost one standard deviation. The authors conclude that a psychological and educational intervention aimed at reducing anxiety is greatly needed for this group of women with a maternal history of breast cancer.

Wellisch, Gritz, Schain, Wang and Siau (1991) investigated differences between daughters of women with breast cancer and a matched control group (women without a family history of breast cancer) in several areas including: (1) knowledge and attitudes about breast cancer, (2) health behaviors, (3) quality of mother-daughter relationships, (4) sexuality and body image, and (5) two areas of psychological functioning which included symptomatology and coping behaviors. The researchers utilized a structured interview, written questionnaires and standardized instruments including: (1) Brief Symptom Inventory, (2) Derogatis Sexual Functioning Inventory, (3) Sexual Arousability Inventory, (4) Ways of Coping Checklist to gather information from 120 women. The

authors conclude that the "most important finding is the lack of differences between daughters of women with breast cancer and the well-matched comparisons" (p. 332). Overall, no differences between groups were found in psychological symptoms, coping styles, BSE and mammographic screening practices, health knowledge or body-image ratings. These results are in contrast to the previous studies reviewed in that these women with a breast cancer history "showed good overall coping styles with few signs of significant dysfunctions in relation to the control group" (p. 324). One major area of difference was that women with a maternal history of breast cancer "showed significantly less frequent sexual intercourse, lower sexual satisfaction and greater feelings of vulnerability to breast cancer and they identified a greater number of symptoms of breast cancer" (p. 324).

In Part II of the above study, Wellisch, Gritz, Schain, Wang and Siau (1992) explored the characteristics of the distressed daughter of a woman with breast cancer. The authors determined that the two major variables that were most likely to influence psychological adjustment were (1) daughter's developmental phase (age at the time of her mother's diagnosis), and (2) mother's survival status. Of the 60 daughters with a history of breast cancer, 30 were selected

whose mothers were living and 30 were selected whose mothers had died. The daughter's age at the time of her mother's diagnosis was divided into three categories:
(1) childhood (0-10 years, n=9, 15% of the sample),
(2) adolescence (11-20 years, n=15, 25% of the sample),
(3) adulthood (older than 21 years, n=36, 60% of the sample). The results showed that adolescent daughters "reported feeling significantly more uncomfortable about involvement in their mothers' illness" (p. 171) than the adult daughters.

Overall, the daughters who were adults at the time of their mother's diagnosis had the least adjustment problems, daughters who were children had moderate adjustment problems and daughters who were adolescents had the greatest adjustment problems.

Based on the daughter's age at the time of her mother's diagnosis, the subjects were divided into two groups (0-20 and +20 years) and compared on the basis of mother's survival. The younger daughters (0-20) at the time of mother's diagnosis, were "significantly more likely to have mothers who died of their disease" (p. 175). Daughters whose mothers had died were "more likely to report (1) long-term life plan changes and (2) role changes with their mothers during the mothers' illness" (p. 171). The authors also point out that

psychological symptomatology as measured by the Global Symptom Index (from the BSI) could be predicted by three variables: "(1) issues of discomfort with involvement with the mother during her illness, (2) lack of resolution about their mother's illness and (3) lack of satisfaction with sexual intimacy" (p. 178). The authors are quick to point out that replication studies are needed for several reasons: this is primarily retrospective data and the demographics of this group of daughters in terms of SES, education and ethnicity "are not representative of the entire population". However this study identifies a subgroup of daughters who are less-resolved and more distressed about their mother's breast cancer, which stresses the importance of prospective studies that may help predict women at greatest risk for psychological distress (Wellisch, Gritz, Schain, Wang and Siau, 1992).

Another study that investigates daughters of women with breast cancer is a dissertation by Dworsky (1990). The purpose of this study is to identify the effects of an educational program conducted through the mail that tests the following hypotheses: first, women with a family history of breast cancer will be more knowledgable and more fearful of breast cancer than women without a family history. Secondly, educational intervention conducted through the mail will

change beliefs, attitudes and health practices of women participating in this study by increasing knowledge, decreasing fear and will increase motivation to practice "preventive breast care". Participants included three hundred twenty-one women who had participated in two previous epidemiology studies of breast cancer: 190 women randomly selected as controls and 131 women who are daughters and sisters of premenopausal patients with bilateral breast cancer (therefore a high risk group). These women were then sent questionnaires looking at breast cancer knowledge and screening practices, and "breast fears including a 'personal happiness' inventory". Once pretest information had been returned the women were then sent four educational pamphlets from the American Cancer Society and National Cancer Institute and were asked to read, review and rate which best suited their own educational needs. One hundred sixty-four women completed and returned the posttests. The women were divided into two groups: women with a family history (N = 80) and women without a family history (N = 84). The study participants ranged in age from 20-75 years. The author summarizes the results as follows: women with a family history of breast cancer entered the study better educated (mean pretest score was 81.9 versus 74.9), although women without a family history scored higher on the posttest (mean score was

95.9 versus 92.8). Women with a family history reported being more fearful than those without a family history. The women with "high fear scores" tended to be younger, have a family history of breast cancer, less likely to have had a mammogram, and overall "more nervous, worried and less happy than women with lower fear scores". Of this "high fear" group, 47 percent reported that the educational program decreased their fear and were more interested in additional breast cancer information. Twenty-seven percent of the "high fear" group reported that the educational program increased their fear.

Although methodologically weak in some areas, such as the lack of standardized measures, the above study represents a first step toward investigating educational interventions for women with a maternal history of breast cancer.

In summary, Chapter Two highlighted a review of the literature addressing the impact of breast cancer on daughters with a maternal history of the disease. Clearly, the review of the above literature suggests a significant need for health care professionals to become more aware and involved in the needs of the entire family when caring for patients with cancer.

Although these studies provide a first step in understanding the acute and chronic effects of breast cancer on individuals whose parent have the diagnosis, there are

significant methodological weaknesses. Most of the limited psychological, nursing or psychiatric literature report anecdotes, isolated case reports and clinical impressions (Grandstaff, 1976; Wellisch, Mosher and Van Scoy, 1978; Kelly, 1980; Lamb, 1984). Only a few of the above studies used control groups or standardized measures (Kash, Holland, Halper and Miller, 1992; Wellisch, Gritz, Schain, et al, 1991) and only one study used randomization (Dworsky, 1990).

Because of the complex issues surrounding the developmental phase of adolescence, the present study focused on women between the ages of twenty to forty. In addition, psychological factors may be more complex if women are dealing with the death of their mothers as well as the impact of the disease. Therefore, women were excluded from this study if their mothers had died of breast cancer.

Based on this review of the literature of the impact of breast cancer on family members, specifically, daughters, this study will address several hypotheses:

(1) There is no difference in knowledge about breast cancer between the experimental and control group immediately after attending breast cancer classes and
at a follow-up time.

(2) There is no difference in the awareness of risk for breast cancer to self between the experimental and control group

immediately after attending breast cancer classes or at a follow-up time.

(3) There is no difference in psychological variables (anxiety, depression and somatization) between the experimental and control group immediately after attending breast cancer classes and at a follow-up time.

(4) There is no difference in health behaviors practiced between the experimental and the control group before or after attending breast cancer classes.

CHAPTER III

METHODOLOGY

The purpose of this randomized, controlled study included: (1) to identify women with a maternal history of breast cancer, (2) to assess knowledge about breast cancer in this population, (3) to determine awareness of susceptibility to breast cancer in this "at-risk" group, (4) to examine the impact of information about breast cancer on psychological symptoms (i.e. anxiety, depression and somatization) of women attending two didactic group sessions compared to a control group (women not attending the classes), (5) to determine health-promoting behaviors practiced by these women, specifically early detection methods of screening for breast cancer. All women received an information sheet, signed a consent form, completed a standardized self-report measure SCL-90-R, a pretest, demographic questionnaires and a posttest. Their responses provided both quantitative and qualitative data for analysis.

The didactic group experience was piloted with five women who did not have a maternal history of breast cancer. They were recruited by the author and the R.N. who presented the didactic group classes. (See Appendix A, The Pilot Study).

The classes were held two evenings, a Tuesday and Thursday from 6-8 pm. The pilot study determined the understandablility of the content of the class, the difficulty with the timing of the class, the scheduling of the content of the classes, and assessed acceptability of homework assignments and overall identified the strengths and weaknesses of the classes. Data obtained from this pilot study was descriptive in nature and resulted in frequency rates of rates of responses.

Design of Study

The design of this study is presented in Campbell and Stanley (1963, p. 8), the number four design "true experimental designs", the Pretest-Posttest Control Group Design. The following is the diagram of the design.

R O X O O

R O O O

According to Campbell and Stanley (1963), the pretest-posttest control group design "controls for all seven sources of possible threats to internal validity, specifically history maturation, testing, instrumentation, regression, selection, mortality and interaction of selection and maturation, etc". This is primarily accomplished because this design uses the process of randomization, a major strength of this study.

Another strength of this study is that it added a follow-up time (6-12 months) to evaluate for lasting effects of the intervention.

Subjects

There were a total of fifty-nine women who participated in this study. All women who participated had mothers living with breast cancer and were aware of their mothers' diagnosis. A computerized list of all women with the diagnosis of breast cancer was generated from both the Section of Medical Oncology and from the Tumor Registry of a large urban medical center. This list was then presented to the physicians of these women. If the women had Stage I or II breast cancer and were within an age range to have a daughter between 20 and 40 years of age, a letter was mailed to them informing them of this study. Those interested in receiving more information and/or willing to grant permission for this investigator to call their daughters, then signed a consent form (Appendix B) and mailed it to this investigator. The daughters were then contacted by telephone. If they met eligibility criteria (between the ages of 20 and 40 and have mothers living with breast cancer), then they were given a detailed explanation of the study, which included the concept of randomization. Those agreeing to participate were then randomized to attend two 2 hour classes or be placed on a wait-list control group with the option of attending the classes at a later time.

Because not enough women agreed to participate in the study using this method, a news release was also published in the newsletter of a national breast cancer organization as

well as a local newspaper explaining the study and asking for volunteers. The same procedure was followed for these women. The criteria were then changed to include women whose mothers were living with breast cancer without knowing the stage of the mothers' disease. Women were excluded from the study if their mothers had died from breast cancer.

Instruments

All subjects were given a written information sheet explaining the study and were asked to complete the following:

(1) an information sheet and consent form (Appendix B),

(2) a demographic information sheet and questionnaire (Appendix C) requesting information such as address, age, education and occupation. In addition, the women were asked questions about (a) awareness of risk to self for breast cancer, (b) health behaviors practiced and (c) information concerning the family members of each of the subjects.

(3) All women completed the Symptom Check List-90-R (SCL-90-R) (Appendix D) both before and after the class as well as in the final questionnaire packet.

(4) The women were asked to complete a pretest (Appendix E) consisting of 25 true/false questions.

(5) And a posttest (Appendix F), was given at the end of the second class, which was identical to the pretest.

(6) Six to twelve months after agreeing to participate with this study, all women were mailed a final questionnaire (Appendix G) which asked about awareness of risk to self for breast cancer, health behaviors practiced, physician visits, and status of other family member's health, as well as the same posttest and the SCL-90-R.

The Symptom Check List-90-Revised (SCL-90-R) is a 90 item self-report symptom inventory designed primarily to reflect the psychological symptom patterns of psychiatric and medical patients. The instrument measures somatization, obsessive-compulsive symptoms, interpersonal sensitivity, depression, anxiety, phobic anxiety, psychoticism, paranoid ideation, hostility and global indices of psychopathology. Furthermore, the global indices provide an assessment of the (1) intensity of perceived distress, (2) the number of symptoms experienced and (3) a summary measure combining intensity and a number of symptoms.

The Clinical Psychometrics Research Unit of Johns Hopkins University devised the SCL-90-R, which evolved from the Hopkins Symptom Checklist (HSCL). This instrument had many drawbacks and was found to be clinically inadequate, which led to a preliminary version of the SCL-90. Based on early clinical experiences and psychometric analyses, the test was modified and validated in the present R (revised) form (Derogatis, Rickels & Rock, 1976),

The SCL-90-R consists of 90 self-description items that are rated on a 5-point scale of distress ranging from 0 (not at all) to 4 (extremely). An important aspect of any clinical assessment procedure is the time set reference given to the person to make his/her response. The standard time frame for the SCL-90-R is "7 days including today". The major rationale for this selection concerns the fact that the most recent 7 days in a person's time frame usually provides the most relevant information to one's clinical status (Deragotis, 1977). Under usual circumstances the SCL-90-R requires 15-30 minutes to complete. The test manual recommends that the measure be administered by someone who provides a positive impression of the benefits of psychological assessment.

The SCL-90-R is a measure of current, point-in-time, psychological symptom status. It is <u>not</u> a measure of personality, except indirectly, in that certain personality "types" and "disorders" may manifest a charateristic profile on the primary symptom dimensions (Deragotis, 1977).

The SCL-90-R may be used in a single, one-time assessment of the person's clinical status, or it may be used repeatedly either to document trends through time, or in a pre-post evaluations. Test-retest reliabilities are very good with an inability to detect any significant "practice" effects. Table 4 gives reliability information for each of the 9 symptom areas.

Table 4.

Symptom Check List-90-Revised

Symptom Dimension	Internal Consistency (coefficient) a	Test-Retest (r-tt) b
I. Somatization	.86	.86
II. Obsessive-Compulsive	.86	.85
III. Interpersonal Sensitivity	.86	.83
IV. Depression	.90	.82
V. Anxiety	.85	.80
VI. Hostility	.84	.78
VII. Phobic Anxiety	.82	.90
VIII. Paranoid Ideation	.80	.86
IX. Psychoticism	.77	.84

(a) N=219 "symptomatic volunteers"
(b) N=94 heterogeneous psychiatric outpatients with one one week time elapse between tests.
Taken from SCL-90-R manual.

The SCL-90-R is designed to reflect psychological symptom status in a broad spectrum of individuals, ranging from non-patient "normal" respondents, through medical patients of various types, to individuals with psychiatric disorders. This broad spectrum of patients includes: alcoholics, drug users, students, patients with cancer and heart disease, and those with sexual disorders.

The SCL-90-R enjoys a fair amount of success within an oncology population. Craig and Abeloff (1974) used the test to demonstrate clinical levels of psychological distress among patients with cancer, and Abeloff and Derogatis (1977) used

the SCL-90-R to characterize a specific symptom picture of patients with breast cancer. Subsequently, Derogatis (1980) utilized the "90" to argue that women diagnosed with breast and gynecological cancers present a unique psychological picture. In addition, Derogatis, Abeloff and Melisaratos (1979) used the SCL-90-R in a study that demonstrated length of survival with metatastatic breast cancer was distinctly related to coping style, a conclusion that was also reported by Rogentine and colleagues (1979) using the SCL-90-R with patients with malignant melanoma.

The SCL-90-R has been used successfully as a psychiatric screening measure among patients with cancer. Derogatis, Lobo, Folstein and Abeloff (1983) used the "90" in a series of consecutive admissions to the cancer center with patients who had been prescreened positive or negative for psychiatric disorders by the General Hospital Questionnaire. The "90" discriminated positively from negatively screened patients, and also distinguished between positively screened patients judged in need of psychiatric intervention versus those judged to be without such a need (Derogatis, 1985).

The SCL-90-R was chosen for this study for several reasons: (1) it has a fairly respectable reliability record, (2) the SCL-90-R is one of very few instruments that has had a broad utilization in oncology, and (3) therefore it would be interesting to determine validity with family members of

patients with cancer, specifically breast cancer, and (4) under usual circumstances it requires approximately 15-20 minutes to complete.

The primary intent of the didactic course was to share very general information about breast cancer. (See Appendix H) The curriculum was developed by combining the most recent published information about breast cancer, including: several books, ACS pamphlets, and chapters from major textbooks. The primary focus was to highlight important general information, specifically, awareness of risk, etiology of the disease, present facts and dispell myths, discuss risk factors and detail and encourage the practice of early detection methods. The course purposely did not include information about the treatment of breast cancer.

Various methods were used in the presentation of material, for example, handouts, slides, a BSE video, along with the ACS model for identifying normal vs. abnormal breast lumps, actual mammograms demonstrating normal vs. abnormal findings, homework assignments and a relaxation tape.

A panel of experts including two internationally known oncologists who specialize in breast cancer and two oncology nurse clinical specialists reviewed the didactic course material for content validity.

A review of the literature as well as conversations with other researchers in the field of breast cancer were contacted

to identify instruments to test for breast cancer knowledge. The review revealed only one instrument, The Breast Cancer Knowledge Test developed by McCance, Mooney, Smith and Field (1990). This measure was fairly limited because it only measured knowledge about screening and detection of breast cancer. Therefore, a measure was developed specifically to corelate to the course material presented. Reliability of this questionnaire will be discussed in Chapter IV.

Procedure

Once the study and the concept of randomization were explained to the daughters and they agreed to participate, subjects were randomized to attend the classes or receive questionnaires in the mail and attend the classes at a later time. (Approximately forty-five women declined to participate in this study). The randomization procedure consisted of using a random numbers list, the odd numbers were to attend the classes and the even numbers to the wait-list control group. If a woman received an odd number, the next step was to find a class time that suited multiple schedules. Depending on the women's schedule she would be assigned to the most convenient class of her choice. If a woman received an even number, she became part of the control group. It was then explained that she would be receiving a total of three packets of questionnaires in the mail. The first would be mailed within several days after the telephone conversation. The first and

second packets consisted of an information sheet/ consent form, a demographic sheet and questionnaire, the SCL-90-R, and the pretest. The women were asked to complete the forms as soon as possible and to return them in the stamped addressed envelope that had been supplied. It was explained that a second packet, similar to the first, would be mailed within one month of the completion of the first packet. A third packet would be mailed to them in approximately six months following the return of the second packet. For those women in the wait-list group, the final packet included a place for them to mark if they would like to attend the classes or receive information by mail.

The classes were held at a large urban medical center in classrooms that were equipped with slide projector and VCR. The pilot study and the actual didactic courses were given by a master's-prepared Oncology Nurse. (This author interviewed several Oncology nurses and selection was based on level of experience, maturity and the nurse's ability to be flexible given the scheduling requirements of this study). Upon arrival at the medical center the volunteers were given the information/ consent form, demographic sheet, SCL-90-R, questionnaires and pretest, which took approximately twenty minutes to complete.

After the women completed the initial questionnaires, the nurse gave an introduction to the classes and the handout,

(see Appendix I), followed by an eight minute relaxation tape that was played in order to help the women "wind down" from the hassles of their day. This was followed by the start of the formal part of the class. The first class ran approximately 1 hour and 45 minutes. The information that was given in the course included:

- Benign versus malignant tumors,
- Incidence of breast cancer,
- Risk factors and family history,
- Explanation of homework assignment, (between the 1st and 2nd class the women completed a family Genogram focusing on Breast Cancer in their family). (See Appendix J).
- Methods for early detection of breast cancer including:
    - Yearly Physician Examination,
    - Mammography (examples of normal and abnormal mammograms are presented).
    - Monthly Breast Self-Examination

The course content for the second class included:

- Review and questions from last week,
- Relaxation tape was again played,
- Discussion of other risk factors: hormone factors, life-style factors and fibrocystic changes,
- Review of early detection methods,
- View ACS video on Breast Self-Examination,

- Discuss homework assignment (their genogram),
- Closing comments and completion of posttest.

The second class took approximately 1 hour and 40 minutes. (See Appendix H for course outline and specific information that was presented).

The schedule of the five classes held is as follows: First group: August 21 and 28, 1991, eight women were scheduled to attend, five women attended both classes. Two women completed only the first class, and one woman was a "no show", meaning she failed to call and cancel. The two women who did not attend were telephoned the next day and it was learned that one woman's babysitter was unable to come and the other woman was unable to return from vacation at the scheduled time.

The second group of classes were held on September 14th and 21st. Seven women were scheduled to attend, four attended both classes, two of the women (they were sisters) called the morning of the first class to cancel; and one woman was a "no show". This investigator was unable to reach the "no show" woman for follow-up.

The third group of classes was held on October 30 and November 6, 1991. Six women were scheduled to attend, four women attended the first class, one woman was a "no show" and one woman was unable to attend the second class. The woman unable to attend the second class was called for follow-up

purposes. She explained she had babysitting difficulties and possibly would be interested in attending the next group of classes. The investigator was unable to reach the "no show" for follow-up.

The fourth group of classes were held on December 7 and December 14, 1991. Twelve women were scheduled to attend, ten women attended both classes, with one calling to cancel and one "no show".

The fifth group of classes were held on March 24 and March 31, 1992. Ten women were scheduled to attend, seven women attended both classes, two women unable to attend the second class and one "no show".

In summary, forty-three women committed to attend the classes. Twenty-nine women attended both classes, five women attended one class, three women canceled and six women did not show for the classes. Twenty-five women have completed the final questionnarie, with four outstanding as of Nov. 9, 1992.

In the control group (those in the wait-list group), thirty-one women agreed to the study, with one woman dropping out after receiving the pretest packet. All women in the control group (N=30) have completed the six or twelve month questionnaires.

Analysis of Data

Demographic information and answers to some of the pre and posttest questions were analyzed by calculating

frequencies (means, standard deviations, ranges).

A repeated measures (or time series) analysis was performed to test the first three hypotheses:

(1) There will be no difference in knowledge scores about breast cancer between the experimental group and the control group over time (pretest, posttest and 6-12 month follow-up).

(2) There will be no difference in awareness of risk to self for breast cancer between the experimental group and the control group over time (pretest, posttest and 6-12 month follow-up).

(3) There will be no difference in anxiety, depression and somatization scores between the experimental group and the control group over time (pretest, posttest and 6-12 month follow-up).

A correlational analysis (chi square) was performed for hypothesis #4: there is no difference in health behaviors practiced between the experimental and the control group.

CHAPTER IV

RESULTS

This study addressed the daughters' cognitions and behaviors relating to a maternal history of breast cancer as an outgrowth of several null hypotheses:

(1) There is no difference in knowledge about breast cancer between the experimental group and the control group immediately after attending breast cancer classes and at a 6-12 month follow-up.

(2) There is no difference in awareness of risk to self for breast cancer between the experimental and the control group immediately after attending breast cancer classes and at a 6-12 month follow-up.

(3) There is no difference in anxiety, depression and somatization levels between the experimental and control group immediately after attending classes about breast cancer and at a 6-12 month follow-up.

(4) There is no difference in health behaviors practiced between the experimental and the control group immediately after attending information classes about breast cancer and at a 6-12 month follow-up.

Seventy-four women initially agreed to participate in this study. The experimental group included forty-three women who were randomly assigned to attend two 2 hour classes on specific evenings of their choice. Of the forty-three women, six women never arrived for the first class, three called to cancel, and five women were unable to attend the second class. Therefore, there are thirty-four evaluable cases for pretest information and twenty-nine evaluable cases for posttest information in the experimental group. (The posttest was one week after the pretest). Of the twenty-nine, three women did not return the 6-12 month questionnaire.

Thirty-one women were randomly assigned to the control group, one woman did not return the original pretest packet, therefore, there were thirty evaluable cases in the control group. All control group women returned the 6-12 month questionnaire.

Demographic Information

Table 5 describes demographic information for sixty-four women who participated in this study and compares the various population characteristics of the two groups. Demographic information is described for thirty-four women in the experimental group, which includes the five women who attended the first class, but who were unable to attend the second class.

Table 5.

Demographic Information for All Participants

	Experimental N = 34	Control N = 30
Age of Participants		
Mean	30.3 years	31.2 years
Range	22-40 years	22-40 years
Education (completed)		
High School	8 (23)	3 (10)
College	20 (59)	15 (52)
Post Graduate	6 (18)	11 (38)
	34 100	29 100
Daughter's Age at Time of Mother's Dx*		
Mean	24.4 years	27.0 years
Range	2-40 years	9-39 years
Standard Deviation	8.39 years	6.41 years
Mother's Age at Dx*		
Mean	53.0 years	52.8 years
Range	38-70 years	42-75 years
Standard Deviation	7.64 years	7.04 years
Number of Years Living w/ Breast Cancer History		
Mean	5.8 years	4.2 years
Range	6 months - 27 years	6 months- 28 years

Dx* denotes the word diagnosis

Table 5 compares the various population characteristics of the two groups. Overall the groups were very well balanced. The participants ranged in age from 22 years to 40 years with

a mean age of 30.7 years. There is a high educational level represented in both groups with a slightly higher post-graduate level in the control group.

The daughters' age at the time of their mothers' diagnosis of breast cancer ranged in age from 2 to 40 years with a mean age of 24.4 years for the experimental group and a mean of 27 years for the control group.

General demographic information about the mothers of the participating daughters includes the following: the age of the participants' mothers at the time of their diagnosis of breast cancer ranged from 38-75 years with a mean of 53 years for the experimental group and 52.8 for the control group.

The length of time that the mothers had been diagnosed with breast cancer ranged from 6 months to 28 years, with a mean of 5 years (standard deviation of 6.3 years). The groups were similar in this category.

The stages of the mothers' breast cancer at the time of the study ranged from Stage I to Stage IV. Information about each mother's stage of disease was unobtainable.

The following is a summary of the responses reported by the daughters in both the experimental and control group to the question "what was the type of primary treatment that your mother received for breast cancer?".

(1) The daughters reported that 80 percent of their mothers had received a mastectomy as the primary type of treatment for

their breast cancer.

(2) The daughters reported that 28 percent of their mothers had had breast reconstructive surgery.

(3) In addition, the daughters reported that 38 percent of their mothers had received radiation therapy.

(4) According to the daughters, 46 percent of their mothers had received chemotherapy and 32 percent had received hormone therapy. (The mothers' medical records were not available to check the accuracy of the daughters' reports).

In the early phases of this dissertation, the attempt was made to only include women whose mother's had a Stage I or II breast cancer. This inclusion criteria created difficulty for accruing subjects, therefore inclusion criteria was changed to include all stages of breast cancer. Women were not eligible if their mothers had died of breast cancer.

Between Time 2 and Time 3, two of the participant's mothers in the experimental group had died and one of the participant's mothers in the control group had died.

The occupations of the women in the experimental group included a wide variety of professions with the most frequently reported being that of homemaker (3), attorney (3) teacher (2), students, (2) and marketing consultant (2). Other occupations reported included: accountant, sales, computer engineer, secretary and health care professions such as nurse, molecular biologist and pharmacy technician.

In the control group the most frequent occupations reported included: homemaker (9), teacher (3), office manager (3), and graduate student (2). Other occupations reported included: marketing consultant, chef, public relations, credit analyst, social worker/therapist, art historian and dance instructor.

Analysis of First Null Hypothesis

In order to test the first null hypothesis (there is no difference in knowledge about breast cancer between the experimental and the control group) the Breast Cancer Knowledge Questionnaire was evaluated.

The questionnaire consisted of 25 true\false questions asking general information about breast cancer (see Appendix E). The questionnaire was evaluated for reliability using the Hoyt method, which yielded a reliability coefficient of 0.65. This method is based on using analysis of variance, treating persons and items as sources of variance. The sources of variance accounted for individuals taking the test over three separate time points. This is not the most favorable reliability score to obtain, however, it was not the intention of this study to develop an instrument for testing knowledge of breast cancer. However based on the results of this study, this would be a worthwhile area for further exploration.

The knowledge scores were based on the number of correct responses to the Breast Cancer Knowledge Questionnaire.

Sixty-four women answered the pretest questionnaire with a mean of 18.4 correct answers (standard deviation = 2.0) with a range of correct answers from 14-24.

Table 6 contains the mean scores and standard deviations of knowledge scores between the experimental and the control group over three time periods. In the experimental group the three time points included: (1) the pretest, which was given at the beginning of the first night of class, (2) the posttest, which was one week later at the end of the final class and (3) a follow-up time period ranging from five to twelve months after attending the classes.

For the control group the three time points included: (1) the pretest, which was mailed to the participants after they agreed to participate in the study, (2) the posttest, which was mailed immediately after receiving the pretest packet and (3) the final packet, which was mailed approximately 4-6 months after receiving the posttest responses.

The mean knowledge score for the experimental group was 18.20 (standard deviation of 2.01) and the mean knowledge score for the control group was 18.73 (standard deviation of 2.10). These scores represent very little difference between the two groups as measured at Time 1, which is the pretest measurement.

In the experimental group at Time 2, there was a mean knowledge score of 23.76 (standard deviation of 1.27). In the

control group at Time 2, the mean knowledge score was 19.70 (standard deviation of 1.96).

At Time 3 the mean score was 22.26 (standard deviation of 2.14) in knowledge scores in the experimental group and the mean score was 19.79 (standard deviation of 2.48) in knowledge scores in the control group.

Table 6.

Breast Cancer Knowledge Questionnaire Scores

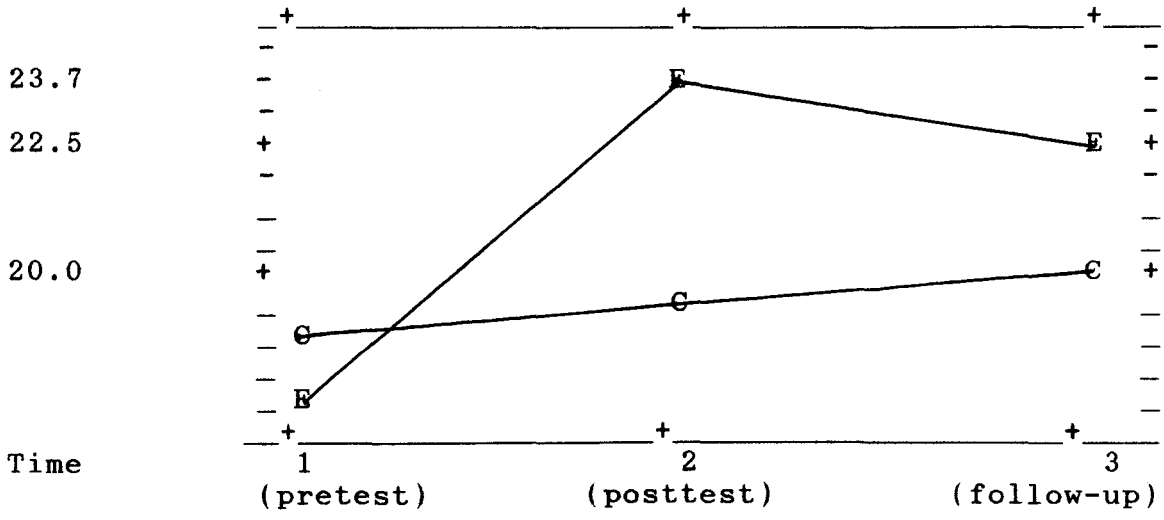
	Experimental	Control
Knowledge Score (Time 1)	N = 34	N = 30
Cell Means	18.20	18.73
Standard Deviation	2.01	2.10
Knowledge Score (Time 2)	N = 29	N = 30
Cell Means	23.76	19.70
Standard Deviation	1.27	1.96
Knowledge Score (Time 3)	N = 26	N = 29
Cell Means	22.27	19.79
Standard Deviation	2.14	2.48

Figure 1 contains a plot of the interaction of mean scores between the experimental and the control group, which indicates a disordinal interaction. This plot indicates confounding inferences to main effects and significant

differences between the experimental and control group means for both group and knowledge. Because of differences between the experimental and control group noted in Figure 1, a repeated measure analysis of variance and the Tukey's HSD post hoc test of significance was applied for each time period (See Table 7).

Figure 1.

Plot of the Knowledge Scores Between the Experimental and Control Groups



A repeated measure analysis of variance was used to analyze the knowledge scores for the experimental group and the control group at the three time points. As can be seen in Table 7 both groups of women appear to have approximately the same knowledge score at pretest measurement (Time 1) with the control group being slightly higher.

There is an extremely robust statistically significant difference ($p= 0.01$) between Time 1 and Time 2, suggesting that there was a positive impact from the intervention with significant information gained by the women who attended the classes.

At Time 3 there is again a statistically significant difference in knowledge scores ($p= 0.01$) between the two groups, suggesting that the experimental group retained some of the information gained from the classes.

In summary, at Time 1, the first null hypothesis, there will be no difference in knowledge about breast cancer between the experimental group and the control group fails to be rejected.

At Times 2 and 3, the first null hypothesis, there will be no difference in knowledge about breast cancer between the experimental and the control group is rejected, with the experimental group showing a statistically significant higher knowledge score.

Table 7.

Repeated Measure Analysis of Variance for Knowledge Scores with Post Hoc Test of Significance

Time 1		Experimental (N = 34)		Control (N = 30)
Mean + S.D.		18.20 (2.01)		18.73 (2.10)
Source	D.F.	Mean Square	F Value	Probability
Group	1	4.43	1.05	0.30

Time 2		Experimental (N = 29)		Control (N = 30)
Mean + S.D.		23.76 (1.27)		19.70 (1.96)
Source	D.F.	Mean Square	F Value	Probability
Group	1	242.89	87.84	0.000
Tukey HSD			(p = 0.01)	

Time 3		Experimental (N = 26)		Control (N = 29)
Mean + S.D.		22.27 (2.14)		19.79 (2.48)
Source	D.F.	Mean Square	F Value	Probability
Group	1	84.05	15.47	0.0002
Tukey HSD			(p = 0.01)	

Analysis of Second Null Hypothesis

In order to evaluate the second null hypothesis (there is no difference in awareness of risk to self for breast cancer between the experimental and control group) the pretest question "what percentage best describes YOUR chance of developing breast cancer some day?" was examined with repeated measure analysis of varience as well as a Tukey HSD post hoc test for significance. (See Table 8).

As was discussed in Chapter One, women with a maternal history of breast cancer have approximately a 20 percent chance of developing breast cancer.

As can be seen in Table 8, at Time 1 both groups significantly overestimated their chances of developing breast cancer someday. At Time 1, the experimental group reported a 47 percent risk (mean score) with a range of 10 to 100 percent risk to self for developing breast cancer someday. At Time 1, the control group reported a 57 percent risk (mean score) with a range of 20 to 100 percent risk to self for developing breast cancer someday.

Table 8.

Repeated Measure Analysis of Variance for Percent of Risk with Tukey HSD Test of Significance

Time 1		Experimental (N = 32)		Control (N = 30)
Mean + S.D.		0.47 (0.24)		0.58 (0.25)
Range		0.10 - 100%		0.20 - 100%
Source	**D.F.**	**Mean Square**	**F Value**	**Probability**
Group	1	0.18	3.06	0.085

Time 2		Experimental (N = 29)		Control (N = 30)
Mean + S.D.		0.21 (0.07)		0.41 (0.23)
Range		0.10 - 0.50		0.10 - 0.90
Source	**D.F.**	**Mean Square**	**F Value**	**Probability**
Group	1	0.60	19.98	0.000
Tukey HSD			(p = 0.01)	

Time 3		Experimental (N = 23)		Control (N = 29)
Mean + S.D.		0.23 (0.13)		0.48 (0.20)
Range		0.10 - 0.55		0.15 - 100%
Source	**D.F.**	**Mean Square**	**F Value**	**Probability**
Group	1	0.83	27.72	0.000
Tukey HSD			(p = 0.01)	

There is a statistically significant difference in the perceived percent of risk (mean scores) between the two groups at Time 2 ($p < 0.01$). The experimental group reported a perceived 21 percent risk (an accurate percent of risk) and the control group reported a perceived 41 percent risk to self. This suggests that there was a positive effect from the breast cancer classes on the experimental group.

At Time 3 there is also a statistically significant difference ($p = 0.01$) in percentage of risk reported between the experimental group and the control group between Time 2 and Time 3. The experimental group reported a 23 percent risk (slightly higher than Time 2) and the control group reported a 48 percent risk (again a continued overestimate of risk).

In summary, at Time 1, the second null hypothesis, there is no difference in awareness of risk to self for breast cancer between the experimental and the control group is not rejected. However, for Times 2 and 3, there is a difference between the experimental and control groups, therefore the hypothesis is rejected.

Awareness of Perceived Risk to Average Woman

To understand the participant's perception of the average woman's risk of developing breast cancer, the women were asked to respond to the following question: "What percent best describes the AVERAGE woman's chances of developing breast cancer someday"? The responses to this question were examined

by performing a repeated measure analysis of variance as well as a Tukey HSD test of significance. (See Table 9).

As was discussed in Chapter One, the average woman's lifetime risk for developing breast cancer is approximately 10 percent. As seen in Table 9, there was a statistically significant difference in the perceived risk for breast cancer in the average woman between the two groups at all three time points. At Time 1, the experimental group reported 20 percent (mean score) as the average woman's risk for developing breast cancer, with the range being from 5 to 90 percent.

The control group at Time 1 perceived the average woman's risk to be 32 percent (mean score), with a range from 10 to 90 percent. Both groups overestimated the risk, however, the control group perceived a greater risk than the experimental group. The difference between the groups is statistically significant at the $p< 0.01$ level.

At Time 2, the experimental group reported the average woman's risk to be 10 percent (mean score), an accurate answer, suggesting a positive effect from the breast cancer classes. The control group reported a mean score of a 21 percent risk for the average woman developing breast cancer, a decrease from Time 1, although still an overestimate. There is a highly statistically significant difference ($p=0.01$) in perceived risk for the average woman developing breast cancer between the two groups.

Table 9.

Repeated Measure Analysis of Variance for Average Woman's Percent of Risk with Tukey HSD Test of Significance

Time 1		Experimental (N = 33)		Control (N = 30)
Mean + S.D.		0.20 (0.16)		0.32 (0.20)
Source	D.F.	Mean Square	F Value	Probability
Group	1	0.24	7.39	0.0085
Tukey HSD			(p = 0.01)	

Time 2		Experimental (N = 28)		Control (N = 30)
Mean + S.D.		0.10 (0.02)		0.21 (0.14)
Source	D.F.	Mean Square	F Value	Probability
Group	1	0.16	14.31	0.004
Tukey HSD			(p = 0.01)	

Time 3		Experimental (N = 25)		Control (N = 29)
Mean + S.D.		0.11 (0.03)		0.29 (0.17)
Source	D.F.	Mean Square	F Value	Probability
Group	1	0.45	27.87	0.0000
Tukey HSD			(p = 0.01)	

At Time 3, the mean score for the experimental group was 11 percent, an accurate response for the average woman's risk

of developing breast cancer. Whereas the mean score for the control group was 29 percent, a continued overestimate of the average woman's risk. The difference between the two groups remains statistically significant at the $p<0.01$ level.

Analysis of Third Null Hypothesis

Anxiety Results

In order to evaluate the third null hypothesis (there is no difference in anxiety levels between the experimental group and the control group after attending breast cancer classes the Symptom Check-List Revised (SCL-90-R) was evaluated.

Raw scores were entered into the computerized program which generated T scores for each of the nine subscales and three global indices of distress. The analysis was primarily looking at three psychological variables: anxiety, depression and somatization, therefore the T scores for these three variables were evaluated by performing frequency statistics as well as a repeated measure analysis of variance over three time periods to examine for possible differences between the experimental and control groups.

Table 10 contains the cell means and standard deviations for anxiety scores in the experimental and control group over 3 time periods. At Time 1, the anxiety mean score for the experimental group was 50.64 (9.90) and the anxiety mean score for the control group was 51.82 (10.85).

Table 10.

Means and Standard Deviations for SCL-90-R Anxiety Scores Between Experimental and Control Groups Over Time

Time 1	Experimental (N = 25)	Control (N = 28)
Mean	50.64	51.82
Standard Deviation	9.90	10.85
Range of Scores	37 - 72	37 - 77

Time 2	Experimental (N = 25)	Control (N = 28)
Mean	48.80	52.57
Standard Deviation	9.33	9.52
Range of Scores	37 - 70	37 - 71

Time 3	Experimental (N = 25)	Control (N = 28)
Mean	48.72	51.71
Standard Deviation	9.99	10.44
Range of Scores	37 - 68	37 - 72

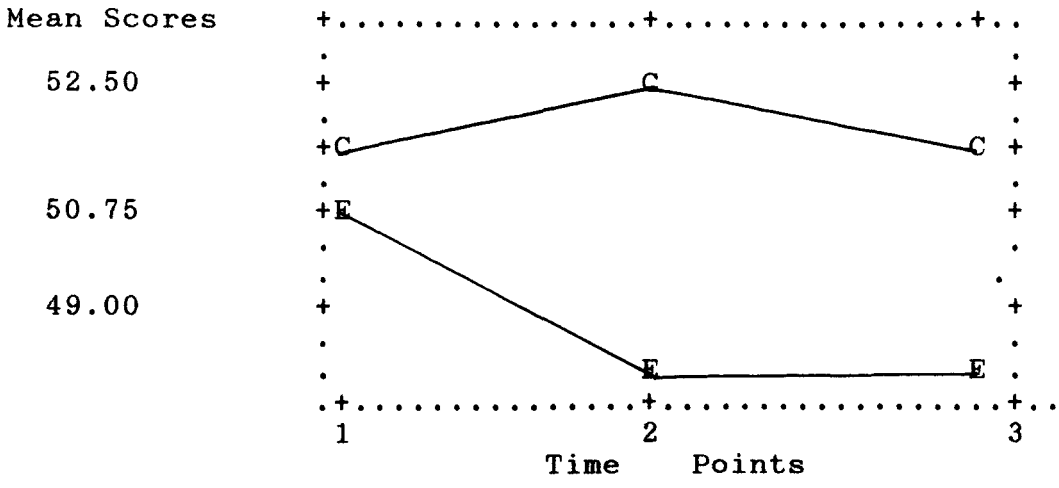
At Time 2, the anxiety mean score for the experimental group was 48.8. (9.33) and the mean score for the control group was 52.57 (9.52).

At Time 3, the anxiety mean score for the experimental group was 48.72 (9.99) and the mean score for the control group was 51.71 (10.44).

Figures 2, 3 and 4 demonstate the decrease in anxiety, depression and somatization scores from Time 1 through Time 3. Although not statistically significant, it may be assumed that the breast cancer classes contributed to this decrease. Of interest is the decrease in anxiety scores in the experimental group was maintained from Time 2 to Time 3.

Figure 2.

Plot of SCL-90-R Anxiety Scores Between Experimental and Control Group Over Three Time Points



Although there appears to be a decrease in the anxiety scores for the experimental group from Time 1 to Time 2 which holds for Time 3, and the control group scores remain about the same over the 3 time points, however, there was no

statistically significant differences between the two groups. Therefore the null hypothesis can not be rejected (there are no differences in anxiety levels between the two groups before or after attendance at breast cancer classes). (See Table 11).

Table 11.

Results of Repeated Measure Analysis of Variance for Anxiety Scores Between Experimental and Control Group Over TIme

Source	D.F.	Mean Square	F	Probability
Mean	1	407578.27	1775.81	0.000
Group	1	278.05	1.21	0.276
ANX 1	2	13.60	0.37	0.690
AG (Interaction)	2	23.33	0.64	0.528

Depression Results

In addition to assessing anxiety scores, depression scores were also evaluated by the SCL-90-R computerized scoring system. A repeated measure analysis of variance was used to evaluate differences in depression scores between the experimental and control groups over three different time points. The results are contained in Table 12.

Table 12.

Means and Standard Deviations for SCL-90-R Depression Scores Between the Experimental and Control Group Over Time

Time 1	Experimental (N = 25)	Control (N = 28)
Mean	54.00	53.53
Standard Deviation	9.33	7.81
Range of Scores	34 - 75	34 - 69

Time 2	Experimental (N = 25)	Control (N = 28)
Mean	49.92	53.78
Standard Deviation	10.46	7.65
Range of Scores	34 - 81	34 - 69

Time 3	Experimental (N = 25)	Control (N = 28)
Mean	51.76	52.85
Standard Deviation	10.98	7.69
Range of Scores	34 - 73	34 - 70

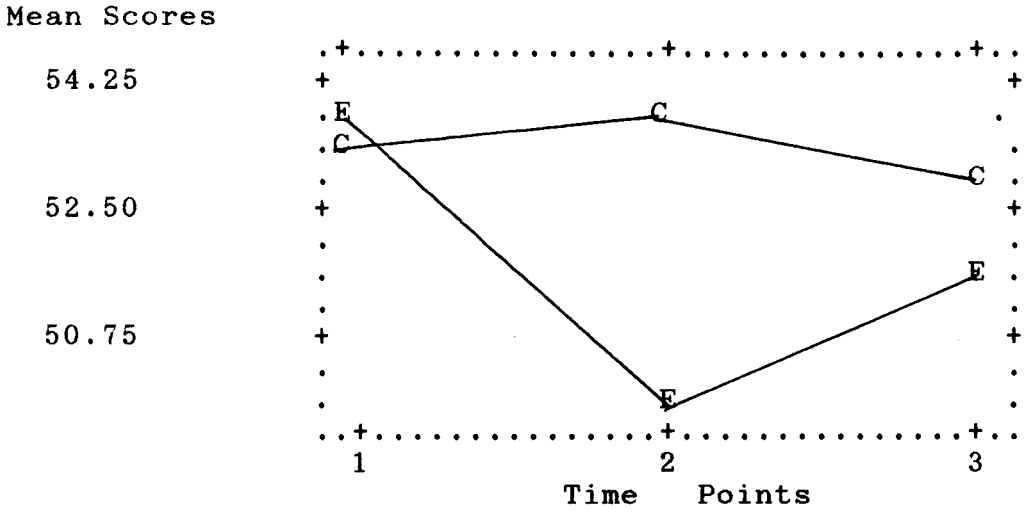
As seen in Table 12, at Time 1, the experimental group had a mean depression score of 54.00 (9.33) with scores ranging from 34 to 75. The mean score for depression in the control group 53.53 (7.81) with scores ranging from 34 to 69.

At Time 2, the mean scores for depression for the experimental group were 49.92 (10.46). The mean scores for depression for the control group were 53.78 (7.65).

At Time 3, the mean scores for depression for the experimental group were 51.76 (10.98). The control group mean scores for depression were 52.85 (7.69).

Figure 3.

Plot of SCL-90-R Depression Scores Between Experimental and Control Group Over Three Time Points



As can be seen in Figure 3, both groups have somewhat higher depression scores than anxiety scores at Time 1. There is a decrease in scores between Time 1 and Time 2, however, the decrease does not appear to have lasting effects. At Time 3 both groups are still lower than at Time 1, but are beginning to merge.

Table 13 contains the results of the repeated measure analysis of variance for depression scores between the two groups over three time points. Although there is a decrease in the depression scores for the experimental group between Time 1 and Time 2, there is no statistical difference seen.

Table 13.

Repeated Measure Analysis of Variance for Depression Scores for Experimental and Control Groups Over Time

Source	D.F.	Mean Square	F	Probability
Mean	1	439224.19	2263.62	0.0000
Group	1	89.09	0.46	0.50
Depression	2	52.87	2.12	0.12
DG (Interaction)	2	63.51	2.54	0.08

As shown in Table 13, there are no statistically significant differences in depression scores as measured on the SCL 90-R between the experimental and the control group over three time points. Therefore the third null hypothesis (there is no difference in depression scores between the two groups) cannot be rejected.

Table 14.

Means and Standard Deviations for SCL 90-R Somatization Scores Between the Experimental and Control Group Over Time

Time 1	Experimental (N = 25)	Control (N = 28)
Mean	50.64	51.75
Standard Deviation	8.05	8.98
Range of Scores	35 - 66	35 - 68

Time 2	Experimental (N = 25)	Control (N = 28)
Mean	47.44	51.35
Standard Deviation	8.74	9.03
Range of Scores	35 - 66	35 - 65

Time 3	Experimental (N = 25)	Control (N = 28)
Mean	49.72	52.10
Standard Deviation	10.19	8.00
Range of Scores	35 - 72	35 - 62

Somatization Results

Somatization is the third psychological variable to be evaluated. The T scores from the SCL-90-R computerized scoring system were analyzed by computing frequencies which resulted in the following findings that are contained in the above table. At Time 1, the mean score for somatization for the experimental group was 50.64 (8.05) and the mean score for somatization for the control group was 51.75 (8.98).

At Time 2, the mean score for somatization for the experimental group was 47.44 (8.74) and the mean score for somatization for the control group was 51.35 (9.03).

At Time 3, the mean score for somatization for the experimental group was 49.72 (10.19) and the mean score for somatization was 52.10 (8.00). Figure 4. contains the results.

Figure 4.

Plot of SCL-90-R Somatization Scores Between Experimental and Control Group Over Three Time Points

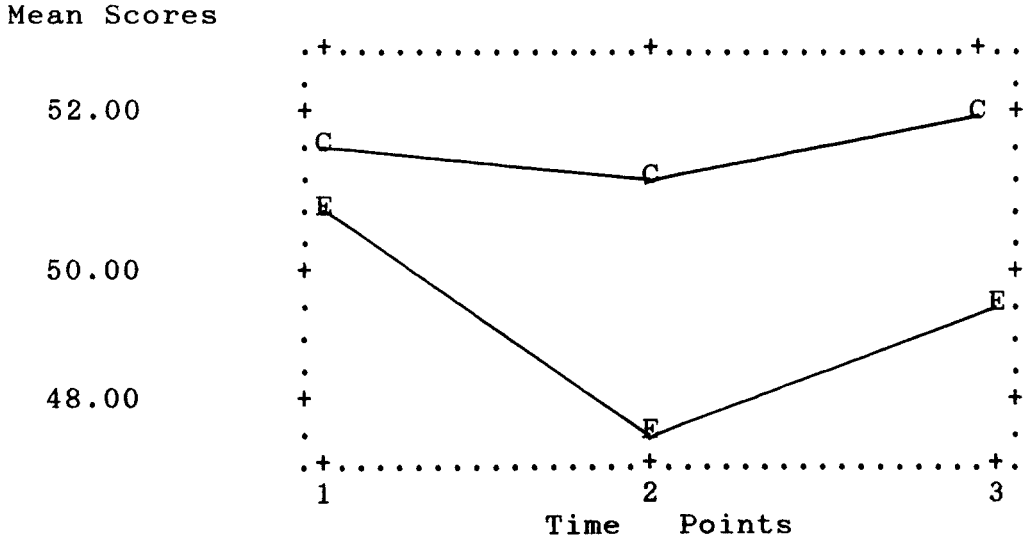


Table 15 contains the results for the repeated measure analysis of variance for somatization scores between the two groups over three time periods. Although there was a decrease

in somatization scores in the experimental group from Time 1 to Time 2, there was no statistical difference seen between the two groups. Therefore, the third null hypothesis (there is no difference in somatization scores between the two groups was accepted.

Table 15.

Repeated Measure Analysis of Variance for Somatization Scores for Experimental and Control Groups Over Time

Source	D.F.	Mean Square	F Value	Probability
Mean	1	404228.68	2378.48	0.000
Group	1	242.01	1.42	0.23
Somatization	2	49.32	1.51	0.22
(Interaction) SG	2	26.08	0.81	0.45

Analysis of Fourth Null Hypothesis

There will be no difference in health behaviors practiced between the experimental and control group. This hypothesis was evaluated by analyzing three separate health behaviors: Pap test screening, obtaining Mammograms and evaluating the frequency of breast self-examination.

Pap Test Screening

At Time 1 the pretest question, "Have you ever had a Pap test?" was asked, and "If yes, when was your last one?" This question was evaluated by looking at frequencies. All 64 women

answered "Yes" to this question with a mean time of 9 months (s.d. of 8.5 months) since their last Pap test.

At Time 3, in the final questionnaire the women were asked, "Since the time you agreed to participate in this study, have you been to a physician for a Pap test?" This question was evaluated by looking at frequencies. In the experimental group, 8 women reported NO (30 percent) and 18 replied YES, therefore, 70 percent of this group (N=26) had received another Pap test.

In the control group, 6 women responded NO (20 percent) and 24 women responded YES, therefore 80 percent of this group (N=30) had received another Pap test.

A Pearson chi-square correlation was performed to test for differences between the experimental and control group in obtaining a Pap test. The results yeilded a chisquare value of 0.862 ($p = 0.35$) showing no statistically significant differences between the two groups.

Mammography Utilization

To evaluate Mammography as a practiced health behavior, at Time 1 the women were asked, "Have you ever had a Mammogram?". A total of 34 women in the experimental group responded; 20 (59 percent) reported YES, while 14 (41 percent) replied NO. A total of 28 women in the control group responded at Time 1; 14 reported YES (50 percent) and 14 reported NO (50 percent).

According to American Cancer Society guidelines, the cost/benefit ratio for obtaining mammograms for women under age 30, (even for those at higher risk) is not effective. Therefore this question was further explored by performing a Pearson chi-square correlation based on participants 30 years of age and older. Table 16 contains the results for women 30 years of age or older in the experimental group at Time 1.

Table 16.

Differences in Use of Mammography Between the Experimental and Control Group at Time 1 for Women 30 Years of Age and Older

Mammograms	Experimental	Control
YES	13 (77 percent)	12 (75 percent)
NO	4 (23 percent)	4 (25 percent)
Total	17 (100 percent)	16 (100 percent)

Pearson Chi-square = 0.010 (p = 0.92)

Of the women in the experimental group who were 30 years of age or older, 13 of 17 (77 percent) had obtained a mammogram, while 4 out of 17 (23 percent) had not ever had a mammogram. In the control group 12 out of 16 (75 percent) had obtained a mammogram, while 4 out of 16 (25 percent) had not ever had a mammogram. These results yielded a chi-square of

0.010 resulting in a p value < 0.92. Therefore, at Time 1, no statistically significant differences were found in obtained mammograms between the experimental and control group.

The responses at Time 1 to the second part of the question, "If yes, when was your last mammogram?" are as follows. Of the 34 women responding YES, the mean number of months was 13.52 (s.d.= 14.65) with a range of one week to 64 months ago.

At Time 1, the "yes" responses to this question were divided into five categories based on frequency of mammograms, with the number of women responding reported in parentheses. The responses included: baseline mammograms (15), yearly mammograms (7), every 2 years (3), as needed (4) and every 6 months (1) for a total of 30 responses.

In the final questionnaire (Time 3) the participants were asked, "Since the time you agreed to participate in this study, have you had a Mammogram? This question was evaluated by performing a Pearson chi-square correlation between the experimental and control group and obtained Mammograms at Time 3 for women 30 years of age and older. (See Table 17).

Table 17.

Differences in Use of Mammography Between the Experimental and Control Group at Time 3 for Women 30 Years of Age and Older

Mammograms	Experimental	Control
YES	7 (58 percent)	8 (50 percent)
NO	5 (42 percent)	8 (50 percent)
	12 (100 percent)	16 (100 percent)

Pearson Chi-square = 0.19 (p = 0.66)

In the experimental group, a total of 26 women responded to the question of obtaining a mammogram since participating in this study. Twelve of the 26 women were 30 years of age or older, seven had obtained a mammogram and five women had not.

Of the 30 women in the control group, 16 were 30 years of age or older, eight had obtained a mammogram and eight had not.

A Pearson chi-square correlation was performed to look for differences between the experimental and control groups from Time 1 to Time 3. (See Table 18).

Table 18.

Differences in Mammograms Obtained in the Experimental Group Between Time 1 and Time 3

		Experimental Group		
T		Time 1		
I		NO	YES	Total
M	NO	8	11	19
E	YES	2	5	7
3	Total	10	16	26

Pearson chi-square = 0.40 (p = 0.53)

In the experimental group, eight women reported that they had never had a mammogram at either Time 1 or Time 3. Two women who had not had a mammogram at Time 1, did obtain a mammogram between Time 1 and Time 3. Eleven women reported YES to having had a mammogram at Time 1. Five women reported having had a mammogram at Time 1 and also obtained a mammogram between Time 1 and Time 3.

Table 19.

Differences in Mammograms Obtained in the Control Group Between Time 1 and Time 3

		Control Group		
		Time 1		
		NO	YES	Total
TIME 3	NO	10	6	16
	YES	3	8	11
	Total	13	14	27

Pearson chi-square = 3.24 (p = 0.07)

In the control group, 10 women had not obtained a mammogram at Time 1 nor at Time 3. Three women had not obtained a mammogram at Time 1, however they had obtained a mammogram by Time 3. Six women had obtained a mammogram at Time 1, but did not obtain a mammogram between Time 1 and Time 3. Eight women had obtained a mammogram at Time 1 and also obtained a mammogram between Time 1 and Time 3.

Breast Self-Examination

To evaluate breast self-examination as the third health behavior practiced, frequencies were calculated for responses to the question, "Have you ever done breast self-examination"? At Time 1, a total of 31 out of 34 women (91 percent) in the experimental group replied YES, and 3 women (9 percent) replied NO.

At Time 1, 27 out of 30 women in the control group replied YES (90 percent) and 3 (10 percent) replied NO. A Pearson chi-square value of 0.026 ($p = 0.87$) was found, therefore there is no statistically significant difference in performing breast self-examination between the experimental and control group at Time 1.

At Time 1 the women were asked, "when was the last time you examined your breast"? In order to evaluate this question the responses were calculated in months or portions of a month and frequencies were performed. In the experimental group, 31 women responded resulting in a mean score of 2.5 months, (s.d. = 6.32) ranging in time from one week to 36 months.

In the control group, 24 women responded to the question resulting in a mean score of 3.5 months (s.d.= 6.02) ranging in time from 1 month to 24 months.

Table 20 contains the results of the frequency of BSE between the experimental and control group at Time 3.

Table 20.

Frequency of Breast Self-Examination Between the Experimental and Control Group at Time 3

Frequency	Experimental		Control	
	N	%	N	%
More than once/month	3	11	4	13
Monthly	13	50	13	43
Every other month	6	23	3	10
Four times a year	1	04	2	07
Twice a year	0	0	2	07
Once a year	1	04	1	03
Not at all	2	08	5	17
Total	26	100	30	100

Pearson chi-square value = 4.50 (p = 0.60)

As seen in the above table, 13 women (50 percent) in the experimental group and 13 women (43 percent) in the control group practice BSE on a monthly basis, which is the recommendation from the American Cancer Society. Six women (23 percent) in the experimental group and three women (10 percent) in the control group practice BSE every other month, also likely to be an effective frequency. Three women (11 percent) in the experimental group and 4 women (13 percent) in the control group practice BSE more than once a month, which is more than is necessary. These numbers account for 84 percent of the women in the experimental group and 66 percent of the women in the control group are performing BSE within

the ACS guidelines for frequency. Therefore the majority of these "high risk women" are already practicing BSE at the correct frequency. Only four women (16 percent) in the experimental group and 10 women (34 percent) in the control group are not performing BSE frequently enough and could therefore improve in the practice of this health behavior.

To evaluate for possible changes in the practice of BSE between Time 1 and Time 3, responses were recategorized and then reexamined. Forty-seven women in both the experimental and control groups reported their frequency of BSE at both Time 1 and Time 3.

Overall, 27 women reported no change in the frequency of BSE practice. Of these 27 women, 21 continued to practice BSE monthly. Thirteen women increased their frequency of BSE practice, while five women decreased their frequency of BSE.

In the experimental group thirteen women did not change their frequency of BSE, 11 continued a monthly practice, one continued to practice more than once a month and one continued an every other month schedule. Six women increased their BSE and four women decreased their frequency of BSE.

In the control group, 24 women were reevaluated for changes in frequency of BSE from Time 1 to Time 3. Fourteen women did not change the frequency of their BSE, seven women increased their freqency and three women decreased their frequency of BSE.

Overall, because the majority of women were correctly practicing an appropriate frequency of BSE, there were too few numbers to demonstrate any statistically significant differences between the two groups.

Summary of the Results

The experimental group included 43 women who were randomized to attend two 2 hour classes. There are 34 evaluable cases for pretest information. Due to scheduling problems there are 29 evaluable cases for posttest evaluation. There are a total of 30 evaluable cases in the control group. The two groups appear to be fairly homogeneous in demographic background.

The following is a summary of the results by hypotheses. (1) Based on repeated measure analysis of varience using a Tukey HSD test of significance, at Time 1, the first null hypothesis (there will be no difference in knowledge about breast cancer between the experimental and control group) is not rejected. At Times 2 and 3, the first null hypothesis is rejected due to a statistically significant difference ($p<0.01$) between the groups in knowledge about breast cancer.

(2) Based on repeated measure analysis of varience as well as the Tukey HSD post hoc test of significance, the second null hypothesis (there will be no difference in awareness of risk to self for breast cancer between the experimental and control group) is not rejected at Time 1. However, there is a

statistically significant difference in awareness of risk to self between the 2 groups between Time 1 and Time 2, which holds up at Time 3 at the $p < 0.01$ level. Therefore, the second null hypothesis is rejected for Times 2 and 3.

Three psychological variables: anxiety, depression and somatization as measured on the SCL-90-R were evaluated using a repeated measure analysis of varience in order to test the third null hypothesis (there will be no differences in anxiety, depression and somatization scores between the experimental and control groups immediately after the classes and at follow-up).

(3) Although not statistically significant, there is a decrease in anxiety scores for women in the experimental group between Time 1 to Time 2, which is maintained at follow-up (Time 3). The scores for the women in the control group remain about the same over the three time points. In summary, there are no statistically significant differences between the two groups in the three psychological variables, therefore the third null hypothesis can not be rejected.

(4) Although not statistically significant, there is a decrease in depression scores for the experimental group between Time 1 to Time 2, while the control group scores remain about the same over the three time points. Therefore, the third null hypothesis can not be rejected.

(5) Although not statistically significant, there is a decrease in somatization scores in the experimental group between Time 1 to Time 2, while the control group remains approximately the same. Therefore the third null hypothesis can not be rejected.

The fourth hypothesis (there will be no difference in health behaviors practiced between the experimental and control groups immediately after the classes and at follow-up), was evaluated by analyzing frequencies of three separate health behaviors: Pap test screenings, obtained mammograms and frequency of breast self-examination.

(6) At Time 1 all of the women in both the experimental and control group (N=64) had received a Pap test. Between Time 1 and Time 3, 70 percent of the experimental group and 80 percent of the control group had received another Pap test. A Pearson chi-square correlation was performed to test for differences between the two groups. No statistically significant differences were found between the two groups, therefore the null hypothesis (there will be no difference in Pap test screening between the experimental and control group) can not be rejected.

(7) Obtained mammograms is the second health behavior to be evaluated. Evaluation of differences in mammograms obtained between Time 1 and Time 3 resulted in no statistically significant differences between the two groups.

Therefore the fourth null hypothesis (there is no difference in health behaviors practiced (obtained mammograms) between the experimental and control groups) can not be rejected.

(8) Evaluation of breast self-examination practices showed that 84 percent of women in the experimental group and 66 percent of women in the control group are performing BSE on a monthly or every other month basis, which is in accordance with American Cancer Society guidelines. Overall, because the majority of women were practicing BSE on an appropriate schedule, the numbers for those not practicing BSE correctly were too small to calculate for any statistically significant differences between Time 1 and Time 3 between the two groups. Therefore the fourth null hypothesis, there is no difference in health behaviors practiced (changes in frequency of BSE practice) between the experimental and control group can not be rejected.

CHAPTER V

SUMMARY, DISCUSSION AND CONCLUSIONS

Summary

Using the Health Belief Model (Rosenstock, 1990) as a theory base and recognizing the potential severity and chronicity of breast cancer, it was appropriate to address several issues that effect the daughters of women with breast cancer. Specifically, the purpose of this randomized, controlled, intervention study was:

(1) to better understand their knowledge about breast cancer,

(2) to identify an awareness of their perceived risk for the disease,

(3) to identify psychological factors that may or may not be affecting these women (i.e. anxiety, depression and somatization),

(4) to identify early detection health behaviors practiced by this group before and after attending classes about breast cancer,

(5) and to investigate the impact of a didactic group experience about breast cancer on women who potentially have a high risk of developing the disease.

Breast cancer is increasing in incidence with 182,000 new cases occuring in 1993 (ACS, Facts and Figures, 1993). The most important factors influencing a woman's likelihood of developing breast cancer include: advancing age, history of a previous breast cancer and a history of breast cancer in a mother or sister diagnosed prior to menopause (Stoll, 1991).

The five year survival rate for localized breast cancer (Stage I) has risen from 78 percent in the 1940's to 92 percent today. The survival rate is directly related to the size of the breast lesion, therefore early detection of breast cancer remains a crucial key to increased cure rates and survival.

There are three established methods of early detection for breast cancer: physical examination, mammography and breast self-examination. However there is a very low frequency of compliance with these three methods.

Sixty-four women with a maternal history of breast cancer were randomly assigned to attend two breast cancer classes or be placed on a wait-list control group. The women were asked to complete demographic information, the Symptom Check-List-90-Revised (SCL-9-R), a pretest, posttest and follow-up questionnaire.

Limitations of the Study

The most significant limitations of this study include the small sample size, largely middle class, Caucasian

population, as well as a self-selected group of women who voluntarily responded to letters or newspaper solicitations, so the results should not be generalized to all women with a maternal history of breast cancer.

Although the women were demographically similar, the findings revealed a tremendous range in the psychological picture and in the health behaviors practiced by these women. For example, (1) the reported anxiety scores ranged from a score of 32 to 77 (the mean score is 50). (2) Reported depression scores ranged from 34 to 81. (3) Reported breast self-examination frequency ranged from not practicing BSE at all to performing BSE more than once a month. Therefore, no matter how robust the intervention might be, with this diverse range, it is not surprising that few statistically significant differences were found between the two groups.

Another factor to consider is that eventhough the experimental group demonstrated an increase in knowledge due to the breast cancer classes, two - two hour classes may not be powerful enough to alter anxiety levels when countered with the experience of your mother receiving treatments for breast cancer.

Another limitation of this study was the use of self-report measures to assess psychological factors among the population sampled. When self-report measures are used a

"halo" effect (presenting oneself in the best light) must be considered. Considering this effect, subjects might be exaggerating their reported health behaviors as well as under-reporting their feelings and fears.

Another limitation to be considered is the difficulty maintaining a "pure control group" given the design of this study. The results of the study may have been "contaminated" due to the confounding effect of the control group receiving questionnaires that possibly may have promoted health-protective behaviors.

One disappointment with this study centered around the Hoyt reliability coefficient result of 0.65 for the Breast Cancer Questionnaire. These results warrent reevaluation and further exploration of this questionnaire in order to improve the internal consistency. For example, developing specific domains within the test with item subscales, may potentially increase the internal consistency of this questionnaire. The development of this questionnaire was centered around the specific material that was presented during the classes. It was never the intention of this study to develop a standardized instrument to measure knowledge of breast cancer.

In order to strengthen the results of this study, it might have been better to use a second instrument to measure the psychological variables. Several instruments to consider

would be the Profile of Mood States or the State/Trait Anxiety Scale.

DISCUSSION

According to D'Onofrio (1980), a proponent for emancipation in patient education, "education must foster open sharing of information, questions, doubts and concerns, so that providers and consumers of health care can learn from each other" (pg. 278). Given the present "state of the art" with breast cancer information, this philosophy of honesty and sharing is critical. The attempt was made to create this type of atmosphere for the exchange of information during the breast cancer classes that the experimental group attended. The goal was to encourage the daughters to learn the facts and dispel the myths about breast cancer, and motivate them to develop a lifestyle of healthy behaviors.

Knowledge About Breast Cancer

The findings from this study demonstrating that both groups were homogeneous in their pretest knowledge (Time 1), adds to the robustness of the statistically significant differences between the groups shown at posttest (Time 2), which continued 6-12 months later (Time 3). It can be assumed that the breast cancer classes contributed to the increase in knowledge scores in the experimental group. These results are encouraging. The women in the experimental group reported both

verbally and in their evaluations their sense of appreciation for the increased knowledge gained by attending the classes.

One obvious explanation for the fairly good pretest (Time 1) knowledge base is the tremendous explosion of information constantly being presented to the public about breast cancer. Most of this influx of information originates with the consumer/women's movement of the late 1970's and early '80's. Women became much more involved in the many different issues that surround the diagnosis of breast cancer. This involvement can be seen in the change from "being told what to do without having a say", to becoming a partner with the health care team in choosing their treatment options. Women diagnosed with breast cancer have become much more open about the disease. Many women diagnosed with breast cancer present to the health care team with a more sophisticated knowledge base from which to ask more stimulating questions about the causes and treatments for the disease. This surge of energy has also been felt as a major political force that demands answers and action to the many unanswered questions surrounding breast cancer. The most recent transfer of $210 million new dollars for breast cancer research from the Department of Defense budget is an example of this political force (Y-Me Newsletter, 1992).

The need for educational programs for oncology patients

has been recognized and addressed for quite some time now (Schwartz, 1977). Several studies have demonstrated that cancer patient education can improve knowledge, attitudes, health status and possibly health behaviors (Dodd, 1982; Dodd, 1983; Cassileth, Heiberger, March and Stutton-Smith, 1982; Cassileth, Zupkis, Stutton-Smith, 1980; Johnson, 1982; Jacobs, Ross, Walker, and Stockdale, 1983).

In a comprehensive article discussing cancer patient education, Rimer, Keintz and Glassman (1985) recommended several future directions that included:

> (1) increasing the amount of efforts for patient education, (2) having more broadly trained health educators, (3) refining cancer education for more specific points along the cancer care continuum, such as diagnosis, treatment issues, pain control, long-term survivor issues and (4) screen and track patients into different educational options according to their needs. (p. 815).

This present study attempted to incorporate several of those suggestions by extending the invitiation for educational opportunities to include specific family members, as well as refining the educational program to a specific end of the continuum, i.e. the early-detection end.

Awareness of Perceived Risk

As was previously discussed, women with a maternal

history of breast cancer have approximately a 20 percent chance of developing the disease. Pretest results of this study showed that both groups significantly overestimated their chances of developing breast cancer. There are conflicting reports in the literature surrounding perceived awareness of risk by this group of women for developing breast cancer. Most studies would agree that women with a family history have vague and erroneous perceptions of risk to self by either overestimating or underestimating their likelihood of developing breast cancer.

Kelly (1980) reported on a small, self-selected group of women whose mothers had breast cancer, and found that "despite their own anxiety and prevailing belief that their own risk was increased, most daughters had only vague and erroneous information about their own risk" (p. 123). Twenty women (51 percent) of her sample reported their risk was much "higher than average", and four of the 20 women felt certain to get breast cancer, while only two women felt their risk was lower than the average woman's risk.

In another study by Kash, Holland, Halper and Miller (1992), 76 percent of women whose mothers had breast cancer reported a moderate to extreme risk for developing breast cancer, while 24 percent of the women thought their chances were low to none at all, "despite coming to a program for women at high risk for breast cancer".

Wellisch and colleagues (1991) reported that women with a breast cancer history (80 percent) compared to a group of women with no history (22 percent), perceived their chances of developing breast cancer to be significantly higher than the control group ($p < 0.0001$).

One of the strengths of the present study is that the women had to report a specific percentage of risk to self, whereas in the above studies, the women only had to define their risk by categories such as, high, moderate, low or likely or unlikely to develop breast cancer.

The positive effects of the breast cancer classes is evident by the experimental group reporting a more accurate sense of risk to self at Time 2 (posttest) and Time 3. In addition to an increase in knowledge about breast cancer, providing the women with a more accurate sense of risk is another major benefit from the breast cancer classes. One hypothesis might be that if the daughters are more accurate in their estimations of risk to themselves, then on some level they may feel less anxious about developing breast cancer. Many of the participants reiterated this suggestion by commenting that they "can now feel both a little more relaxed and an improvement in their quality of life". In addition, overestimating risk may lead to or be related to a sense of helplessness that, if untreated, could lead to a lower rate of early detection behaviors.

The intent of the information presented in the classes was to give these women with a family history a general idea of their risk for developing breast cancer some day. Because of the nature of this study, it was not possible to provide individual specific details for each woman's own risk. In the future, the strength of these classes is that small groups of women would receive general risk information and through discussions, it could be determined who might need a referral for specific risk analysis counseling.

Psychological Variables

Another purpose of this study was to identify psychological factors (anxiety, depression and somatization) that may or may not be affecting women with a maternal history of breast cancer and assess the impact of receiving information about breast cancer on these variables.

According to the SCL-90-R Manual-II (Derogatis, 1983) the three variables are defined as follows:

(1) the anxiety dimension is composed of a set of signs and symptoms and cognitive aspects that involve nervousness, tension and trembling, panic attacks, and feelings of terror, apprehension and dread.

(2) The symptoms of the depression dimension are fairly broad in range and include symptoms of dysphoric mood and affect, feelings of hopelessness and thoughts of suicide, which are reflected in signs such as withdrawal of life

interest, lack of motivation and loss of vital energy.

(3) The somatization construct reflects distress arising from perceptions of bodily dysfunction. Signs and symptoms include: headaches, faintness and dizziness, cardiovascular and gastrointestinal symptoms, weakness, hot or cold spells, pains in lower back, numbness or tingling in parts of the body. All symptoms can be associated with true physical illness, therefore caution is required when interpreting this construct in certain medical populations (Derogatis, 1983).

Regardless of the symptom dimension, a T score of 50 on the SCL-90-R represents the mean score, and a T score of 70 represents a clinically significant score. Because both groups were within the mean scores of the general population on anxiety, depression and somatization, the results indicated a "fairly normal" psychological picture for this high-risk group of women.

The results of the daughters' reported anxiety scores in this study are somewhat surprising and are lower than expected for this group of women, given past reports in the literature. Royak-Schaler and Lieff-Benderly (1992) describe in their book that "the day that daughters learn of their mother's breast cancer, is the day the world changes-the day they learn that they belong to a high-risk group. This may be the day they begin to confront their own mortality" (p. 40).

Kelly (1980) reported the results of structured interviews

with 39 women who have a maternal history of breast cancer. All but two spontaneously reported "considerable and pervasive anxiety about breast cancer because of their mother's diagnosis". According to these women, "the anxiety is ever present, sometimes brought to the surface by a newspaper article, or learning that a friend or relative has just been diagnosed, or by their own illness, even if it's just a cold" (p. 121). A major difference of this study compared to the present one is that the information about anxiety is gathered from interview data and not from a standardized instrument.

Kash, Holland, Halper and Miller (1992) report that women at "high risk were almost one standard deviation above the mean on all measures of psychological distress on the Brief Symptom Inventory". On two of the subscales, depression and psychoticism, the women were greater than one standard deviation above the mean. (The authors point out that the psychoticism scale is frequently elevated in physically ill patients due to their sense of isolation related to their illness). The authors report "that with the use of standardized cutoffs, 27 percent of these women were defined as having a level of psychological distress consistent with the need for psychological counseling" (p. 28).

Kash and colleagues (1992) used the Brief Symptom Inventory (BSI), which is the brief form of the SCL-90-R. Correlations between the symptom dimensions of the SCL-90-R

and the BSI are based on 600 psychiatric patients and range from .92-.99. More than likely, the inconsistency in anxiety, depression and somatization scores between the two studies is probably not related to differences in the measure.

One possible reason for difference in this psychological picture between Kash and colleagues (1992) study and the present study may be related to eligibility criteria. Eligibility for the Kash study required two or more first-degree relatives (mother, sister and/or daughter) with breast cancer, a first-degree relative with premenopausal breast cancer or a mother and maternal grandmother with breast cancer. This difference may account for the higher anxiety levels reported, since most women with two or more first-degree relatives would be at a considerably higher risk than the woman in this study. (Four women in the experimental group and one women in the control group had two first-degree relatives).

The results of the anxiety scores from this study are in contrast to previously reported studies. Most information from past studies is based on interview and anecdotal data without the use of standardized instruments (Kelly, 1980; Rosenfeld, Caplan, Yaroslavsky et al, 1983; Lamb, 1984; Lichtman, Taylor, Wood et al, 1984).

In addition to methodological weaknesses in past studies, another explanation for this difference in the psychological

picture of this high-risk group of women may be related to a "developmental process". One might hypothesize that these women may be maturing in their abilities to cope with this chronic disease. Several factors may contribute to this "maturing or growth" on the part of the daughters: (1) living in a more open and communicative environment which allows for more discussion about the issues of breast cancer. (2) The daughters may be experiencing more honest communication with their mothers. One element that was not addressed in this study, is that possibly these women have mothers who are better able to cope with their own breast cancer and therefore communicate, either through cognitions and/or behaviors to their daughters a less anxious style. This "mature coping style" may translate into a more "normal" psychological picture for the daughters.

The study by Wellisch and colleagues (1991) also report surprising and similar results to this study. Using the BSI, the authors reported that there were no significant differences between daughters whose mothers had breast cancer and a comparison group on any of the nine symptom subscales. In addition, the scores for both groups were in the normal range on all symptom subscales. The authors cite two possible explanations: (1) a possible "buffering effect from stress patterns due to advanced education and relative affluence and (2) the participants were not coming to medical clinics

seeking help for symptoms and concerns" (p. 332).

Both explanations could possibly account for the women in this present study, although, relative affluence was not evaluated. In addition, discussions that took place after the post-tests were completed revealed that many of these women were dealing with the usual daily stresses that accompany carrers and family responsibilities. Therefore, it seems more likely that only the second suggestion may apply to the participants in this study.

One of the initial concerns in the development of this study, was that attendance at a class in which a high-risk group of women would receive information about breast cancer would cause an increase in anxiety, depression and somatization rather than decreasing these psychological variables.

A study by Berg, Alt, Himmel and Judd (1985) looked at a rheumatoid arthritis patient education program and its effects on knowledge and psychological variables (depression and anxiety). All patients felt the program was beneficial, the content had met their needs and every subject demonstrated an increase in disease-related knowledge. However, the authors reported a "heightening in the correlation of the AIMS anxiety score (Arthritis Impact Measurement Scale), with AIMS physical factors at post-test, as well as an increase in AIMS depression levels, which suggested that a gain in knowledge

about their disease caused an increased concern about their condition" (p. 393). At follow-up testing this correlation was no longer seen. These data suggest that patient education may have "an immediately deleterious psychological effect in patients with more severe disease" (p. 394). This study is in contrast to other literature regarding the impact of information on psychological variables.

Other studies have addressed the impact of patient education on psychological variables and suggest that information reduces anxiety by increasing feelings of control (Anderson, 1978; Lazarus, 1966; Melamed and Siegel, 1975; Flam, B., Spice-Cherry, P. and Amsel, R., 1989). Several other studies have demonstrated little or no change in anxiety levels (Hillier, C. and Slade, P., 1989). In a controlled study (Johnson, 1982) reported that anxiety, meaningfulness in life and knowledge all improved following an educational program.

In summary, there are only a few studies that have empirically documented the psychological status of women with a maternal history of breast cancer. Although this study did not demonstrate any statistically significant differences in psychological variables between the two groups, there was a trend of decreasing anxiety, depression and somatization scores in the experimental group after attending the breast cancer classes. In fact, given the unknown timeline

parameters necessary for developmental change, it may be that the decreases found in this study were meaningful in the lives of these individuals although not found to be statistically significant within the time frame assessed.

Based on the results of this study as well as Wellisch and colleagues (1991), daughters with a maternal history of breast cancer may not be as psychologically distressed as earlier reports would conclude. Health care professionals should be aware that there is probably a significant range to the psychological picture of these women and that future studies must focus on screening and predicting for those in need of psychological counseling.

Health Behaviors

Screening is the process of looking at healthy individuals with no signs or symptoms, in order to detect early signs of a disease (Love, 1991). For many years, the American Cancer Society has provided guidelines for early detection screening practices. The recommendations are reviewed and changed periodically as additional information and technologies become available. The ACS has made efforts to determine that the recommendations are practical, feasible and cost effective, and that the benefits outweigh the costs. At the present time the ACS recommends the following early detection breast cancer screening guidelines:

(1) Women older than 20 years of age should perform monthly

breast self-examination (BSE). There are suggestions from several National Breast Cancer Organizations that BSE education begin in the senior year of high school.

(2) Women between 35-40 years of age should have their first mammogram. For women with a first-degree relative with breast cancer the recommendation includes having a first mammogram approximately five years earlier (around 30 years of age).

(3) Women between 40 and 50 years of age should have mammograms every two years and physical examination of the breast every year.

(4) Women older than 50 years of age should have annual mammograms and annual physical examinations (Dodd,1992).

The use of mammography as a screening method is considered to be the most effective technique currently available for the early detection of breast cancer (Shapiro, 1989; Tabar and Dean, 1987). In this country, the use of mammography has significantly increased. Studies done between 1978 and 1983 indicated that only 15-20 percent of women in the United States reported ever having had mammograms (Howard, 1987). However, by 1990, based on the Mammography Attitudes and Usage Study (MAUS) two-thirds of women aged 40 and over reported having had at least one mammogram. However, only 35 percent of the women reported more than one mammogram, and less than one-third (31 percent) were following national screening guidelines (Marchant and Sutton, 1990). Although

use has increased, minority women, older women and those with less income and education continue to be under-utilizers. "The lack of physician recommendation remains the most important barrier to utilization. Even with no charge mammography, compliance is often disappointing" (Rimer, 1992, pg. 201).

The findings in this study indicate that at pretest 77 percent of women in the experimental group and 75 percent of the control group, 30 years of age or older, reported having obtained a mammogram. These results are one of the highest reported for this high-risk group of women reporting mammography utilization. Among first-degree relatives, previous studies report much lower results (32-66%) for mammography screening practices (Krischer, Cook and Weiner, 1988; Vogel et al 1990; Wellisch et al, 1991; Stefanek and Wilcox, 1991).

To better understand the impact of the breast cancer classes on mammography utilization, all women were reevaluated according to age-appropriateness and symptomatology for obtained or unobtained mammograms between Time 1 and Time 3.

In the experimental group, six of eight women who had not obtained a mammogram at either Time 1 or Time 3 were appropriate in mammography utilization. The other two of eight were 30 years of age or older, had not had a baseline mammogram, but had been told by their physicians to wait until 35 years of age. Two women who should have had a baseline

mammogram at Time 1 but did not, obtained mammograms after attending the breast cancer classes. Eleven women reported having had mammograms at Time 1 but not at Time 3. For six of the eleven this was appropriate, five of the eleven reported having had baseline mammograms, however they were all under 27 years of age. The five women who reported having had mammograms at both Time 1 and Time 3 were appropriate utilization based on symptoms.

Thirty women in the control group were evaluated for mammogram utilization between Time 1 and Time 3 based on age and symptomatology. Results indicated that 27 women had complete information and three were missing data. Twenty-one out of 27 women (78 percent) were appropriate in mammogram utilization according to their age and symptoms. Four out of 27 (15 percent) were inappropriate in their mammogram utilization. For example, two women were obtaining mammograms too frequently (every six months without symptoms), one woman should have obtained a mammogram given her age and family history, and one woman was too young (25 years) to have obtained a mammogram. The remaining two women (7 percent) were 30 years of age, had not had baseline mammograms but were told by their physicians to wait until 35 years of age before obtaining them.

These results are somewhat surprising given the reports in the literature on mammography utilization by first-degree

relatives with breast cancer. Several possible explanations include: (1) the difference between appropriate and inappropriate mammograms obtained between the two groups may be related to the breast cancer classes. (2) It may be that the public educational promotions for breast cancer over the last 10 years have affected this group of women. (3) For those women in the control group who were appropriate in their mammography utilization, the "Hawthorne effect" may be playing a part, (participating in the study may have served as reminders to obtain mammograms).

The few women in the present study who had not obtained mammograms explained that given their age, some of their physicians were not recommending mammography until age 35 or 40, or were recommending mammograms every other year or on a "whenever necessary" schedule.

Although most oncology specialists would recommend baseline mammograms at approximately 30 years of age for first-degree relatives, the answers are still unknown as to what is the most appropriate follow-up screening schedule for this high-risk group.

Rimer (1992) reviewed the mammography literature and discussed factors surrounding routine screening habits of American women. The author discussed an article by Lerman and colleagues (1990). Using 1988 breast cancer survey data, the authors compared women who had one mammogram versus more than

one and found that "women who reported more than one mammogram were more likely to have had a family history of breast cancer, physician recommendation for mammography and perceive a greater personal vulnerability to breast cancer" (p. 199).

A later survey by Rimer and colleagues (1990) looked at women who had obtained one versus two mammograms and found the major contributing factor was again physician recommendation. Rimer's (1992) conclusion is that a "combination of physician recommendation, knowledge and sociodemographic characteristics accounted for repeat mammograms" (p. 199).

Of interest, at Time 3, the question was asked, "How many mammograms have you had in your life"? Surprisingly, a total of 11 women in both groups had obtained three or more mammograms in their life, with 2 women in the control group who had obtained 5 mammograms.

After reviewing the data for the women who had obtained three or more mammograms, it appeared that symptoms such as: calcifications, a lump in the breast or bleeding from a nipple accounted for the increased number of mammograms among these women.

In summary, the findings indicated that the majority of women in this study are following recommended guidelines for mammography screening, which is a significant improvement over past studies reporting screening practices for this high-risk group. In spite of the lack of statistically significant

differences between the two groups, the breast cancer classes appear to have contributed to mammography utilization by motivating four women 30 years of age or older who had not obtained mammograms prior to Time 1 and to obtain them by Time 3.

Breast Self-Examination: There is considerable debate over the usefulness of breast self-examination (BSE) as a screening method for breast cancer. Although BSE is a simple, noninvasive and inexpensive screening method, with some studies suggesting its effectiveness by detecting breast cancer at an earlier stage (Huguley, Brown, Greenberg and Clark, 1988; Hill, White, Jolley and Mapperson, 1988; Shwartz, 1992); it's effectiveness has yet to be scientifically determined (Newcomb, Weiss, Storer, Scholes and colleagues, 1991; Morrison, 1991). O'Malley and Fletcher (1987) reviewed evidence on the value of screening with BSE and concluded that "many unanswered questions remain and require scientific investigation before this method can be advocated as either a supplemental or as a primary screening test for breast cancer. The problem with BSE is not evidence of a lack of effect, but lack of evidence" (p. 2202).

This controversy over BSE's usefulness has caused differences in recommendations from health care agencies. For example, the ACS and Y-ME National Breast Cancer Organization continue to recommend BSE as one of the three established

methods for early detection of breast cancer. Within the National Cancer Institute there appears to be confusion as to whether to recommend BSE or not (Mayer and Solomon, 1992).

Some of these questions surrounding early detection screening methods for breast cancer are being addressed in the National Breast Cancer Screening Study of the NCI of Canada. This study compares annual mammography in postmenopausal women to an initial mammogram, annual clinical examination and instruction in BSE (Fisher, Osborne, Margolese and Bloomer, 1993).

In spite of the controversy regarding the effectiveness of BSE, it seemed appropriate to include a review of BSE in the breast cancer classes, since 85-95 percent of breast lumps are detected by women themselves.

The results of this study indicated that at Time 1, 91 percent of the experimental group and 90 percent of the control group had performed BSE. The results also indicated that the mean time since last performing BSE was 2.5 months for the experimental group and 3.5 months for the control group. Overall, there were minimal changes in the practice of BSE between Time 1 and Time 3. In the experimental group, thirteen women did not change their frequency, six women increased their frequency and four decreased their frequency. In the control group, fourteen women did not change their frequency, seven women increased and three decreased their

frequency.

The recommended frequency is monthly and the results showed that 84 percent of the experimental group and 66 percent of the control group are performing BSE within the ACS guidelines. Since the majority of these high-risk women were already practicing BSE at a correct frequency, the numbers are too small to see statistically significant differences in the frequency of BSE practice between the two groups.

Only one report in the literature is consistent with the results of this study. Kelly (1979) reported that out of 158 women who attended a clinic for "breast concerns", 66 percent of the women surveyed practiced BSE and 80 percent of those who examined their breasts tended to do so at least once a month or more. However, it is unclear whether the women in this study had a family history of breast cancer.

The results from this study and Kelly's (1979) differ from other reported studies of BSE practice among high-risk women. Most studies indicate less than a 50 percent monthly frequency rate of BSE practice (Alagna, Morokoff, Bevett and Reddy, 1987; Wellisch, Gritz, Schain, Wang and Siau, 1991; Krishcer, Cook and Weiner, 1988).

Possible Relationship of BSE and Anxiety.

The fairly normal to moderate levels of anxiety found in this group of women may account for their improved early detection screening practices. In a the study by Lerman,

Trock, Rimer and Jepson (1991), the authors report that women with "moderate levels of worry impact are more likely to practice monthly BSE than women with either high or low levels of impairment" (p.265).

The Lerman and colleagues (1991) findings correlate well with conclusions drawn by Kash, Holland, Halper and Miller (1991). The authors suggest "that high levels of anxiety impaired adherence to both regular clinical breast examinations and performance of BSE" (p. 30).

There is no certainty that the women in this study were practicing BSE as reported or performing BSE accurately. The women were asked at Time 1, "has anyone ever taught you breast self-examination?" It was encouraging to learn that the majority of the women reported receiving BSE instruction from a nurse or physician (26% from nurses; 59% from physicians and 15% from pamphlets), since it has been found that women taught BSE by a nurse or physician perform more of the necessary steps (Laughter, Kean and Drean, 1981).

In order to better understand BSE practice among this high-risk group, the women were asked their reasons for doing BSE. In the experimental group, reasons for doing BSE were: "in order to check for lumps" (24 women); "family history" (1), "protect myself against cancer" (1) and "I'm suppose to" (1). In the control group, reasons for doing BSE were: "to check for abnormalities" (14), "family history" (6) "early

detection" (3) and "it's a healthy thing to do" (1).

For future studies Mayer and Solomon (1992) offer the following recommendations for measuring and reporting BSE frequency: (1) "give subjects permission" to report non-adherence or low adherence". (2) In order to make comparisons across studies, reporting mean numbers of BSE's and time intervals in which they were measured would be helpful. (3) Use a "user-friendly" method for measuring BSE performance that is consistent and acceptable to subjects (Mayer and Solomon, 1992).

Conclusions

Overall, the impact of the didactic group experience on women with a maternal history of breast cancer was a positive one. Knowledge about breast cancer increased, awareness of risk to self became more accurate and anxiety, depression and somatization levels did not increase with more information. The surprising and encouraging findings indicated that the majority of women in this study reported following recommended guidelines for mammography screening and BSE frequency, which is a significant improvement over past studies reporting screening practices for this high-risk group.

A strength of this study is that both groups of women were followed from 6-12 months after their initial participation in order to assess for any possible negative consequences of receiving the breast cancer information.

Results indicated that no measureable negative consequences occurred as a result of attending the classes.

The women in the experimental group were asked to evaluate the breast cancer classes based on class content, how well the classes were taught and whether they would like to hear more about breast cancer. The majority of these women evaluated the didactic group experience as "extremely worthwhile".

Negative comments included: classes were too long; a more current BSE video should have been used; presentation style of the class material was too fast; and the class content was too simplistic. After the posttests were completed, discussion among the participants was encouraged in order to gather suggestions on how to improve the classes.

Most of the women acknowledged difficulty hearing the information about this threatening disease, however the majority felt it was rewarding to dispel myths and receive up-to-date information about breast cancer. Many commented that a reward for attending the classes was the opportunity to meet other women who shared their same concerns and who are living with similar experiences. In fact, some of the participants expressed frustration with the format of the classes and wanted more of a support group approach.

In spite of scheduling hassles, babysitting difficulties, and inconveniences, such as driving great distances, the

majority of the women reported that they greatly appreciated these classes and would appreciate more opportunities like this one made available to them.

Implications for Psychological Interventions

Although sample size limits the generalizability of conclusions which can be drawn from this study, the findings contribute toward a better understanding of women with a maternal history of breast cancer. Strengths of this study included using a randomized design and a standardized measure to assess the impact of the classes and to measure psychological variables in this "at-risk" group.

This study helps to demonstrate that organizing and formalizing breast cancer classes are both feasible and appreciated, and over time, can probably demonstrate economic benefits given their success at promoting early detection behaviors related to both psychological and medical factors. The women who participated in this study expressed appreciation that their needs and concerns had been identified and that opportunities for receiving information and support were available to them.

Part of the success of these classes had to do with the overall atmosphere that was created for these women. As Kelly (1979) suggested, "educational campaigns that produce fear are likely to be less effective than those that inform in a less anxiety-producing manner" (p. 37).

This present study was an outgrowth of several recommendations for future research addressed by this author in a master's thesis. The intent of this study was to provide a first step toward addressing the need for the development of educational interventions for women with a family history of breast cancer. Using this study as a guide, the continued goals for future research and psychological interventions should be to decrease distress, provide education, improve the practice of early detection health behaviors and thereby promoting early detection of breast cancer.

One implication from this study that needs to be addressed when developing future intervention studies is the significant amount of time and energy that was required in order to overcome the difficulties of accessing, recruiting and maintaining participants for this study.

Another implication from the findings of this study suggest that it may be immediately feasable to incorporate the format and content of these classes into an ongoing educational program for already existing Comprehensive Breast Centers. These centers are growing at a significant rate, and as the name implies, comprehensive should extend to include not just patients but also all women (daughters and sisters) with a family history of breast cancer.

A new area that has developed to promote education and support is the Breast Cancer Risk Analysis service. Such a

service is designed to provide information about a woman's risk, background information regarding etiology of breast diseases, risk factors, and provide guidance for appropriate breast health care. In addition, women and their families can find social and psychological support from this specialized service (Kelly, 1991).

Although breast cancer screening, as well as breast cancer risk analysis have the potential for decreasing morbidity and mortality, consequences of receiving information about breast cancer risk and/or early detection breast cancer screening results may have potentially negative psychological side effects. This is a new area for health psychology research. Several recent articles have begun the discussion surrounding the psychosocial and ethical implications for this area that need to be addressed (Lerman, Trock, Rimer, Jepson, Brody and Boyce, 1991; Lerman, Rimer and Engstrom, 1991).

Specific Research Directions

Specific recommendations for future research include: (1) more studies are needed to assess presently used instruments (SCL-90-R, BSI, State-Trait) in order to determine the most accurate measure with which to better predict those family members who may need psychological interventions. (2) More studies are needed using large sample sizes of daughters and sisters, to assess similarities and differences in psychological variables and coping styles. In addition, the

different developmental life-phase issues that affect these women should be evaluated, including specific issues such as body image and sexual functioning.

(3) Future studies might correlate coping styles of women with breast cancer and the coping styles of their daughters. For example, how are the mothers and their daughters similar and/or different in their approach to seeking information as well as their compliance with early detection screening practices.

(4) One major research question at this time concerns the value of support groups. Based on comments from the women in this study, as well as two studies in the literature, (Jacobs and colleagues, 1983; Mumford and colleagues, 1982) an interesting approach would be to use a randomized, three-arm study design to examine outcomes comparing a purely educational program, versus a peer support group therapy or a combination of the two.

(5) Additional studies are needed that focus on improving early detection screening practices of non-White women and women of lower socioeconomic status who have a family history of breast cancer.

(6) Another future direction would be to examine physician recommendations for early detection screening practices for breast cancer. Based on several reports in the literature already cited, lack of physician recommendation is one major

barrier contributing to women following recommended screening guidelines. Focusing attention on the physician may be an important step for health psychology.

Identifying and assessing psychological interventions for women with a maternal history of breast cancer is a new and exciting area for health psychologists. In addition to counseling for the emotional concerns about their mother's illness, adult and adolescent daughters, as well as sisters, would undoubtedly benefit from interventions that provide:

(1) accurate information about breast cancer in general with specific emphasis on risk factors, which must be individually assessed.

(2) Understanding the most effective ways to educate, motivate and sustain early detection health behaviors that match individual styles of coping by the daughters and sisters.

(3) Understanding the particular barriers that each woman may have that prevent the routine practice of health behaviors.

(4) Assessment of individual coping styles as healthy versus unhealthy for each individual daughter and sister, while understanding and respecting various coping methods.

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APPENDIX A

Pilot Study of Didactic Classes

EVALUATION OF BREAST CANCER CLASSES

PILOT STUDY SUMMARY

Bonnie M. Taylor

Loyola University of Chicago

CEPS

Breast cancer effects one out of nine American women during their lifetime (ACS, Facts & Figures, 1992). Although breast cancer continues to be one of the major causes of cancer death among women, the five-year survival rate for localized breast cancer detected early is approximately 92 percent (ACS, Facts & Figures, 1992).

The principle risk factors for breast cancer include: family history, age and menstrual and reproductive history. Clearly, the most significant risk factor is heredity. Women who have a first-degree relative (mother or sister) with breast cancer have a risk two or three times that of the general population (Sattin, Rubin, Webster and colleagues, 1985). The survival rate is directly related to the size of the breast tumor. The larger the lesion, the greater the chance that metastases have occurred. Therefore, early detection of breast cancer remains an essential key to increased cure rates and survival.

There are three established methods of early detection: physical examination, mammography and breast self-examination (BSE). Educating women about these three methods is critical to early detection of breast cancers. Identifying the population that is most in need of early detection and finding the best method to educate women has been a major focus in recent research proposals.

Women with a maternal history of breast cancer have been identified as a "high-risk" group. With breast cancer specifically it is likely that daughters will be emotionally effected by the chronicity of their mothers' disease, however, they may or may not develop a sense of being at risk themselves. Several authors have identified the need for increased education for this group of women for several reasons: (1) more information may decrease potentially high anxiety levels that these women may be experiencing and (2) more education may increase the use of early detection methods (Kelly, 1980; Kelly, 1987; Lichtman, Taylor, Wood, Bluming and colleagues, 1984 and Taylor, 1987). Therefore, it seemed timely to test several questions that need to be addressed in this "at-risk" population. The questions include:

(1) what do women with a maternal history of breast cancer understand about the disease?

(2) What do women with a maternal history of breast cancer perceive their own risk to be for developing the disease? (3) What is the psychological impact of receiving information about breast cancer?

(4) What early detection behaviors do these women practice?

(5) Does this "at risk" group comply with recommended early detection methods set forth by the American Cancer Society?

This dissertation is an intervention study designed specifically for women with a maternal history of breast cancer. This "at risk" group of women will be randomized to attend classes specifically addressing information about breast cancer, risk information and early detection methods or be placed on a wait-list control group.

Before beginning this research a small pilot study was done in order to test the educational component of this dissertation. Specifically, the purposes of the pilot study included:

(1) to evaluate the didactic portion of this study for content and comprehensiveness of the information presented.

(2) To determine the feasability of women attending two classes rather than one class.

(3) To assess potential attendance problems.

(4) To evaluate the homework assignment, length of time for the classes, and location of the classes.

(5) To assess the Clinical Nurse Specialist who was conducting the classes.

Method

Subjects

Participants included five women between 29 and 38 years of age. All the women were friends or acquaintances of the

investigator or the nurse conducting the classes. Their occupations included: a nurse, make-up artist, realtor, office administrator, and advertising copywriter. Their educational levels ranged from two years of college to completion of post-graduate work. A total of seven women agreed to attend the classes, however only five women were able to complete the two classes. The classes were held at the home of the nurse conducting the classes.

Results and Discussion

All five women completed all of the questions on the questionnaire asking about health behaviors practiced and awareness of risk for breast cancer. In addition, all women completed the Breast Cancer Knowledge questionnaire, which included twenty-five true/false questions given before and after the classes.

In response to the question, "What percentage best describes your chance of developing breast cancer some day?" Four of the five women over-estimated their chances of developing breast cancer (+5% to +20%). One woman under-estimated her risk by -5 percent.

Responses to questions concerning early detection behaviors practiced revealed the following information:
(1) none of the five women practiced BSE on a regular basis. (Once a month is the recommendation).

(2) One of the five women had obtained a baseline mammogram. (Three of the five are in the appropriate age range to have obtained a mammogram).

(3) Of the four women who had not had a baseline mammogram, only one intended to get one after having attended the class.

Results of the Breast Cancer Knowledge Quesionnaire are as follows:

Subject	Pretest (% correct)	Posttest (% correct)
1	76%	92%
2	60%	96%
3	68%	100%
4	41%	92%
5	64%	100%

These results clearly demonstrate an increase in the number of correct answers from pretest to posttest.

Participants rated the class experience as extremely worthwhile. All five agreed that inspite of scheduling difficulties, they'd rather attend two classes and receive more information than attend one class and eliminate information. However, the fact that two women out of seven were unable to commit to the classes was interpreted as a

"potential problem area" that may predict accrual problems.

All five women agreed that the content of the classes was excellent as well as understandable. In addition, the women agreed that the homework assignment was actually enjoyable and a very worthwhile exercise. All five women agreed that the length of the classes was very tolerable (each night was approximately an hour and a half).

The participants also offered many other constructive suggestions and comments. Examples include: allow for more question and answer time and spend more time presenting the "statistics" of breast cancer. In addition, the women suggested that the nurse take on a slower presentation style.

In summary, the purposes of the pilot study were achieved. In addition, the pilot study proved to be an invaluable educational experience for the Oncology Clinical Specialist as well as the participants.

APPENDIX B

Information Sheet/Consent Form

Dear Study Participant,

Thank you for agreeing to participate in this study. The following packet is the first part of the study. This packet has four parts: (1) consent form, (2) questionnaire (SCL-90), (3) demographic section that asks health-related questions about you and your family, and (4) a pretest that includes some True\False questions asking about breast cancer.

Please sign the consent form, read each page carefully and answer all of the questions.

In several months you will be receiving another packet similar to this one. Please complete it and return it to me as soon as possible.

All of the information will be coded so that it remains confidential at all times. THANK YOU for your cooperation. If you have any questions, please feel free to call me.

Bonnie Taylor, R.N., M.A.
531 W. Briar Pl.
Chicago, Illinois, 60657
312 935 - 9740

AFTER SEPTEMBER 1st my address will be

3024 N. Kenmore, 60657

INFORMATION SHEET / CONSENT FORM

Because health professionals (psychologists, nurses and physicians) would like to better understand how to help people deal with risks to their health, I am being asked to participate in this study. This study examines an individual's attitudes, feelings and understanding of risks to her health especially related to her family's health history. With these results it is hoped that health care professionals will provide better education to patients and their families.

If I agree to participate I understand that I will be expected to complete some questionnaires (requiring approximately thirty minutes) and this request will be repeated again in about six months. I also understand that all study participants will be randomly assigned to either attend two educational classes, or be randomly assigned to a wait-list and asked to attend the classes at a later date.

I understand that at no time during the study will I be put at risk. If at any time during the study I would like to withdraw from participation, I am able to do so without penalty or prejudice. If any questions may arise at any time during the study the investigator will be happy to discuss them.

All information and responses to questionnaires will remain confidential. When the study is written up, only group information will be reported and individual subjects will never be identified. At the conclusion of the study, those interested in receiving a summary of the findings may do so by asking the investigator.

I have read, been given the chance to ask questions, and understand the information in this Subject Information Sheet. I volunteer to participate based on this information and may request a copy of this Information Sheet.

_____ _____

Volunteer's Signature and Date

Investigator's Signature and Date

I was present during the explanation referred to above, as well as the volunteer's opportunity to ask questions, and hereby witness her consent to participate in this study.

_____

Witness's Signature & Date

DEMOGRAPHIC INFORMATION

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

TELEPHONE _____WORK #_____

BIRTHDATE _____

OCCUPATION_____

EDUCATIONAL LEVEL COMPLETED

High School _____

College _____

Post Graduate_____

ETHNICITY

African American _____

Asian _____

Caucasian_____

Hispanic _____

Other _____

Please turn to next page.

APPENDIX C

Demographic Information/Questionnaire

The following pages will address questions about your health and that of your family. Please answer ALL the questions.

(1) Have you ever had a Pap Test?

NO _____ YES _____

(2) If yes, when was your last one? _____

(3) What is the MAIN reason you get a Pap Test?

_____

(4) Have you ever had a Mammogram ?

NO _____ YES _____

(5) If yes, when was your last one? _____

(6) How often do you get Mammograms? _____

(7) What is the MAIN reason for getting your Mammogram?

_____

(8) Have you ever done Breast Self-Examination (BSE)?

NO _____ YES _____

(9) If yes, when was the last time you examined your breast? _____

(10) What is the MAIN reason you do BSE?

_____

(11) Has anyone ever taught you Breast Self-Examination?

NO _____ YES _____

(12) If yes, who taught you? Nurse _____ Doctor_____

Other _____

(13) At what age did you begin having periods?_____

(14) Have you ever used birth control pills?

NO_____ YES_____

(15) If yes, how old were you when you started them? _____

(16) What is the total number of years you've taken them?_____

(17) Have you ever had a biopsy of your breast?

NO_____ YES_____

(18) If yes, how many times?_____

(19) If you have children, how old were you when you delivered your first child? _____

(20) How many sisters do you have?_____

(21) Have any of your sisters been diagnosed with breast cancer?

NO_____ YES_____ If yes, how many?_____

(22) Do any other close relatives have breast cancer?

NO_____ YES_____

If yes, type of relative, for example, grandmother.

Mother's Relatives	Father's Relatives
_____	_____
_____	_____
_____	_____

(23) What percentage best describes YOUR chance of developing breast cancer some day?

Answer from 0 to 100% _____

(24) What percentage best describes the AVERAGE woman's chances of developing breast cancer some day?

Answer from 0 to 100%_____

(25) What was YOUR age at time of your mother's breast cancer diagnosis? _____

(26) What was your MOTHER'S age at the time of her breast cancer diagnosis? _____

(27) What was the type of primary treatment your mother received for breast cancer?

Please check all that apply.

SURGERY

Mastectomy left_____ right_____ both_____

Lumpectomy left_____ right_____ both_____

RADIATION THERAPY _____

CHEMOTHERAPY _____

HORMONE THERAPY _____

RECONSTRUCTIVE SURGERY _____

(28) What do you believe is the cause of breast cancer?

_____

APPENDIX D

Symptom Check List-90-Revised

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SCL—90—R

SIDE 1

INSTRUCTIONS:

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered circles to the right that best describes **HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY.** Mark only one numbered circle for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask the technician.

SEX

MALE ○

FEMALE ○

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR ___ SEP ___ DIV ___ WID ___ SING ___

DATE		
MO	DAY	YEAR

ID. NUMBER

AGE

EXAMPLE

HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	①	①	②	●	④

VISIT NUMBER: _____

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1.	Headaches	1	①	①	②	③	④
2.	Nervousness or shakiness inside	2	①	①	②	③	④
3.	Repeated unpleasant thoughts that won't leave your mind	3	①	①	②	③	④
4.	Faintness or dizziness	4	①	①	②	③	④
5.	Loss of sexual interest or pleasure	5	①	①	②	③	④
6.	Feeling critical of others	6	①	①	②	③	④
7.	The idea that someone else can control your thoughts	7	①	①	②	③	④
8.	Feeling others are to blame for most of your troubles	8	①	①	②	③	④
9.	Trouble remembering things	9	①	①	②	③	④
10.	Worried about sloppiness or carelessness	10	①	①	②	③	④
11.	Feeling easily annoyed or irritated	11	①	①	②	③	④
12.	Pains in heart or chest	12	①	①	②	③	④
13.	Feeling afraid in open spaces or on the streets	13	①	①	②	③	④
14.	Feeling low in energy or slowed down	14	①	①	②	③	④
15.	Thoughts of ending your life	15	①	①	②	③	④
16.	Hearing voices that other people do not hear	16	①	①	②	③	④
17.	Trembling	17	①	①	②	③	④
18.	Feeling that most people cannot be trusted	18	①	①	②	③	④
19.	Poor appetite	19	①	①	②	③	④
20.	Crying easily	20	①	①	②	③	④
21.	Feeling shy or uneasy with the opposite sex	21	①	①	②	③	④
22.	Feelings of being trapped or caught	22	①	①	②	③	④
23.	Suddenly scared for no reason	23	①	①	②	③	④
24.	Temper outbursts that you could not control	24	①	①	②	③	④
25.	Feeling afraid to go out of your house alone	25	①	①	②	③	④
26.	Blaming yourself for things	26	①	①	②	③	④
27.	Pains in lower back	27	①	①	②	③	④
28.	Feeling blocked in getting things done	28	①	①	②	③	④
29.	Feeling lonely	29	①	①	②	③	④
30.	Feeling blue	30	①	①	②	③	④
31.	Worrying too much about things	31	①	①	②	③	④
32.	Feeling no interest in things	32	①	①	②	③	④
33.	Feeling fearful	33	①	①	②	③	④
34.	Your feelings being easily hurt	34	①	①	②	③	④
35.	Other people being aware of your private thoughts	35	①	①	②	③	④

Leonard R. Derogatis, Ph.D.

HOW MUCH WERE YOU DISTRESSED BY		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Feeling others do not understand you or are unsympathetic	36	①	①	①	①	①
37. Feeling that people are unfriendly or dislike you	37	①	①	①	①	①
38. Having to do things very slowly to insure correctness	38	①	①	①	①	①
39. Heart pounding or racing	39	①	①	①	①	①
40. Nausea or upset stomach	40	①	①	①	①	①
41. Feeling inferior to others	41	①	①	①	①	①
42. Soreness of your muscles	42	①	①	①	①	①
43. Feeling that you are watched or talked about by others	43	①	①	①	①	①
44. Trouble falling asleep	44	①	①	①	①	①
45. Having to check and double-check what you do	45	①	①	①	①	①
46. Difficulty making decisions	46	①	①	①	①	①
47. Feeling afraid to travel on buses, subways, or trains	47	①	①	①	①	①
48. Trouble getting your breath	48	①	①	①	①	①
49. Hot or cold spells	49	①	①	①	①	①
50. Having to avoid certain things, places, or activities because they frighten you	50	①	①	①	①	①
51. Your mind going blank	51	①	①	①	①	①
52. Numbness or tingling in parts of your body	52	①	①	①	①	①
53. A lump in your throat	53	①	①	①	①	①
54. Feeling hopeless about the future	54	①	①	①	①	①
55. Trouble concentrating	55	①	①	①	①	①
56. Feeling weak in parts of your body	56	①	①	①	①	①
57. Feeling tense or keyed up	57	①	①	①	①	①
58. Heavy feelings in your arms or legs	58	①	①	①	①	①
59. Thoughts of death or dying	59	①	①	①	①	①
60. Overeating	60	①	①	①	①	①
61. Feeling uneasy when people are watching or talking about you	61	①	①	①	①	①
62. Having thoughts that are not your own	62	①	①	①	①	①
63. Having urges to beat, injure, or harm someone	63	①	①	①	①	①
64. Awakening in the early morning	64	①	①	①	①	①
65. Having to repeat the same actions such as touching, counting, or washing	65	①	①	①	①	①
66. Sleep that is restless or disturbed	66	①	①	①	①	①
67. Having urges to break or smash things	67	①	①	①	①	①
68. Having ideas or beliefs that others do not share	68	①	①	①	①	①
69. Feeling very self-conscious with others	69	①	①	①	①	①
70. Feeling uneasy in crowds, such as shopping or at a movie	70	①	①	①	①	①
71. Feeling everything is an effort	71	①	①	①	①	①
72. Spells of terror or panic	72	①	①	①	①	①
73. Feeling uncomfortable about eating or drinking in public	73	①	①	①	①	①
74. Getting into frequent arguments	74	①	①	①	①	①
75. Feeling nervous when you are left alone	75	①	①	①	①	①
76. Others not giving you proper credit for your achievements	76	①	①	①	①	①
77. Feeling lonely even when you are with people	77	①	①	①	①	①
78. Feeling so restless you couldn't sit still	78	①	①	①	①	①
79. Feelings of worthlessness	79	①	①	①	①	①
80. The feeling that something bad is going to happen to you	80	①	①	①	①	①
81. Shouting or throwing things	81	①	①	①	①	①
82. Feeling afraid you will faint in public	82	①	①	①	①	①
83. Feeling that people will take advantage of you if you let them	83	①	①	①	①	①
84. Having thoughts about sex that bother you a lot	84	①	①	①	①	①
85. The idea that you should be punished for your sins	85	①	①	①	①	①
86. Thoughts and images of a frightening nature	86	①	①	①	①	①
87. The idea that something serious is wrong with your body	87	①	①	①	①	①
88. Never feeling close to another person	88	①	①	①	①	①
89. Feelings of guilt	89	①	①	①	①	①
90. The idea that something is wrong with your mind	90	①	①	①	①	①

APPENDIX E

Pretest Questionnaire

PRETEST QUESTIONS

The following are questions concerning general information about Breast Cancer. Please read them carefully and circle TRUE or FALSE for each one.

(1) TRUE FALSE Over 70% of all breast cancers occur in women who are older than 50 years of age.

(2) TRUE FALSE Having a child at a younger age (under 30) increases the risk of developing breast cancer.

(3) TRUE FALSE There is some evidence that breast cancer is "catching" (contagious).

(4) TRUE FALSE The longer a woman has periods (number of years) the more prone she is to developing breast cancer.

(5) TRUE FALSE Seventy percent of women who develop breast cancer have no known family history of the disease.

(6) TRUE FALSE Women who have their 1st full-term pregnancy after age 30 have less risk of developing breast cancer.

(7) TRUE FALSE Birth control pills can reduce the risk of developing breast cancer.

Please turn to next page.

(8) TRUE FALSE Fibrocystic changes in the breast increase the risk of developing breast cancer.

(9) TRUE FALSE A woman has a greater chance of developing breast cancer if her sister has breast cancer rather than her mother.

(10) TRUE FALSE Drinking alcohol, even in moderate amounts, may increase the risk of developing breast cancer.

(11) TRUE FALSE Participating in vigorous athletics at an early age can reduce the risk of developing breast cancer.

(12) TRUE FALSE Breast self-examination (BSE) is recommended on a monthly basis for all women over age 20.

(13) TRUE FALSE The best time to perform BSE is just before the time of your period.

(14) TRUE FALSE Fifty percent of lumps found on a mammogram are too small to be felt.

(15) TRUE FALSE Screening for breast cancer by mammography should begin after age 50.

(16) TRUE FALSE Breast cancer tends to develop at an earlier age (before age 50) in women with a family history of the disease.

(17) TRUE FALSE Breast cancer becomes less common as women get older.

(18) TRUE FALSE Women with a mother or sister with breast cancer have a 2 in 10 or 20% chance of developing the disease in their lifetime.

(19) TRUE FALSE Women with a family history of breast cancer have equal to or slightly better chance of survival than women with breast cancer without a family history.

(20) TRUE FALSE Every woman between 35 and 40 years of age should have a baseline mammogram.

(21) TRUE FALSE If a mother has breast cancer, then all of her daughters will develop the disease as well.

(22) TRUE FALSE The average woman without a family history of breast cancer has a 10% or 1 in 10 chance of developing breast cancer in her lifetime.

(23) TRUE FALSE The majority of American women perform Breast Self-Examination every month.

(24) TRUE FALSE Unless breast cancer runs in her family, a woman does not need to do Breast Self-Examination (BSE).

(25) TRUE FALSE A woman does not need to get a mammogram unless her physician recommends the test to her.

APPENDIX F

Posttest Questionnaire

POSTTEST QUESTIONS

The following are questions concerning the information discussed in the two classes that you attended. Please read them carefully and circle TRUE or FALSE for each one. Please return this to Joan before leaving the class tonight.

(1)	TRUE	FALSE	Over 70% of all breast cancers occur in women who are older than 50 years of age.
(2)	TRUE	FALSE	Having a child at a younger age (under 30) increases the risk of developing breast cancer.
(3)	TRUE	FALSE	There is some evidence that breast cancer is "catching" (contagious).
(4)	TRUE	FALSE	The longer a woman has periods (number of years) the more prone she is to developing breast cancer.
(5)	TRUE	FALSE	Seventy percent of women who develop breast cancer have no known family history of the disease.
(6)	TRUE	FALSE	Women who lhave their 1st full-term pregnancy after age 30 have less risk of developing breast cancer.
(7)	TRUE	FALSE	Birth control pills can reduce the risk of developing breast cancer.

(8)	TRUE	FALSE	Fibrocystic changes in the breast increase the risk of developing breast cancer.
(9)	TRUE	FALSE	A woman has a greater chance of developing breast cancer if her sister has breast cancer rather than her mother.
(10)	TRUE	FALSE	Drinking alcohol, even in moderate amounts, may increase the risk of developing breast cancer.
(11)	TRUE	FALSE	Participating in vigorous athletics at an early age can reduce the risk of developing breast cancer.
(12)	TRUE	FALSE	Breast self-examination (BSE) is recommended on a monthly basis for all women over 20 years of age.
(13)	TRUE	FALSE	The best time to perform BSE is just before the time of your period.
(14)	TRUE	FALSE	Fifty percent of lumps found on a mammogram are too small to be felt.
(15)	TRUE	FALSE	Screening for breast cancer by mammography should begin after age 50.
(16)	TRUE	FALSE	Breast cancer tends to develop at an earlier age (before age 50) in women with a family history of the disease.

(17) TRUE FALSE Breast cancer becomes less common as women get older.

(18) TRUE FALSE Women with a mother or sister with breast cancer have a 2 in 10 or 20% chance of developing the disease in their lifetime.

(19) TRUE FALSE Women with a family history of breast cancer have equal to or slightly better chance of survival than women with breast cancer without a family history.

(20) TRUE FALSE Every woman between 35 and 40 years of age should have a baseline mammogram.

(21) TRUE FALSE If a mother has breast cancer, then all of her daughters will develop the disease as well.

(22) TRUE FALSE The average woman without a family history of breast cancer has a 10% or 1 in 10 chance of developing breast cancer in her lifetime.

(23) TRUE FALSE The majority of American women perform Breast Self-Examination every month.

(24) TRUE FALSE Unless breast cancer runs in her family, a woman does not need to do Breast Self-Examination (BSE).

(25) TRUE FALSE A woman does not need to get a mammogram unless her physician recommends the test to her.

PLEASE READ CAREFULLY AND ANSWER ALL OF THE QUESTIONS.

(26) What percentage best describes YOUR chance of developing breast cancer some day?

Answer from 0 to 100% _____

(27) What percentage best describes the AVERAGE woman's chances of developing breast cancer some day?

Answer from 0 to 100% _____

EVALUATION OF EACH CLASS

(1) Has the information been helpful toward a better understanding of breast cancer?

1	2	3	4	5
Of Little Help				Extremely Helpful

(2) Has the information about breast cancer been TAUGHT in an understandable fashion?

1	2	3	4	5
Confusing				Very Understandable

(3) Would you like to hear more about breast cancer?

1	2	3	4	5
Absolutely Not		Possibly		Can't wait to hear more

(4) Please feel free to add any additional comments or suggestions about the class.

_____

_____

_____

SCL—90—R

SIDE 1

INSTRUCTIONS:

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered circles to the right that best describes **HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY.** Mark only one numbered circle for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask the technician.

SEX

MALE ○

FEMALE ○

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR ___ SEP ___ DIV ___ WID ___ SING ___

DATE			ID. NUMBER	AGE
MO	DAY	YEAR		

VISIT NUMBER: _____

EXAMPLE HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	①	①	①	●	①

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1.	Headaches	1	①	①	①	①	①
2.	Nervousness or shakiness inside	2	①	①	①	①	①
3.	Repeated unpleasant thoughts that won't leave your mind	3	①	①	①	①	①
4.	Faintness or dizziness	4	①	①	①	①	①
5.	Loss of sexual interest or pleasure	5	①	①	①	①	①
6.	Feeling critical of others	6	①	①	①	①	①
7.	The idea that someone else can control your thoughts	7	①	①	①	①	①
8.	Feeling others are to blame for most of your troubles	8	①	①	①	①	①
9.	Trouble remembering things	9	①	①	①	①	①
10.	Worried about sloppiness or carelessness	10	①	①	①	①	①
11.	Feeling easily annoyed or irritated	11	①	①	①	①	①
12.	Pains in heart or chest	12	①	①	①	①	①
13.	Feeling afraid in open spaces or on the streets	13	①	①	①	①	①
14.	Feeling low in energy or slowed down	14	①	①	①	①	①
15.	Thoughts of ending your life	15	①	①	①	①	①
16.	Hearing voices that other people do not hear	16	①	①	①	①	①
17.	Trembling	17	①	①	①	①	①
18.	Feeling that most people cannot be trusted	18	①	①	①	①	①
19.	Poor appetite	19	①	①	①	①	①
20.	Crying easily	20	①	①	①	①	①
21.	Feeling shy or uneasy with the opposite sex	21	①	①	①	①	①
22.	Feelings of being trapped or caught	22	①	①	①	①	①
23.	Suddenly scared for no reason	23	①	①	①	①	①
24.	Temper outbursts that you could not control	24	①	①	①	①	①
25.	Feeling afraid to go out of your house alone	25	①	①	①	①	①
26.	Blaming yourself for things	26	①	①	①	①	①
27.	Pains in lower back	27	①	①	①	①	①
28.	Feeling blocked in getting things done	28	①	①	①	①	①
29.	Feeling lonely	29	①	①	①	①	①
30.	Feeling blue	30	①	①	①	①	①
31.	Worrying too much about things	31	①	①	①	①	①
32.	Feeling no interest in things	32	①	①	①	①	①
33.	Feeling fearful	33	①	①	①	①	①
34.	Your feelings being easily hurt	34	①	①	①	①	①
35.	Other people being aware of your private thoughts	35	①	①	①	①	①

HOW MUCH WERE YOU DISTRESSED BY.		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Feeling others do not understand you or are unsympathetic	36	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	37	0	1	2	3	4
38. Having to do things very slowly to insure correctness	38	0	1	2	3	4
39. Heart pounding or racing	39	0	1	2	3	4
40. Nausea or upset stomach	40	0	1	2	3	4
41. Feeling inferior to others	41	0	1	2	3	4
42. Soreness of your muscles	42	0	1	2	3	4
43. Feeling that you are watched or talked about by others	43	0	1	2	3	4
44. Trouble falling asleep	44	0	1	2	3	4
45. Having to check and double-check what you do	45	0	1	2	3	4
46. Difficulty making decisions	46	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	47	0	1	2	3	4
48. Trouble getting your breath	48	0	1	2	3	4
49. Hot or cold spells	49	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	50	0	1	2	3	4
51. Your mind going blank	51	0	1	2	3	4
52. Numbness or tingling in parts of your body	52	0	1	2	3	4
53. A lump in your throat	53	0	1	2	3	4
54. Feeling hopeless about the future	54	0	1	2	3	4
55. Trouble concentrating	55	0	1	2	3	4
56. Feeling weak in parts of your body	56	0	1	2	3	4
57. Feeling tense or keyed up	57	0	1	2	3	4
58. Heavy feelings in your arms or legs	58	0	1	2	3	4
59. Thoughts of death or dying	59	0	1	2	3	4
60. Overeating	60	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	61	0	1	2	3	4
62. Having thoughts that are not your own	62	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	63	0	1	2	3	4
64. Awakening in the early morning	64	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	65	0	1	2	3	4
66. Sleep that is restless or disturbed	66	0	1	2	3	4
67. Having urges to break or smash things	67	0	1	2	3	4
68. Having ideas or beliefs that others do not share	68	0	1	2	3	4
69. Feeling very self-conscious with others	69	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	70	0	1	2	3	4
71. Feeling everything is an effort	71	0	1	2	3	4
72. Spells of terror or panic	72	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	73	0	1	2	3	4
74. Getting into frequent arguments	74	0	1	2	3	4
75. Feeling nervous when you are left alone	75	0	1	2	3	4
76. Others not giving you proper credit for your achievements	76	0	1	2	3	4
77. Feeling lonely even when you are with people	77	0	1	2	3	4
78. Feeling so restless you couldn't sit still	78	0	1	2	3	4
79. Feelings of worthlessness	79	0	1	2	3	4
80. The feeling that something bad is going to happen to you	80	0	1	2	3	4
81. Shouting or throwing things	81	0	1	2	3	4
82. Feeling afraid you will faint in public	82	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	83	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	84	0	1	2	3	4
85. The idea that you should be punished for your sins	85	0	1	2	3	4
86. Thoughts and images of a frightening nature	86	0	1	2	3	4
87. The idea that something serious is wrong with your body	87	0	1	2	3	4
88. Never feeling close to another person	88	0	1	2	3	4
89. Feelings of guilt	89	0	1	2	3	4
90. The idea that something is wrong with your mind	90	0	1	2	3	4

APPENDIX G

Final Questionnaire

Bonnie Taylor, R.N., M.A.
3024 N. Kenmore
Chicago, Ill., 60657
312 935-9740

26 May 1992

Dear _____

Hope you have not forgotten who I am!! This is the final questionnaire for the Breast Cancer Study for which you agreed to participate. Once again, please answer ALL questions and return this packet to me in the envelope enclosed as soon as possible. If you would like, I will mail the results of this study to you as soon as they are available. If you did not attend the formal classes and would like to, you will have an opportunity to do so after all the final questionnaires have been returned. If you have any questions, please do not hesitate to give me a call. I greatly appreciate your continued cooperation with this study.

Gratefully yours,

Bonnie Taylor, R.N., M.A.

Please check if you:

_____ would like to attend the two, two-hour classes.

_____ would like to receive a summary of the results of this study.

(1) Since the time you agreed to participate in this study, (approximately 6-12 months ago), have you been to a physician for a Pap Test? NO _____ YES _____

(2) If yes, approximately when _____

(3) What were the results of the Pap Test? _____

_____

(4) Since the time you agreed to participate in this study, (approximately 6-12 months ago), have you had a Mammogram? NO _____ YES _____

(5) If yes, approximately when _____

(6) What were the results of the Mammogram? _____

_____

(7) If no, do you have an appointment for one? When?

_____

(8) Do you plan to get a Mammogram? NO _____ YES _____

(9) How many Mammograms have you had in your life? _____

(10) Since the time you agreed to participate in this study, have you performed Breast Self-Examination? NO _____ YES _____

(11) If yes, how often do you perform BSE? _____

_____More than once a month

_____Once a month

_____Every other month

_____Four times a year

_____Twice a year

_____Once a year

_____Not at all

(12) If you do not perform BSE, please describe what stops you?_____

(13) From the time you agreed to participate in this study, has anyone taught you Breast Self-Examination?

NO_____ YES_____

(14) If yes, who taught you: Nurse _____ Doctor_____

Other _____

(15) From the time you agreed to participate in this study, have you had a biopsy of your breasts?

NO _____ YES _____

(16) If yes, what were the results of the biopsy?

_____

(17) From the time you agreed to participate in this study, have you been to see a physician for a check-up? NO _____ YES _____

(18) If yes, what was the reason? _____

_____

(19) From the time you agreed to participate in this study, have you altered your diet in any way?

NO _____ YES _____

(20) In what way? Please check the appropriate column.

	Increased	Decreased	No Change
Calorie Intake	_____	_____	_____
Fat Intake	_____	_____	_____
Other changes	_____	_____	_____

(21) From the time you agreed to participate in this study, have you read any books related to breast cancer? NO _____ YES_____

(22) If yes, which one/ones? _____

_____

(23) From the time you agreed to participate in this study, have any close relatives been diagnosed with breast cancer? NO _____ YES _____

(24) If yes, please comment. _____

_____

(25) What percentage best describes YOUR chance of developing breast cancer some day?
Answer range from 0 to 100% _____

(26) What percentage best describes the AVERAGE woman's chances of developing breast cancer some day?
Answer range from 0 to 100%_____

(27) From the time you agreed to participate in this study, is there anything that you've done to become more informed about breast cancer? NO _____ YES _____

(28) Please comment. _____

_____

SCL—90—R

SIDE 1

INSTRUCTIONS:

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered circles to the right that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY. Mark only one numbered circle for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask the technician.

SEX

MALE ○

FEMALE ○

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR ___ SEP ___ DIV ___ WID ___ SING ___

DATE						ID. NUMBER				AGE	
MO		DAY		YEAR							

VISIT NUMBER: _____

EXAMPLE HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	①	①	①	●	①

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1.	Headaches	1	①	①	①	①	①
2.	Nervousness or shakiness inside	2	①	①	①	①	①
3.	Repeated unpleasant thoughts that won't leave your mind	3	①	①	①	①	①
4.	Faintness or dizziness	4	①	①	①	①	①
5.	Loss of sexual interest or pleasure	5	①	①	①	①	①
6.	Feeling critical of others	6	①	①	①	①	①
7.	The idea that someone else can control your thoughts	7	①	①	①	①	①
8.	Feeling others are to blame for most of your troubles	8	①	①	①	①	①
9.	Trouble remembering things	9	①	①	①	①	①
10.	Worried about sloppiness or carelessness	10	①	①	①	①	①
11.	Feeling easily annoyed or irritated	11	①	①	①	①	①
12.	Pains in heart or chest	12	①	①	①	①	①
13.	Feeling afraid in open spaces or on the streets	13	①	①	①	①	①
14.	Feeling low in energy or slowed down	14	①	①	①	①	①
15.	Thoughts of ending your life	15	①	①	①	①	①
16.	Hearing voices that other people do not hear	16	①	①	①	①	①
17.	Trembling	17	①	①	①	①	①
18.	Feeling that most people cannot be trusted	18	①	①	①	①	①
19.	Poor appetite	19	①	①	①	①	①
20.	Crying easily	20	①	①	①	①	①
21.	Feeling shy or uneasy with the opposite sex	21	①	①	①	①	①
22.	Feelings of being trapped or caught	22	①	①	①	①	①
23.	Suddenly scared for no reason	23	①	①	①	①	①
24.	Temper outbursts that you could not control	24	①	①	①	①	①
25.	Feeling afraid to go out of your house alone	25	①	①	①	①	①
26.	Blaming yourself for things	26	①	①	①	①	①
27.	Pains in lower back	27	①	①	①	①	①
28.	Feeling blocked in getting things done	28	①	①	①	①	①
29.	Feeling lonely	29	①	①	①	①	①
30.	Feeling blue	30	①	①	①	①	①
31.	Worrying too much about things	31	①	①	①	①	①
32.	Feeling no interest in things	32	①	①	①	①	①
33.	Feeling fearful	33	①	①	①	①	①
34.	Your feelings being easily hurt	34	①	①	①	①	①
35.	Other people being aware of your private thoughts	35	①	①	①	①	①

HOW MUCH WERE YOU DISTRESSED BY		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Feeling others do not understand you or are unsympathetic	36	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	37	0	1	2	3	4
38. Having to do things very slowly to insure correctness	38	0	1	2	3	4
39. Heart pounding or racing	39	0	1	2	3	4
40. Nausea or upset stomach	40	0	1	2	3	4
41. Feeling inferior to others	41	0	1	2	3	4
42. Soreness of your muscles	42	0	1	2	3	4
43. Feeling that you are watched or talked about by others	43	0	1	2	3	4
44. Trouble falling asleep	44	0	1	2	3	4
45. Having to check and double-check what you do	45	0	1	2	3	4
46. Difficulty making decisions	46	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	47	0	1	2	3	4
48. Trouble getting your breath	48	0	1	2	3	4
49. Hot or cold spells	49	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	50	0	1	2	3	4
51. Your mind going blank	51	0	1	2	3	4
52. Numbness or tingling in parts of your body	52	0	1	2	3	4
53. A lump in your throat	53	0	1	2	3	4
54. Feeling hopeless about the future	54	0	1	2	3	4
55. Trouble concentrating	55	0	1	2	3	4
56. Feeling weak in parts of your body	56	0	1	2	3	4
57. Feeling tense or keyed up	57	0	1	2	3	4
58. Heavy feelings in your arms or legs	58	0	1	2	3	4
59. Thoughts of death or dying	59	0	1	2	3	4
60. Overeating	60	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	61	0	1	2	3	4
62. Having thoughts that are not your own	62	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	63	0	1	2	3	4
64. Awakening in the early morning	64	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	65	0	1	2	3	4
66. Sleep that is restless or disturbed	66	0	1	2	3	4
67. Having urges to break or smash things	67	0	1	2	3	4
68. Having ideas or beliefs that others do not share	68	0	1	2	3	4
69. Feeling very self-conscious with others	69	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	70	0	1	2	3	4
71. Feeling everything is an effort	71	0	1	2	3	4
72. Spells of terror or panic	72	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	73	0	1	2	3	4
74. Getting into frequent arguments	74	0	1	2	3	4
75. Feeling nervous when you are left alone	75	0	1	2	3	4
76. Others not giving you proper credit for your achievements	76	0	1	2	3	4
77. Feeling lonely even when you are with people	77	0	1	2	3	4
78. Feeling so restless you couldn't sit still	78	0	1	2	3	4
79. Feelings of worthlessness	79	0	1	2	3	4
80. The feeling that something bad is going to happen to you	80	0	1	2	3	4
81. Shouting or throwing things	81	0	1	2	3	4
82. Feeling afraid you will faint in public	82	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	83	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	84	0	1	2	3	4
85. The idea that you should be punished for your sins	85	0	1	2	3	4
86. Thoughts and images of a frightening nature	86	0	1	2	3	4
87. The idea that something serious is wrong with your body	87	0	1	2	3	4
88. Never feeling close to another person	88	0	1	2	3	4
89. Feelings of guilt	89	0	1	2	3	4
90. The idea that something is wrong with your mind	90	0	1	2	3	4

APPENDIX H

Didactic Course

DIDACTIC COURSE OUTLINE

I. Introduction to General Cancer Information

II. Information Specific to Breast Cancer

- A. Incidence of Breast Cancer
- B. Risk Factors
  - 1. Age
  - 2. Family History
- C. Hormonal Risk Factors
- D. Fibrocystic Changes
- E. Life-style Factors
  - 1. Alcohol consumption
  - 2. Diet

III. Preventive Health Behaviors

- A. Physician Breast Examinations
- B. Mammography
- C. Breast Self-Examination

IV. Recommended Reading

Thank you for participating in these classes. You are all here because you know someone who is living with breast cancer. We recognize that this is not an easy task - hearing about breast cancer and dealing with this information which can increase anxiety.

Classes began with a RELAXATION TAPE.

How much do you know about breast cancer? Well, if you're like most women probably not enough. Just the slightest suggestion of these two words can bring ripples of anxiety, fear and denial into most of us. The major goal of these two classes you will be attending is to increase your knowledge about breast cancer. Specifically, increase your knowledge about your own risk and increase your habit of practicing health behaviors to minimize your risk. If you remember only one thing about breast cancer it should be that <u>your best protection is EARLY DETECTION.</u>

What causes breast cancer? We know that breast cancer develops from the abnormal growth of breast tissues. It is frustrating that at this time we do not know what causes the abnormal growth of these cells. Possible factors that may play a part in the development are HEREDITY and HORMONES. One way to help counter the frustration is to become familiar with what we DO KNOW about breast cancer. WHAT IS CANCER?

Cancer is not one disease but many different diseases. There are more than 100 different types of cancer and several different types of breast cancer. They all have one thing in common: abnormal cells that grow and replace or displace normal healthy cells.

Healthy or normal cells that make up the body's tissues grow, divide and replace themselves in an orderly fashion. This is a normal on-going process that keeps the body in good working condition. However, sometimes cells lose their ability to control their growth, by growing too rapidly and without any order. This result can lead to too much tissue and tumors are formed. These tumors can be benign or malignant.

SLIDE ONE BENIGN TUMORS

- Grow in an orderly and timely fashion.
- Are not cancerous.
- Do not spread to other parts of the body.
- Are seldom a threat to one's life.

SLIDE TWO MALIGNANT TUMORS

- Grow faster than normal cells.
- Grow in an "out of control" fashion.
- Are cancerous.
- Spread and REPLACE or DISPLACE healthy tissues and organs.

Any questions about the slides so far?

HOW DOES A TYPE OF CANCER GET IT'S NAME?

INCIDENCE

The American Cancer Society estimates that in 1991 approximately 175,000 American women will develop breast cancer. This number has increased significantly from 155,000 in 1990. This revised estimate means that the risk for developing breast cancer rises from one in ten women to one in nine women (ACS, 1991). Several explanations for this increase include:

(1) the "baby boom" generation is getting older,

(2) a longer life expectancy for women,

(3) improved techniques in mammography,

(4) increased use of early detection screening methods,

(5) to be honest, there is a true increase in incidence.

Breast cancer becomes more common as women get older. Over 70 percent of all breast cancers occur in women who are older than 50, and less than 2 percent of all breast cancer occurs before 30 years of age (Lynch, Watson and Conway, 1988). According to American Cancer Society statistics, in 1987 the average white woman's risk for developing breast cancer was about 2 percent from birth to 50 years of age and only 6 percent from birth to 70 years of age. It might be more accurate to state from 25

to 50 or 70 rather than birth, since breast cancer generally does not occur in women less than 25 years of age. Only if a woman were to live to age 110 would her risk be 10 percent ercent. More than one-third of the risk is expressed after 75 years of age and more than one-half of the risk is after 65 years of age. The average black woman's risk is a little lower, about 8 percent to age 110, but the risk is rising rapidly and approaching that of white women.

RISK FACTORS

"Risk factors" describes a term that refers to factors that are identified that make some people more susceptible than others to a particular disease. For example, people with high blood pressure have a greater chance of having a "stroke" than those with low blood pressure. Individuals who smoke have a greater chance of developing lung cancer than those who do not smoke. Individuals with a high cholesterol level have a greater chance of developing heart disease than those with low levels of cholesterol.

Before discussing specific risk factors for breast cancer, let's spend a few moments clarifying several different types of risks.

ABSOLUTE RISK is the ratio of the number of events to a total population. For example, absolute risk of breast cancer is the ratio of number of times breast cancer

occurs in the general population. It is usually discussed in two possible ways: either as the number of cases per a specified population, for example, 50 cases per 100,000; or as a CUMULATIVE risk up to a particular age. This CUMULATIVE RISK can be misleading. This is the common "1 in 10" lifetime risk for white women that is used so often.

Let's explain the "1 in 10" lifetime risk. Dr. Susan Love describes absolute risk or the "1 in 10" lifetime risk very well in her "Breast Book". First of all, it does not mean that if there are 10 women in a room that 1 of those women will get breast cancer. There are several assumptions that are made when discussing the cumulative number, that are not necessarily true for all women. The assumptions include:
(1) The absolute risk of getting breast cancer is assumed to be the same for all women (Love, 1990).
(2) It is assumed that all women will live to be 110 years of age (Seidman, Nushinshi, Gelb, et al, 1985).

What the number actually means is that IF you take 10 white women at age 25, and IF they all start with an equal risk of getting breast cancer, and IF they all live to 110, the chances are that one of them will get the disease during her lifetime. The problem with this "1 in 10 " number is that it will overestimate the risk for women with NO risk factors and underestimate for the women with risk factors (Love,1990).

SEE HANDOUT

Another method for looking at risk is ATTRIBUTABLE RISK. This concept looks at the amount of disease in the population that could be prevented by altering risk factors (Love, 1990). For example, according to Dr. Miller (1987) the total fat in one's diet may possibly account for 26-27 percent of breast cancers. Stated another way, the attributable risk is that one in four women with breast cancer possibly could have prevented the disease by altering one's eating habits. However there might still be 75 percent of breast cancers or three out of four that would not be affected by decreasing dietary fat (Love, 1990).

RELATIVE RISK is another type of risk. This is a comparison of all the incidence of breast cancer among women with a particular risk factor to women without a particular risk factor.

THE NEXT COUPLE OF SLIDES WILL SUMMARIZE THE RISK FACTORS ASSOCIATED WITH BREAST CANCER. PLEASE FOLLOW ALONG WITH THE SLIDES AND YOUR HANDOUT. SLIDE 3

MAJOR risk factors for developing breast cancer include:

(1) increasing age,

(2) history of breast cancer in a mother or sister,

(3) a previous history of cancer (although this is now thought to be a secondary risk factor).

SLIDE 4

SECONDARY risk factors include:

(1) history of breast cancer in a maternal or paternal grandmother or aunt,

(2) nulliparity (not having had children),

(3) having a first child after 30 years of age,

(4) early menarche and late menopause,

(5) history of atypical hyperplasia.

(6) moderate amounts of alcohol intake before 30 years of age.

WE WILL GO THROUGH EACH OF THESE AS WE MOVE ALONG

SLIDE 5

POSSIBLE risk factors include:

(1) obesity or high intake of animal fat,

(2) estrogen replacement therapy,

(3) radiation exposure at an early age.

It is important to keep in mind that at this time, there is no known cause of breast cancer. Presently, there are many different factors that fit into the breast cancer puzzle and that either increase or decrease a woman's chances of developing breast cancer.

FAMILY HISTORY

One of the major categories for risk factors is

genetic. If there is a family history of breast cancer, women tend to either overestimate or underestimate their chances of developing the disease. It is hoped that these classes will correct any misconceptions about your risk for breast cancer.

Dr. David Anderson at M.D. Anderson Cancer Center has identified two different types of family histories. In the first type of family, Type I, breast cancer is present in a single generation, for example, two or more sisters are affected, but their mothers and daughters are not. In the second type of family, Type II, breast cancer is present in two or more generations, for example, a grandmother and mother or a sister and mother are affected (Kelly, 1991).

In the past it was thought that there were only two kinds of breast cancer: one that is inherited and one that is not. According to Dr. Lynch and colleagues (1988) pure hereditary cancer is quite rare. Between 5 -7 percent of all breast cancers will fall into this category. Present thinking is that there is another group that appears to be more common than the family type and is called SPORADIC.

In fact, most (70 percent) of breast cancers are called SPORADIC, meaning there is no genetic or familial association that can be identified. This means that only

30 percent of patients with a diagnosis of breast cancer have a close relative with the disease. Even though this is a minority of the women with breast cancer, this is an important group because they can be identified and taught in order to increase awareness of risk and awareness of preventive health behaviors that can lead to EARLY DETECTION. Early detection leads to higher CURE rates.

The average American woman has a 10 percent or 1 in 10 chance of developing breast cancer in her lifetime. If a woman has a mother OR sister (first-degree relative) with breast cancer than her chances of developing the disease increase to 20 percent or 1 in 5 (Anderson & Badzioch, 1985). This chance is NOT greater if the sister has the disease rather than the mother. This number will depend on the mother's age and menopausal status at the time of her diagnosis and whether she had unilateral or bilateral disease (Sattin, Rubin & Webster, 1985). Generally speaking, the risk increases if the mother develops breast cancer at an earlier age (under 50), which usually means that she is premenopausal and if she developed breast cancer in both breasts.

A woman with a mother AND sister with breast cancer has a 50 percent or 1 in 2 chance of developing breast cancer in her lifetime. Because of this potential

increase in risk, women in this category may require earlier education about breast cancer which emphasizes early detection.

If a woman with a family history of breast cancer develops the disease, and if the breast cancer is found early then the chances of cure are 90 percent. There is a tendency for women with a family history of breast cancer, to develop the disease at an earlier age (between 20 -44 years of age) than that of the general population which is between (50 -59 years of age). However women with a family history of breast cancer have a survival equal to or better than that of other patients with breast cancer without a family history (Anderson & Badzioch, 1985).

One aspect to emphasize is that having a family member with breast cancer does not guarantee that you will develop the disease. If a woman has a mother with breast cancer, this does not guarantee that she will develop the disease.

It is important for women to be fully informed about their family's disease history. A first step in determining this information is to "map out" a family tree. This is called a GENOGRAM. We thought it might be an interesting and educational exercise to give you a homework assignment between these two classes.

I'm going to pass around the homework assignment. Let's go over this together so that everyone is clear about the assignment. This is an example of a Genogram. Let's talk about the page with Figure One.

First begin talking to other family members, preferably older family members and dig through old family records to determine illnesses and perhaps causes of death of past family members.

HORMONAL RISK FACTORS

The next risk factor to discuss is probably the most obvious risk factor: hormonal risk factors. We DO know that hormones play an important part in breast cancer because it's the most common type of cancer in women and is rare in men. We really DO NOT understand the specific role that hormones play, but we do know that there is a connection between age and the length of time that one menstruates. That is the longer one has periods (number of years), the more prone she is to developing breast cancer. For example, women who begin their periods before age 12 and do not begin menopause until after age 50 have a greater risk of developing breast cancer.

According to Dr. Henderson (1990) the circumstantial evidence linking changes in normal menstrual function with

the probability of developing breast cancer is overwhelming. Girls who have late onset of menarche are also likely to have a delay in having regular ovulatory cycles, and this delay may have a protective effect independent of age at menarche. The risk of developing breast cancer is almost twice as high among women who start their periods early and begin having regular cycles compared with women who have early onset of menarche and a delay of 5 years or more until the beginning of regular cycles (Henderson, 1990).

One major theory being examined is that anything that delays the age of menarche or especially the frequency of regular ovulatory cycles will decrease a woman's risk. For example, both strenuous physical activity and malnutrition are known to decrease regular ovulation. In one study the incidence of breast cancer was much lower in women who participated in high school and college athletics (Frisch, Wyshak, Albright, et al, 1985). From past studies several hypotheses or theories have emerged:

(1) events in the adolescent years may be critical in affecting the lifelong chances of developing breast cancer.

(2) Interventions that slow menarche or that decrease the frequency of regular periods throughout a woman's lifetime may substantially reduce the risk of getting breast cancer.

When we talk about HORMONES we're primarily focusing on

ESTROGENS. Estrogens are one of two hormones produced by the ovaries and are the substances that make us women, for example, estrogens help in the development of breasts.

Pregnancy can also affect the potential development of breast cancer. Women who have their first full-term pregnancy before age 20 have less risk of developing breast cancer than women who are over 30 when they have their first child. Women who have no children are also at risk, but the risk is less than women who have their children after age 30 (Lynch, Watson, Conway, et al, 1988).

At this time we have no scientific answers about how the interaction of hormones relates to breast cancer. It appears unlikely that hormones "cause" breast cancer. However there are several interesting theories that we might briefly discuss. One possible explanation is that between the time a girl begins to menstruate and the time of her first pregnancy the breast tissue is extremely sensitive to carcinogens. For example, diet, alcohol and radiation exposure appear to have an effect on breast tissue early in one's life rather than later. It may be that "developing breasts" may be more susceptible to carcinogens than breasts that are finished developing.

EXOGENOUS HORMONES

These are hormones taken externally as drugs, for example the birth control pill. THere have been over 25 studies looking at the relationship between breast cancer and oral contraceptives. The vast majority of these studies have shown no associations between use of "the pill" and development of breast cancer. One solid conclusion that CAN be drawn from all of these studies is that birth control pills offer no protection against the development of breast cancer as was once thought. However, at this time evidence supports the safety of oral contraceptive use especially when used for limited durations of 2 to 4 year periods. The one subgroup where evidence exists for an increased frequency of breast cancer is women below 20 years of age using the pill.

ESTROGEN REPLACEMENT THERAPY (ERT) FOR POSTMENOPAUSAL WOMEN

Again the same conclusion can be drawn for prolonged estrogen exposure as with oral contraceptives, that ERT does not decrease the risk of developing breast cancer. The results of the many studies reported are very controversial and make it impossible to draw any reliable conclusions. We simply do not have enough information to

properly inform women about the risks and benefits to ERT as they relate to breast cancer development. Overall the association of ERT with breast cancer is weaker than the association of ERT with endometrial cancer (Henderson, 1990). In the end, women must evaluate the risks versus benefits of ERT. For example if osteoporosis runs in her family, then taking estrogens may be very beneficial compared with the unknown risk of developing breast cancer.

FIBROCYSTIC CHANGES

Many of you may have heard the term "fibrocystic disease" or may have been told that you have fibrocystic breasts. In the past "fibrocystic disease" was a catch -all phrase used to describe all sorts of symptoms such as breast pain, swelling, tenderness, and discharge. It is an outdated term no longer in use because it is recognized that pathologically the findings in the breast are not a disease but are changes that occur to some degree in all of us. Today the preferred term used is "fibrocystic changes" which refers to both variations in the normal lumpiness of the breast and to changes that occur during the menstrual cycle.

Fibrocystic changes do not in themselves predispose an individual to an increased risk of breast cancer. The

significance of fibrocystic changes and breast cancer is that they may mask an early cancer or make it difficult to detect a cancer.

The subject of "fibrocystic disease" leads to a few myths that need to be corrected. It was once thought that eliminating caffeine from one's diet would improve or eliminate "fibrocystic disease". This is not true. Vitamin E has also been recommended to treat fibrocystic changes in the breast, however there is no sound scientific data to support either of these "so-called" solutions.

LIFE STYLE FACTORS

Life style risks such as diet, alcohol and certain drugs are attributable risks over which we have some control. An association (not a cause and effect) has been made between high fat intake and the incidence of breast cancer. For example, the rate of breast cancer in Japanese women is very low and their dietary fat is 12 to 15 percent of their calorie intake. Compare this with American women who have a greater incidence of breast cancer and their dietary fat is 40 percent of their calorie intake. However the incidence of breast cancer increases as Japanese women move to the U.S. and begin to Westernize

their diet and add fat. This picture is especially true for the daughters of Japanese-American women (Buell, 1973). One theory is that fat intake makes more of a difference when the person is young and still growing rather than in an older person (Love, 1990).

However, the relationship between high-fat intake and breast cancer is still not based in any sound scientific studies. In fact one aspect from the Japanese studies of fat content that may confuse the data is that Japanese women are typically older (16 years of age) when they begin menarche.

At this time, the fact that a low fat intake is recommended for other diseases such as heart disease suggests it's a wise idea to cut back on dietary fat.

Another life-style factor to discuss is alcohol consumption. The suggestion has been made that drinking alcoholic beverages, even in moderate amounts, may increase the risk of developing breast cancer. In fact, the link between risk of breast cancer and alcohol consumption is probably stronger than that of any other environmental correlation.

An analysis of many studies suggested that about 13 percent of all cases of breast cancer in the U.S. might be attributable to alcoholic consumption

(Longnecker, Berlin, Orza, et al, 1988). The results of this study showed that the daily consumption of 12 gm of alcohol (equivalent of one standard drink of beer, wine or liquor) was associated with a relative risk of 1.4 (a 40 percent increase in the probability of developing breast cancer). Three drinks per day would almost double a woman's risk (Henderson, 1990).

An interesting observation that came out of this major study was again the association between age and an environmental factor. For example, a woman who drank less than one alcoholic drink per week while under 30 years of age had no significant increase in breast cancer later in life (after 30), even if her alcoholic intake increased to 1 to 2 drinks per day.

In spite of this information, it is doubtful that women will become teetotalers. However, it points out another argument that early exposure to environmental factors in "developing" breast tissue may contribute to the risk of developing breast cancer later in life. Adolescence and young adulthood may be the critical time period for developing healthy habits that will contribute to a longer, healthier life. Several of these healthier habits might include:

(1) limiting the fat content in a girl's/woman's diet.

(2) Maintaining an ideal body weight.

(3) Encouraging participation in vigorous athletics, preferably several years before menstruation (periods) begin and continuing in high school and college.

(4) Alcohol consumption in excess of one or two drinks per week should be discouraged before 30 years of age.

(5) Developing preventive health behaviors for early detection of breast cancer is essential for all women. These would include: monthly breast self-examination, yearly physician breast examinations and routine mammography.

REVIEW PREVENTIVE HEALTH BEHAVIORS

(Let them do the review for you).

GO OVER THE NCI MAMMOGRAM PAMPHLET.

NOW LET'S WATCH A GOOD VIDEO WITH OUT OF DATE FASHIONS ABOUT BREAST SELF-EXAMINATION.

HOW TO MINIMIZE RISK OF BREAST CANCER

Dr. Mary Dan Eades uses the concept of the Golden Triangle to discuss the three major established methods of early detection of breast cancer. These consist of yearly physician breast examinations, monthly breast self-examinations and routine mammography. It is important to stress that all three of these methods are used TOGETHER, not one in place of another.

EARLY DETECTION is the key to increased cure rates and survival. It is important to keep in mind that the five year survival rate for localized breast cancer (Stage 1) has risen from 78 percent in the 1940's to 90 percent today (ACS, 1990). The survival rate is directly related to the size of the tumor. The smaller the tumor, the greater the chance for cure. Therefore finding a tumor at its earliest possible point is the goal of early detection screening methods.

Physical examination should occur on a yearly basis when women visit their physicians for their "Pap test". If a breast examination is not done at this time, you need to ask for one. A proper breast examination performed by a health professional should include feeling the breast and underarms with their fingers in order to detect lumps. The medical term for this is palpation.

The health care professional will also be checking for "dimpling" of the skin and any possible discharge or rash around the nipples. This is a good time to get instruction on BSE to verify that you are performing it correctly. PROPER BSE is one of the keys to early detection. Improper BSE has no preventive benefit.

BREAST SELF-EXAMINATION

Breast self-examination (BSE) is recommended by the American Cancer Society (ACS) and the National Cancer Institute (NCI) on a monthly basis for all women over age 20.

Many women are reluctant to practice BSE. Frequent comments by women include: "everything feels like a lump" or "my breasts are too lumpy" or "I can not tell what is normal or abnormal", and most common, "I don't want to check my breasts for fear I might find something". It is important to remember that all breasts are lumpy, especially before menopause. The best person to become familiar with the normal lumps and lumpiness of your breasts is yourself. The lumpiness is not abnormal, but if there is a change in the normal lumpiness, then a visit to your physician is required.

BSE is a simple and safe procedure without a financial cost to women who practice it. Women need to keep in mind that breasts come in all sizes and shapes and will even change in a woman during her lifetime. Your monthly menstrual cycles, pregnancy, childbirth, breast-feeding, age, weight, birth control pills and other hormones may change the shape, size and feel of your breasts. One of the advantages of monthly self-examination

is that each woman "gets to know" her breasts and what is normal for her and what feels abnormal.

The best time to practice BSE is 2 or 3 days after the end of your period because your breasts are less likely to be swollen or tender. If you no longer have periods, then choosing a particular day of the month, for example, the first day of the month or a birth date. Being consistent is one of the important aspects to BSE.

There is some controversy as to the benefit of practicing BSE. One major argument in favor of teaching and encouraging women to perform monthly BSE is based on a report by Huguley and Brown (1981). In a study of over 2000 women they found that the more frequently women performed BSE, the more likely BSE was successful as being the first method to detect cancer. (It is interesting to note that over 95 percent of all lumps in the breast are detected by women themselves). When cancer was discovered by BSE it was at an earlier stage than after all other methods except mammography. This finding indicates that the practice of BSE can play an important role in EARLY diagnosis of breast cancer.

There are several areas of concern surrounding the topic of BSE. Results from several surveys have found that most women know about BSE and understand it's

importance, but too few women actually practice BSE. The results of these studies found that 95 percent of women surveyed know about BSE, 66 percent of the women report practicing BSE in one year's time, and 27 percent perform monthly BSE, however only 13 percent perform BSE correctly (ACS, 1973; ACS, 1978; NCI, 1981). The majority of American women do not perform BSE. Several factors have been reported that may relate to the lack of performance of proper BSE. These include: (1) embarassment, (2) lack of confidence by women in the actual performance of BSE and in knowing the difference between normal and abnormal breast tissue, and (3) remembering to do BSE. The results of these studies help us to focus on how to make BSE a more comfortable health behavior to practice.

- Let's go through the pamphlet on BSE.
- Go over basic anatomy at this time from pamphlets.

NEXT WEEK WE WILL REVIEW THIS AGAIN AND PRACTICE FEELING WHAT AN ABNORMAL LUMP FEELS LIKE.

MAMMOGRAPHY

Mammography is a radiographic technique (an x-ray) that allows one to see the internal structure of the breast. It can detect non-palpable (unable to feel) lumps. In addition, physicians are able to detect changes in breast

tissue that may be an early clue for a cancer that might be developing by comparing a current mammogram with an earlier one. Eighty-five percent of breast cancers will be detected by mammography. Fifty percent of lumps found on a mammogram will have been too small for you or your physician to have felt.

Physicians and nurses recommend mammography because it can be very effective at finding cancers at an early stage. Unfortunately, most women do not take advantage of this preventive health behavior and as a result, their breast cancers are not found as early as one would hope. Many studies have shown that only 37 percent of women over the age of 40 have ever had a mammogram. In addition, more than half of American physicians fail to recommend routine mammograms to their women patients. If your physician does not recommend a mammogram then find one who will follow the ACS recommended guidelines.

All women between 35 and 40 years of age should have a baseline mammogram. After 40 all women should have routine mammograms every 1 to 2 years until age 50. After 50, mammography should be done every year.

PASS AROUND THE MAMMOGRAMS - POINT OUT THE LUMPS

In the past there was concern over radiation exposure from mammography. Currently, radiation doses delivered by modern techniques and equipment are so low that the benefits far outweigh the risks. The American Cancer Society requires that radiation doses delivered by mammography should not exceed one rad. However the efficiency of some facilities performing mammograms varies, so the American College of Radiology has developed a volunteer certification program to assure a safe testing. A list of certified facilities can be obtained by calling the Cancer Information Service at 1 800 4-CANCER.

Here's a description of what it's like to get a mammogram. It is requested that you not wear deodorant or powder the day of your mammogram. First of all, you undress from the waist up, put on a gown so that it opens from the front. The technician, usually a woman, places your breasts between two plastic cold plates and then some pressure is applied to flatten the breasts in order to get a good, clear picture. This will feel uncomfortable and even hurt but will only last a few seconds. Much of the discomfort can be avoided if you schedule the mammogram during the time in your monthly cycle when your breasts are least likely to be tender, sore or swollen. Usually 2 to 4 views or pictures are taken of each breast.

It generally takes a few days to evaluate the mammogram. If your physician or nurse does not call you with the results, then do not hesitate to call them to discuss the results. In fact, it isn't a bad idea to get copies of the reports and keep your own medical file at home. This will also help you to remember when to schedule your next mammogram.

APPENDIX I

Course Handout

COURSE OUTLINE

A. Course Evaluation

B. What is Cancer?

C. Family Genogram - Homework Assignment

D. Table of Average Risk of Developing Breast Cancer

E. Major Risk Factors

F. Health Behaviors to Practice to Reduce the Risk of Developing Breast Cancer.

G. Recommended Reading

OUTLINE OF SESSIONS

This is a general outline of what will be covered in each didactic session. I estimate that each class will be an hour and one-half in length.

SESSION ONE

Introduction to the course

Relaxation exercise

What is Cancer

Incidence of Breast Cancer

Risk Factors

Family History
Review homework

Preventive Health Behaviors

Review and "Debriefing"

SESSION TWO

Relaxation exercise

Review from last week

Go over homework assignment

Other Risk Factors

- Hormone Factors
- Fibrocystic Changes
- Life-style factors (Diet and Alcohol)

Overall Review and Debriefing

Post test

Future risk at any one time depends upon the age of the woman. Breast cancer becomes more common as women get older.

TABLE 1.

The Average Risk of Developing Breast Cancer in a Given Year in White American Women

AGE	RISK per YEAR
30	1 in 5,900
35	1 in 2,300
40	1 in 1,200
50	1 in 590
60	1 in 420
70	1 in 330
80	1 in 290

* adapted from Stomper, Gelman, Meyer & Gross (1990) New England Mammography Survey- 1988: "Misconceptions of Breast Cancer Incidence", Breast Disease, May.

TABLE 2.

FAMILY HISTORY and RISK OF BREAST CANCER

FAMILY HISTORY	RELATIVE RISK
None	1.0
First-degree relative	
Mother	2.1
Sister	2.1
Mother and Sister	13.6
Second-degree relative	
Grandmother	1.5
Aunt	1.5

* adapted from Sattin, Rubin, Webster and colleagues (1985) "Family History and the Risk of Breast Cancer", Journal of the American Medical Association, 252, pg. 1908.

MAJOR RISK FACTORS

FOR DEVELOPING BREAST CANCER

PRIMARY RISK FACTORS

- INCREASING AGE
- HISTORY OF BREAST CANCER IN A MOTHER OR SISTER
- PREVIOUS HISTORY OF CANCER

SECONDARY RISK FACTORS

- HISTORY OF BREAST CANCER IN MATERNAL or PATERNAL GRANDMOTHER or AUNT
- HAVING FIRST CHILD AFTER 30 YEARS OF AGE
- NOT HAVING HAD CHILDREN
- EARLY MENSTRUATION and LATE MENOPAUSE
- HISTORY OF ATYPICAL HYPERPLASIA
- MODERATE TO HIGH ALCOHOL CONSUMPTION
- HISTORY of CANCER of the ENDOMETRIUM OVARY or COLON

POSSIBLE RISK FACTORS

- OBESITY or HIGH INTAKE OF ANIMAL FAT
- ESTROGEN REPLACEMENT THERAPY

PREVENTIVE HEALTH BEHAVIORS

Pamphlets from the American Cancer Society and National Cancer Institute will be given to each woman and gone through in class.

BREAST SELF-EXAMINATION (BSE)

MAMMOGRAPHY

HORMONAL RISK FACTORS

(1) The longer a woman has periods (number of years) the more prone she is to developing breast cancer.

(2) Women who have their first full-term pregnancy before age 20 have less risk of developing breast cancer than women who are over 30 when they have their first child.

EXOGENOUS HORMONES

BIRTH CONTROL PILLS

(1) Safe to use in 2-4 year periods of time.

(2) As of present research findings they do not cause breast cancer.

(3) Birth control pills do not protect from breast cancer.

(4) Women under age 20 using the birth control pill have an increased risk of developing breast cancer.

LIFE STYLE FACTORS TO HELP REDUCE RISK

(1) Maintain an ideal body weight.

(2) Limit the fat content in your diet.

(3) Encourage athletics in girls and young women preferably before menstruation begins.

(4) Discourage drinking more than 1-2 drinks per WEEK in women under 30 years of age.

(5) Practice EARLY DETECTION guidelines for breast cancer.

RECOMMENDED READING

Baker, Nancy (1991) Relative Risk: Living with a Family History of Breast Cancer. N.Y., N.Y.: Viking Press.

Brinker, Nancy (1990) The Race is Run One Step at a Time: My Personal Struggle with Breast Cancer. New York, New York: Simon and Schuster.

Dackman, Linda (1990) Up Front: Sex and the Post-Mastectomy Woman New York, New York: Viking Press.

Eades, Mary Dan (1991) If it Runs in Your Family: Breast Cancer New York, New York: Bantum Books.

Kahane, Deborah (1990) No Less A Woman: 10 Women Shatter the Myths of Breast Cancer. New York, New York: Prentice-Hall.

Love, Dr. Susan, M.D. (1990) Dr. Susan Love's Breast Book Reading Massachusetts: Addison-Wesley.

APPENDIX J

Homework Assignment

GENOGRAM

A genogram is a visual picture drawn with symbols to help look at our family's roots. This homework assignment is given to help you understand your family's health picture. Specifically, we want to help you understand your own inherited risk for breast cancer. We will use the standard genogram symbols. In addition to the basic symbols, you may want to draw a double line under your own symbol to distinguish yourself from the rest of your family. When you've finished drawing the skeleton of your family tree, you'll have a diagram that looks similar to Figure 1 in this packet. For the purpose of this homework assignment, please fill in family cancer histories, especially breast cancers. After the classes you may want to go back and fill in other health histories such as heart disease or diabetes. We will go over the Genograms in the second class, so in order to get the most of the class, please come with the assignment finished.

VITA

The author, Bonnie M. Taylor, was born June 12, 1948 in Chicago, Illinois. She became a Registered Nurse in 1969 following graduation from Little Company of Mary School of Nursing. In 1980, Mrs. Taylor received a Bachelor of Science degree in Health Science from the College of St. Francis. In 1989, Mrs. Taylor received a Master of Arts degree in Counseling and Educational Psychology from Loyola University.

Mrs. Taylor has been employed in a variety of positions at several Chicago area hospitals including: Medical and Coronary Intensive Units at Little Company of Mary Hospital, Surgical Intensive Care Unit at Columbus Hospital and Kidney Transplant and Hemodialysis Unit at Rush-Pres-St.Luke's Medical Center. The most special position to her was that of Oncology Nurse with Dr. Janet Wolter in the Section of Medical Oncology at Rush Medical Center where she practiced from 1973-1986.

In addition to finishing her doctoral studies at Loyola, Mrs. Taylor serves on the Woman's Board of Rush Medical Center and on the Board of Y-ME National Organization for Breast Cancer Information and Support.

PUBLICATIONS and ABSTRACTS

Bonomi, P., Mladineo, J., Morrin **(Taylor, B.)**, Wilbanks, G. & Slayton, R. (1979). Phase II trial of hexamethylmelamine in ovarian carcinoma resistent to alkylating agents. Cancer Treatment Reports 63, 137-138.

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APPROVAL SHEET

The dissertation submitted by Bonnie M. Taylor has been read and approved by the following committee:

Dr. Gloria J. Lewis, Director
Associate Professor, Counseling and Educational Psychology, Loyola University of Chicago

Dr. Jack Kavanagh
Chairperson and Professor, Counseling and Educational Psychology, Loyola University of Chicago

Dr. Carol Harding
Associate Professor, Counseling and Educational Psychology, Loyola University of Chicago

Dr. Katherine Billingham
Private Practice, Chicago, Illinois

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is, therefore, accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

November 15, 1993
Date

Director's Signature