The Psychological Impact of Maternal History of Breast Cancer

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THE PSYCHOLOGICAL IMPACT OF MATERNAL HISTORY

OF BREAST CANCER

by

Bonnie M. Taylor

A Thesis Submitted to the Faculty of the Graduate School of Loyola University of Chicago in Partial Fulfillment of the Requirements for the Degree of Master of Arts

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CHAPTER I

INTRODUCTION

Breast cancer is the leading cause of cancer death in women in the United States and the most prominent cause of death for women 35-54 years of age (Goodman, 1987). Breast cancer is slowly increasing in incidence and prevalence. In 1963 the incidence of breast cancer was 1 in every 18 women with an estimated life span of 72 years (Shimkin, 1963). An estimated 130,000 new cases of breast cancer will occur in the U.S. during 1987 (ACS, Facts & Figures, 1987). One in 10 women in her life time will develop breast cancer. Of those new cases it is estimated that 41,300 deaths (41,000 women and 300 men) will occur. Only lung cancer comes close to breast cancer as a cause of death in women.

Risk Factors

The principle risk factors for breast cancer include family history and menstrual and reproductive history (Harris, Hellman, Canellos & Fisher 1985). Clearly, the most major 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.

This risk is further increased if the relative was 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).

Menstrual factors are another risk factor with association to the functioning ovary. 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. In addition, women who have an early menarch and those who have a late natural menopause appear to have an increased risk (Harris, Hellman, Cannelos & Fisher, 1985).

A strong association exists between breast cancer and a woman's age at the time of her first full-term pregnancy. 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). Women who bear their first child after age 30 actually have significantly higher risk than do those who remain nulliparous (Henderson, Pike & Gray, 1981).

There is an association between a woman's age and the occurrence of breast cancer. 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).
Early Detection

The five-year survival rate for localized breast cancer has risen from 78% in the 1940's to 90% today (ACS, Facts & Figures, 1987). 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, mammography and breast-self examination (BSE). 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 personnel and BSE is advised especially in younger women.
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 sample of women toward whom little attention has been directed, that is toward daughters who have a maternal history of breast cancer.
The Health Belief Model

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).

Specifically, the HBM consists of several dimensions. It predicts that preventive health actions would more likely be performed by individuals who (1) feel threatened by a disease; (2) perceive the benefits of the preventive action to outweigh the cost of doing such action; (3) are exposed to some behavioral cues to action; and (4) all of these are modified by a set of demographic and social factors. This model has been modified by Becker and his colleagues (Becker, 1974; Becker & Maimon, 1975) to account for additional types of health-related behaviors such as compliance to therapeutic treatments.

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.

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 Barie (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 the particular illness (such as having a high risk for breast cancer) and (2) by an individual's perceptions of the severity and the consequences of getting a particular illness, (such as, living with a mother who has gone through treatment for breast cancer). These two factors, the susceptibility and the severity comprise the perceived threat of the disease. Once an individual
identifies the threat of a disease, health behaviors are evaluated in terms of their potential benefits in reducing the threat against the "barriers to action" or costs. A cue to action becomes necessary to perform the appropriate health behavior. For example, finding a breast lump (cue) may contribute to a perceived threat of disease. Seeing a physician (an appropriate behavior) can reduce this perceived threat.

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 daughters 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 (Disch, 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 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 this lack of investigation, it seems timely to look at the daughters of women with breast cancer. Since little is known concerning their awareness of risk, the value they place on health and whether or not they practice health-protective behaviors, a 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, value of health, and 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 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) value their health,
(2) view themselves at risk and (3) demonstrate behaviors to minimize the risk. However this hypothesis has never been tested. The purpose of this controlled descriptive study was to identify in women with a maternal history of breast cancer (1) an awareness of the value of health, (2) to identify an awareness of the risk to self and if this awareness existed, (3) to denote any behaviors that might minimize their risk.

Summary

Chapter One highlights the knowledge of breast cancer including incidence, risk factors and early detection and screening for the disease. 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 cancer on family members with specific emphasis on the psychosocial perspectives of children, specifically daughters who have a maternal history of breast cancer.

Chapter Three will include the methodology comprising the design, subject selection, instrumentation, procedural details and treatment of the data from the questionnaires and interviews.

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 counseling and future research.
CHAPTER II

REVIEW OF THE LITERATURE

Estimates have been made that cancer will affect approximately 3 out of 4 families over the next few years (ACS, Facts & Figures, 1987). Although most individuals with cancer live with their families and spend most of their time at home, the literature has often limited its focus to the individual with cancer, neglecting the emotional effects of cancer on family members. This review of the literature will focus primarily on the psychosocial impact of breast cancer on the family, spouse/partner, and the children whose parent has breast cancer.

Psychosocial Impact of Breast Cancer on the Family

In her comprehensive review of the literature on the impact of cancer on the family, Northouse (1984) cites specific problems and details three phases that families move through during the course of a patient's illness.

During the initial phase of cancer, family members feel excluded from care, have difficulty communicating with medical staff and experience considerable emotional tension. In the adaptation phase family members have problems with lifestyle changes, meeting the needs of the well family members and living with uncertainty. In the terminal phase family members experience role strain, communication problems, especially on the subject of death and feelings of loss.
A study by Cassileth, Lusk, Strause, Miller et al, (1985) discussed potential differences in coping issues between the person with cancer and their family. In this broad and descriptive study the authors compared psychological status and attempted to discover differences in psychological distress between persons with cancer and their matched relatives.

Self-report tests of anxiety, mood disturbance and mental health were given to two hundred one subjects with varying type of cancers and their next-of-kin. Despite wide variation among individuals, the psychological status of patients was closely correlated with that of their families. The study suggests that supportive interventions for the person with cancer and for their relatives should be beneficial if either or both demonstrate psychological distress.

Vess, Moreland & Schwebel (1985) studied the impact of multiple cancer diagnoses on the reassignment of roles within the family and attempted to analyze the process of role change throughout the family life cycle. Family and marital self-report instruments were given to 30 women and 24 men in 54 families. An audiotaped, semistructured interview was conducted with both spouses in 26 families and with one spouse in 23 families; no interviews were conducted in the remaining 5 families. The results indicated that the spouses' communication patterns strongly influenced how well roles were enacted, the amount of role strain and role conflict and the level of cohesion and conflict in the family. The method that the family used for reassigning roles also significantly influenced how well roles were
performed and the level of cohesion in the family (Vess, Moreland & Schwebel 1985b). In this study open communication allowed spouses to negotiate more effectively in the reassignment of roles which resulted in less role strain and conflict. The openness allowed increased discussion of feelings and strengthened emotional support which allowed for greater family cohesion and less family conflict.

However, a descriptive study by Thorne (1985) disputes the role of such open communication. The author used phenomenological theory and qualitative methods to gather perspectives from eight families living with multiple types of cancer who participated in repeated intensive interviews. Field notes and verbatim transcripts of these interviews were analyzed and interpreted. The author concluded that there were discrepancies between family and health care professionals in basic assumptions about effective and ineffective coping styles. For example, health care professionals assume that open communication is more desirable than silence. However Thorne (1985) reported that some family patterns do not include verbalizing feelings, but rather to accept and "ignore" the emotional aspects of an illness. If such strategies have been in place for past family experiences and are consistent, understood and shared by all family members, then interfering with their sense of normalcy may not be appropriate.

An article by Welch (1981) described the results of an exploratory study identifying family coping issues during the cancer experience. Forty-one family members of adults with cancer completed a 30-item Likert format Family Coping Strategies questionnaire, which
was compiled by the author as a result of pilot study findings. A rank-ordering questionnaire entitled Specific Family Needs was also completed, which prioritized helpful nursing interventions for family members. The author concluded that the successful improvement in delivery of nursing care to the person with cancer had an indirect but important effect on improving family coping strategies. For example, it appeared that the most effective nursing intervention was not one focused on the family's particular need but rather one focused on the patient's needs so that the family was reassured that the patient was receiving the best possible nursing care. This alleviated the family's apprehension (Welch, 1981).

Another study by Welch (1982) investigated the process of anticipatory grief in family members of adults with cancer. Forty-one family members, coping with all stages of illness as well as a variety of treatment modalities, completed a 12-item questionnaire compiled from Faschingbauer Texas Inventory of Grief (Faschingbauer, DeVaul & Zisook, 1977). Subgroups of family members with high degrees of unresolved grief included: 1- family member's whose relative received treatment on a specialized oncology unit; 2- those who reported a sense of pre-discharge panic; 3- those who reported continued periods of crying at the thought of the family member having cancer; 4- family members of persons undergoing bone marrow transplantation. When a family member had previously lost another relative to cancer, total grief scores were significantly lower. Elderly family members also had lower grief scores (Welch, 1982).
Wellisch, Mosher & Van Scoy (1978) discussed the structure and purposes of a multiple family therapy group for individuals living with cancer and their families. This descriptive study reported several of the groups' purposes which included (1) improving communication between the person with cancer and their family and with their physicians; and (2) developing coping strategies to better deal with the impact of everyday living with cancer.

Cohen & Wellisch (1978) discussed the psychosocial management of families with a chronic or terminally ill person with cancer. According to Cohen because of recent advances in medical treatment, cancer has changed from an acute to chronic catastrophe. The family system of a person with cancer moves into a state of "limbo" where interactions, plans and socio-economic realities are continually imbalanced and ever-changing. In their paper, the authors presented two case reports describing family therapy interventions based on structured family therapy theory. Family coping styles were examined; and therapists' strategies and pitfalls were described (Cohen and Wellisch, 1978).

A new approach by Kelly (1987) described risk counseling for relatives of individuals with cancer. It presents the various aspects of cancer risk analysis which provides information about the social, scientific and medical factors that can affect individuals who have a relative with cancer. The premise of the service is that accurate information is power. 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 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).

Psychosocial Aspects of Cancer on the Spouse/Partner

Surprisingly, there are only a few studies in the literature looking at specific family members. Gotay (1984) examined the views of individuals diagnosed with cancer and their spouses during the early and advanced stages of the illness. Several factors were evaluated in 112 individuals diagnosed with cancer and their spouses including: problems, coping mechanisms and problem resolutions. The most common concern for all involved was the disease itself. Overall, the similarities among reactions of patients and their mates in the early and the advanced-stages of the disease were more striking than their differences. This was found in spite of the early stage disease being virtually 100 percent curable with the women being diagnosed only two weeks prior to the interviews. The author suggested that health-care providers be alert to the distress caused by the diagnosis of cancer, even if the outcome may be cure (Gotay, 1984).

Wellisch, Mosher & Van Scoy (1978) highlighted topics that presented in a family therapy group. The authors observed that husbands and wives coping with the impact of mastectomy occupied a significant portion of the groups time. Through clinical observations
and self-reports of the group participants, the authors observed that most husbands are very anxious and concerned by the effects of a spouses' mastectomy; but a certain subgroup of husbands have had a great deal of difficulty coping; will deny any problems and are unable to cope with or be supportive to their spouses' problems with self-image. Other research has found that spouses experience high levels of sleep disorders, eating disorders and work difficulties during the period of their wives' hospitalization (Wellisch, Mosher & Van Scoy, 1978).

Although some people experience mastectomy as the beginning of the end of the relationship (Wellisch, Mosher & Van Scoy 1978), other people have reported that their marital relationships have improved as a result of increased closeness due to the stress of the breast cancer (Grandstaff, 1976). However most marriages will return to preoperative levels of closeness and satisfaction (Ervin, 1973).

Another descriptive study looking at the effects of mastectomy on 24 male spouses was done by Sabo, Brown and Smith (1986). The authors explored the psychosocial aspects of 24 men and their reactions and adjustments to mastectomy by using an in-depth interview and questionnaire with clinical observations of a multisession men's support group of which 6 of the 24 men participated. The study found that men placed a high priority on their wives' adjustment but kept their own feelings at bay. The men adopted the role of "protective guardian" during their wives' hospitalization which helped foster denial as a coping mechanism, and which later blocked communication between the spouses. Repeated measures analysis of the questionnaire
data indicated that support members became significantly more communicative with spouses about mastectomy issues than did control group members. These quantitative findings paralleled the clinical observations.

Another study by Wellisch (1981) indicated that male partners who are more involved in decision-making and hospital visitation are more supportive and cope better themselves. In fact, the finding suggests that most couples (approximately 80%) will cope well, however the authors noted four categories of men who have difficulties in providing their partners with effective support. These include (1) men with overt psychopathology such as manic-depressive illness; (2) men with character disorders such as chronic infidelity, alcohol and drug abuse; (3) men who are so dependent on their partners that they cannot tolerate a reversal of roles in which the woman becomes the dependent partner; and (4) men who are clinically unable to communicate with their partners about emotional issues.

Baider, Rizel & De Nour (1986) attempted to gather information about the adjustment of two different types of primary treatments for the diagnosis of breast cancer. Specifically looking at the adjustment to less surgery, i.e. lumpectomy, compared to the adjustment to more surgery, i.e. mastectomy. The authors looked at adjustment, personality and family relations of thirty-two women, postlumpectomy as well as the adjustment of their husbands and compared them to a matched group of thirty-two women, postmastectomy and their husbands. The results indicated that within the postlumpectomy group no differences were found on depression and
anxiety between husbands and wives, however, in the postmastectomy group the women were significantly more depressed and anxious than their husbands. Regarding the adjustment issues, there were no differences found between the two groups of women and their husbands.

Lichtman, Taylor & Wood (1987) looked at social support and marital adjustment after breast cancer. They conducted interviews with 78 women and 62 "significant others", which included 46 husbands, and other close family members, to assess perceptions of social support following the diagnosis of breast cancer. Results of this extensive study suggest that, in general, women with breast cancer feel supported after the diagnosis by people with whom they have close relationships. However, despite overall perceptions of support, communication difficulties do exist. For example, patients saw the cancer as an on-going threat, whereas family members, usually the husband, preferred to view the disease as a crisis with an end. Second, significant others often believe that discussing recurrence or death will not be in the patient's best interest. Third, husbands felt that they could not discuss their concerns and feelings about the disease with their wives, who are generally their chief confidante. Overall, marital satisfaction had remained the same or improved following the diagnosis and treatment of breast cancer. Husbands as a group are more satisfied with their marriages than were their wives. One unexpected finding was that patients perceived their husbands as suffering as much during the cancer experience as they themselves. Factors contributing to successful marital adjustment were (1) if the partners expressed satisfaction with the relationship before the
cancer. (2) if the surgery was less severe (lumpectomy) and (3) if the husbands reacted supportively after the diagnosis. Overall, the majority of patients in this study (three-fourths) reported continued warm and supportive relationships with family and friends.

The Psychosocial Impact of Cancer on the Children

The above review has primarily focused on adult populations. An area in the psychological literature that has been neglected is that of the impact of breast cancer on the patient's relationship with her children.

Wellisch, Mosher & Van Scoy (1978) observed that children who have a parent with cancer have frequently attended their family therapy group sessions. The authors found that the children are very reactive to cancer in a parent but are far less verbal than adults. In younger children reactions observed included regressive behavior in many forms: temperamental moods, loss of bladder control, drawing very aggressive pictures and having problems in school (Wellisch, Mosher & Van Scoy, 1978).

The stresses for adolescents whose parents have cancer can also be extremely intense. The authors discussed the developmental phase of adolescence, specifically 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. This was a retrospective clinical account of six adolescents and their need for psychological interventions because of problems which occurred prior to the diagnosis 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 the family from the cancer on to their own problems. The author 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" (pg. 230) before they felt adequately ready to do so.

Berman, Cragg & Kuenzig (1988) assessed the reactions of ten adolescents and their reactions to the death of a parent from 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 and death. Similar reporting of important events like the diagnosis, death and funeral were found between the adolescent and parent. However on sources of support there was less agreement: parents identified physicians and school personnel, 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 & Kuenzig, 1988). Clearly, this retrospective, descriptive study suggests a need for health care professionals to
become more aware and involved in the needs of the entire family when caring for patients with cancer.

Rosenfeld, Caplan, Yaroslavsky, Jacobowitz et al (1983) reported on a pilot retrospective, exploratory study from Isreal of eight adolescent daughters whose mothers had breast cancer. Two Israeli-born women, a clinical psychologist and a pediatrician training in child psychiatry interviewed the girls, took detailed notes and afterwards filled out an expanded questionaire form. Four research team members (two psychiatrists and two psychologists) assessed the written questionaire forms and arrived at a consensus on each item, (there were few disagreements in the assessment). The authors reported that "most girls were significantly upset and felt inadequately supported during periods of peak stress caused by the illness and its treatment". However in contrast to Wellisch's (1979) six adolescents, none of the girls reacted in a disorganized way or acted out with maladaptive behavior either during the acute phase or at any time afterwards.

Kelly (1980) used a semistructured interview designed to ilicit 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 subject said 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 subjects were concerned about risk, they had only vague and sometimes incorrect information about the significance of the risk (Kelly, 1980).
Lichtman, Taylor, Wood, Bluming et al (1984) describes a study in which 78 patients with breast cancer were interviewed 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 poorer prognosis, more severe surgery, poorer psychological adjustment, and to a lesser degree more difficulty with chemotherapy or radiation therapy were more likely to have problems with their children. The mothers' relationship with their daughters were at a 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 the women studied reported having problems with their sons. 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.

The following table, used with permission from a review article by Northouse (1984), illustrates descriptive and case studies that have examined many interactions of cancer and family variables. The table has been revised and updated and supplies a brief synopsis of the literature on cancer and the family and includes the limited number of studies done specifically related to the daughters of women with breast cancer.
<table>
<thead>
<tr>
<th>Study</th>
<th>Subjects</th>
<th>Phase of Illness</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyk &amp; Sutherland (1956)</td>
<td>38 colon cancer patients</td>
<td>Initial and Convalescent</td>
<td>Spouses play a major role in patients' adaptation.</td>
</tr>
<tr>
<td>Irwin &amp; Meier (1973)</td>
<td>20 family members of cancer patients</td>
<td>Terminal</td>
<td>Both family members and professionals ranked items related to informing family members about the patient highest.</td>
</tr>
<tr>
<td>Hampe (1975)</td>
<td>27 spouses of cancer patients</td>
<td>Terminal</td>
<td>Only 15% of the spouses perceived support from professionals.</td>
</tr>
<tr>
<td>Freiholer &amp; Felton (1976)</td>
<td>25 cancer patients</td>
<td>Terminal</td>
<td>Most desired nursing behaviors were related to physical needs of patients.</td>
</tr>
<tr>
<td>Rose (1976)</td>
<td>26 family members of cancer patients</td>
<td>Terminal</td>
<td>Family members were the primary care givers for physical and emotional needs.</td>
</tr>
<tr>
<td>Lieber, et al. (1976)</td>
<td>38 cancer patients</td>
<td>Adaptation (advanced stage)</td>
<td>Patients and spouses reported increased desires for physical closeness.</td>
</tr>
</tbody>
</table>
Table 1 (continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Subjects</th>
<th>Phase of Illness</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giacquinta (1977)</td>
<td>100 families of cancer patients</td>
<td>All phases</td>
<td>Delineates four stages that family moves through from time of diagnosis to death.</td>
</tr>
<tr>
<td>Vachon. et al. (1977)</td>
<td>73 widows of cancer patients</td>
<td>Terminal</td>
<td>Widows of cancer patients experienced more distress than widows of cardiovascular patients.</td>
</tr>
<tr>
<td></td>
<td>51 widows of cardiovascular patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohen, et al. (1977)</td>
<td>29 family members of cancer patients</td>
<td>Terminal</td>
<td>The more family members were able to communicate with one another, the greater their later adjustment.</td>
</tr>
<tr>
<td>Cancer Care Inc. (1977)</td>
<td>40 well-parents reporting on their children</td>
<td>Adaptation (advanced stage)</td>
<td>Behavioral problems in the children were related to the nature of the parent's illness and the parent's reaction to it.</td>
</tr>
<tr>
<td>Krant &amp; Johnston (1977-1978)</td>
<td>126 family members of cancer patients (spouses, children, siblings)</td>
<td>Terminal</td>
<td>Family members had difficulty discussing death and also had little communication with physician.</td>
</tr>
</tbody>
</table>
Table 1 (continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Subjects</th>
<th>Phase of Illness</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellisch, et al. (1978)</td>
<td>31 husbands of mastectomy patients</td>
<td>Initial-Adaptation</td>
<td>Critical factors related to post-mastectomy adjustment were the husband's involvement in decision making and the quality of the relationship before illness.</td>
</tr>
<tr>
<td>Wessisch. (1979)</td>
<td>6 adolescents whose female parent has breast cancer</td>
<td>2 Terminal, 4 Interval, Multiple diagnoses</td>
<td>Because changes in family roles can be traumatic, interventions should be crisis-reducing, enabling adolescents to grow.</td>
</tr>
<tr>
<td>Kelly (1980)</td>
<td>39 women with maternal Hx of breast cancer</td>
<td>All phases</td>
<td>Counseling daughters with maternal Hx of breast cancer will help obtain better health care; and decrease anxiety.</td>
</tr>
<tr>
<td>Putnam, et al. (1980)</td>
<td>44 cancer patients, 44 family members</td>
<td>Terminal</td>
<td>Half of the patients and half of the family members expressed a preference for the patient to die at home.</td>
</tr>
<tr>
<td>Hinton (1981)</td>
<td>80 cancer patients, 80 spouses</td>
<td>Terminal</td>
<td>Marital partners reported little discussion of the patient's impending death.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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</tr>
<tr>
<td>Grobe, et al. (1981)</td>
<td>27 cancer patients, 28 family members, 29 family members of deceased patients.</td>
<td>Terminal</td>
<td>Patients and family members reported needs to learn more in the area of physical care of the patient.</td>
</tr>
<tr>
<td>Googe &amp; Varricchio (1981)</td>
<td>15 cancer patients, 15 family members</td>
<td>Terminal</td>
<td>Patients and family reported needs in the area of providing physical care.</td>
</tr>
<tr>
<td>Gould &amp; Toghill (1981)</td>
<td>26 relatives of cancer patients</td>
<td>Not Specified</td>
<td>In all routine instances the relatives were told the cancer diagnosis before the patient.</td>
</tr>
<tr>
<td>Edstrom &amp; Miller (1981)</td>
<td>8 families of cancer patients</td>
<td>Adaptation</td>
<td>Family members reported needs in physical care area and in dealing with chronic illness.</td>
</tr>
<tr>
<td>Stedeford (1981)</td>
<td>41 couples (all but one patient had cancer)</td>
<td>Terminal</td>
<td>Couples reported dissatisfaction with communication when told too little information or were told information or were told information in an abrupt manner.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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</tr>
<tr>
<td>Wellisch. (1981)</td>
<td>31 partners of mastectomy patients.</td>
<td>All phases</td>
<td>Most couples cope well. However four categories of men have difficulty providing support to their wives. Different problems exist for adolescents: changes in family role &amp; responsibility, and acting out.</td>
</tr>
<tr>
<td></td>
<td>40 families with 88 children having a cancer parent (half had mothers with breast cancer)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skorupka &amp; Bohnet (1982)</td>
<td>20 primary caret givers</td>
<td>Terminal</td>
<td>Nursing behaviors directed toward patient were ranked higher than those toward family.</td>
</tr>
<tr>
<td>Bond (1982a)</td>
<td>107 relatives of cancer patients</td>
<td>Initial-Adaptation</td>
<td>Family members had little communication with either nurses or physicians.</td>
</tr>
<tr>
<td>1982b)</td>
<td>108 relatives of cancer patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vachon, et al. (1982)</td>
<td>162 widows (45% were cancer widows)</td>
<td>Terminal</td>
<td>The majority of subjects had high distress levels one month after spouse's death.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Welch (1982)</td>
<td>41 family members of multiple cancer Dx</td>
<td>All stages</td>
<td>Anticipatory grief, its normal time periods &amp; varying degrees of intensity are discussed. In addition family members stated that personalized patient care was a most helpful intervention.</td>
</tr>
<tr>
<td>Wellisch, et al. (1983)</td>
<td>447 home-bound married persons with cancer</td>
<td>All stages</td>
<td>Families of older male patients with lung cancer felt more overwhelmed &amp; depressed than other families. Families of younger patients with cervical cancer were more likely to have difficulties in the role shifts mandated by the illness.</td>
</tr>
<tr>
<td>Rosenfeld, et al. (1983)</td>
<td>8 adolescent daughters of mothers with breast cancer</td>
<td>All stages</td>
<td>Girls were significantly upset &amp; felt inadequately supported during periods of peak stress caused by the illness and its treatment of their mothers.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Speigel, et al.</td>
<td>58 women with metastatic breast cancer</td>
<td>Metastatic breast cancer</td>
<td>Optimal adjustment is facilitated among families high in willingness to share feelings, low in expressed conflict &amp; low in moral-religious orientation.</td>
</tr>
<tr>
<td>(1983)</td>
<td></td>
<td></td>
<td>Most relationships with children were strong &amp; grew stronger. Problems with children were more likely when patient had poorer prognosis, more severe surgery, poorer, psychological adjustment; 17% of patients reported that daughters were fearful, withdrawn, hostile or rejecting; only 8% had problems with sons.</td>
</tr>
<tr>
<td>Lichtman, et al.</td>
<td>78 women with breast cancer</td>
<td>All stages</td>
<td></td>
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<tr>
<td>(1984)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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</tr>
<tr>
<td>Gotay (1984)</td>
<td>Early cervical cancer: 42 women 19 mates</td>
<td>Early &amp; Advanced Stages</td>
<td>Most common source of concern was the disease. Coping strategies varied with the stage: information seeking common in early stage &amp; religious faith cited by advanced stage groups. Overall similarities among reactions of both stage patients &amp; mates were more striking than differences.</td>
</tr>
<tr>
<td></td>
<td>Advanced breast or gynecological cancer: 31 women 20 mates</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lewis, et al. (1985)</td>
<td>126 families with mothers with breast cancer; &amp; 43 women and mates</td>
<td>Non-metastatic breast cancer</td>
<td>Multidimensional view of family's experience is needed when giving information, emotional support and interpreting, remembering that family is dealing with more than the issue of breast cancer.</td>
</tr>
<tr>
<td>Wellisch (1985)</td>
<td>All Stages of breast cancer</td>
<td></td>
<td>Review of selected lit discussing 1) interactional themes of patients secondary to breast cancer; 2) impact on social support &amp; support of spouse; 3) impact of breast cancer on parent-child relationship.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Cassileth, et al. (1985)</td>
<td>201 patients and their matched relatives</td>
<td>All stages of multiple diagnoses</td>
<td>Despite large individual variation, psychological status of patients and matched relatives was closely correlated. Supportive interventions for patient or relative should benefit both. Patients and relatives involved with palliative care are more in need of psychological assistance.</td>
</tr>
<tr>
<td>Thorne (1985)</td>
<td>8 families interviewed as a group</td>
<td>All stages of multiple diagnoses</td>
<td>Families might need to perceive themselves not in crisis. Social isolation was expected but not observed. Families need to give as well as receive. Coping styles that families found successful did not conform to professionals view of successful adaptation.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Vess, et al. (1985)</td>
<td>54 patients</td>
<td>All stages of multiple diagnoses</td>
<td>Spouses communication patterns strongly influenced how well roles were enacted, amount of role strain &amp; role conflict &amp; level of cohesion &amp; conflict in family.</td>
</tr>
<tr>
<td></td>
<td>30 women</td>
<td></td>
<td>Follow-up to previous study found that families who used 1) achieved rather than assigned role-assignment method prior to cancer; 2) families with older children who could adopt expanded role functions; 3) families with more interspousal communication experienced less disruption, less role conflict &amp; less role strain over time.</td>
</tr>
<tr>
<td></td>
<td>24 men</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>(All were parents &amp; spouses)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vess, et al. (1985)</td>
<td>54 married patients &amp; spouses with children at home. 5 months later 29 of 45 surviving patients &amp; spouses</td>
<td>All stages of multiple diagnoses</td>
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<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Green (1986)</td>
<td>27 Canadian families:</td>
<td>All stages of breast cancer</td>
<td>Women carried disproportionate &amp; of household duties prior to diagnosis. Although other family members assumed more duties during treatment and recovery period, distribution still skewed toward women. Within a year pre-diagnosis duties returned with women carrying out most of household activities.</td>
</tr>
<tr>
<td></td>
<td>27 women</td>
<td></td>
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<tr>
<td></td>
<td>18 partners</td>
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</tr>
<tr>
<td>Baider, et al. (1986)</td>
<td>32 post-lumpectomy</td>
<td>All breast cancer</td>
<td>Postlumpectomy group: no differences between wives/husbands on depression &amp; anxiety</td>
</tr>
<tr>
<td></td>
<td>- 25 women</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- 21 spouses</td>
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<tr>
<td></td>
<td>32 post-mastectomy</td>
<td>Stages 1 &amp; 2</td>
<td>Postmastectomy group: women were significantly more depressed &amp; anxious than husbands. Both groups: husbands less satisfied than wives with treatment received.</td>
</tr>
<tr>
<td></td>
<td>- 26 women</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- 20 spouses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
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<td>Outcome</td>
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<tr>
<td>Quinn, et al. (1986)</td>
<td>60 patients - 60 spouses one month post-diagnosis</td>
<td>All stages of lung cancer</td>
<td>Support significantly related to psychological distress &amp; changes in distress.</td>
</tr>
<tr>
<td></td>
<td>44 couples four months post-diagnosis</td>
<td></td>
<td>Coping strategies of wishfulfilling fantasy, self-blame, denial &amp; emotional expression were significantly related to greater distress. Spousal support served beneficial function in lessening psychological distress and wishfulfilling fantasy was especially detrimental as coping strategy.</td>
</tr>
<tr>
<td>Sabo, et al. (1986)</td>
<td>24 husbands Breast cancer postmastectomy</td>
<td></td>
<td>Husbands placed high priority on their wives adjustment but kept their own feelings at bay. Men's adaptation of &quot;protective guardian&quot; during hospitalization fostered denial &amp; later blocked communication between spouses.</td>
</tr>
<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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</tr>
<tr>
<td>Quinn &amp; Herndon (1986)</td>
<td>3 families</td>
<td>1 leukemia</td>
<td>Discussion of physiological, emotional &amp; behavior consequences of cancer on well family members. Principles of clinical intervention with families are summarized.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Hodgkin's</td>
<td></td>
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<td></td>
<td></td>
<td>1 child with unspecified</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>diagnosis</td>
<td></td>
</tr>
<tr>
<td>Lichtman, et al. (1987)</td>
<td>78 women</td>
<td>Breast cancer Stages I &amp; II</td>
<td>Majority of women felt supported by family &amp; friends. However, communication difficulties exist - husbands are not comfortable discussing their feelings or concerns with their wives &amp; discourages wives from discussing their concerns of recurrence or death. Husbands as a group were more satisfied with their wives. Overall, marital satisfaction remained the same or improved following the diagnosis.</td>
</tr>
<tr>
<td></td>
<td>64 significant</td>
<td></td>
<td></td>
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<tr>
<td>Study</td>
<td>Subjects</td>
<td>Phase of Illness</td>
<td>Outcome</td>
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<tr>
<td>Berman, et al. (1988)</td>
<td>10 adolescents</td>
<td>Death of a parent</td>
<td>All 10 families kept adolescents well-informed of parent's illness and death. However adolescents reported receiving little or no support from health-care professionals which contributed to feelings of isolation</td>
</tr>
</tbody>
</table>
This table illustrated a review of the literature from 1956 - 1988 briefly describing the outcomes of the studies cited. It focuses on the psychosocial issues of the family experiencing cancer. By listing the subjects and phases of illness one is better able to recognize a significant methodological issue that most studies do not address.

In summary, Chapter Two highlighted studies centered on the psychosocial impact of cancer on family members and attempted to address specific family members i.e., spouses/ partners and children whose parents have cancer. Although these studies provide a first step in understanding the acute and chronic effects of cancer on individuals whose parent have the diagnosis, they have significant methodological weaknesses. Specifically, subjects with several different types of cancer are grouped together (Wellisch, 1978; Welch, 1982; Gotay, 1984; Cassileth, 1985; Thorne, 1985; Vess, 1985; and Quinn, Fontana, & Reznikoff 1986) In many studies the stage of disease is not identified or considered in the analysis (Wellisch, 1978; Kelly, 1980; Welch, 1981; Thorne, 1985; and Vess, 1985). Other methodological problems are noted such as using a single individual to speak for the entire family; or relying on a subjects' long-term recall.

Most of the limited nursing, psychological or psychiatric literature on children whose parent has cancer report anecdotes, isolated case reports and clinical impressions. None of the previously cited literature used control groups. And finally with
the exception of Kelly (1980) none of the studies have evaluated a sense of risk to self nor have they evaluated preventive health practices specific for women at risk for breast cancer.
CHAPTER III

METHODOLOGY

The purpose of this study was threefold: (1) to identify awareness of the value of health, (2) to identify the sense of risk to self and (3) to determine if this awareness influenced health behaviors aimed at reducing risk among thirty women, half of whom had mothers currently under medical care for breast cancer while half served as controls with no history of maternal breast cancer. All women completed self-report measures (Multidimensional Health Locus of Control and the Health Value Scale) and completed a structured interview about susceptibility to disease, risk factors and health behaviors. Their responses provided both quantitative and qualitative data for analysis.

The interview format was developed and piloted with 10 volunteers who were non-professional employees and one nurse all of whom worked with the investigator. (See Appendix A, The Pilot Study). It consisted of 5 open-ended questions directed at obtaining information on awareness of risk to such diseases as diabetes, heart disease and cancer in addition to looking at health behavior practices both healthy and unhealthy. Data obtained from this measure was descriptive in nature and resulted in frequency rates of responses.
Subjects

There were a total of thirty women who participated in this study. Experimental subjects consisted of fifteen women whose mothers have breast cancer. A list of all women with the diagnosis of breast cancer was generated from the Section of Medical Oncology of a large urban medical center in the Midwest. The women were contacted and asked if they had a daughter between 14 and 40 years of age who would be willing to participate in the study. These daughters were then contacted and the study was explained. Those who agreed to participate were scheduled for an interview. A consent form (Appendix B) was signed. Written consent was also obtained from the mothers of the daughters who were under 18 years of age. All daughters were aware of their mother's diagnosis and all mothers were alive at the time of the interview.

The control group consisted of fifteen women between 14 and 40 years of age whose mothers did not have breast cancer. The control subjects were volunteers from a local college and employees from the medical center. They followed a similar procedure of scheduling and signing of a consent form. All subjects were matched for age, race and level of education.

Instruments

The Health Value Scale (HVS) is an adaptation of Rokeach's (1973) Terminal Value Survey. The major limitation of the Rokeach Value Survey is that "health" is not included in the list of values. This explains the revision called the Health Value Scale constructed by K.A. Wallston in 1974, which included 10 items, one of which is "health". This scale is used to determine the relative value placed on health. It consists of 10 values that the subject is asked to rank in order of importance from 1 to 10. A median split of the sample distribution is performed to determine the subjects' rating of health as either "high" or "low". Interpretation of responses to the scale is straightforward. According to Wallston, if health is ranked as 1 or 2 then the value placed on health is considered high. If health is ranked in any other position (3-10), then the value placed on health is considered low. In a written correspondence from K.A. Wallston, he states "we have no reliability information on the Value Survey as we use it. Since it was rank ordering there can be no estimate of internal consistency and we have never given it on a test-retest basis to check its stability." (personal communication, 1986).

The Multidimensional Health Locus of Control (MHLC) measures beliefs about the source of reinforcement, whether it is primarily internal, a matter of chance or under the control of powerful others. This self-administered instrument is an 18-item, 6 point Likert scale, with 6 items representing each of three subscales: Internal Health Locus of Control (IHLC), Chance Locus of Control (CHLC) and Powerful Others Health Locus of Control (PHLC).
The MHLC measures individuals' expectations about their control over their health. The instrument yields scores on three independent dimensions of health locus of control beliefs. The Internal Locus of Control (IHLC) scale measures "health internality"—the extent to which a person believes health is a function of their own behavior. It has been reported that individuals who have internal expectations are more likely to take responsibility for their health (Strickland, 1978). Low scores on the IHLC Scale do not mean that individuals believe that external factors determine their health; all that can be said about low IHLC scores is that they are not indicative of internal beliefs. The CHLC Scale assesses "chance externality"—the degree to which a person believes that their health is unpredictable; a matter of chance, luck or fate. Finally, the PHLC Scale, "powerful others externality", taps the person's beliefs that health is largely determined by the actions of powerful others, either family members, friends or health professionals (Wallston, 1982).

The MHLC scales are superior to the unidimensional HLC scale in at least two ways. Psychometrically, the individual MHLC scales are more internally consistent (thus more reliable) than the HLC scale, which is comprised of both internally and externally worded items. Conceptually, the HLC scale only contains a single powerful-others item, whereas the MHLC has an entire scale (PHLC) devoted to this important construct (Wallston, 1982). Alpha reliabilities for the MHLC scale, forms A and B are 0.830 to 0.859 (Wallston, 1978).
Procedure

The young women who agreed to participate in this study were telephoned by the investigator. The telephone conversation consisted of an explanation that study participation would consist of answering some questions in a 20 minute interview and completing two questionnaires, which would take approximately 10 minutes. It was explained to each participant that a psychologist would be conducting the interview. If the women agreed to participate, then an appointment was arranged to meet with a psychologist who conducted all the interviews. This interviewer was a non-participant in the study planning and was blinded as to the study objectives, hypotheses and the roles of the study participants. At the time of the interview, the examiner gave each participant an information sheet and after assuring the participant that she could stop the interview at any time, obtained a signed consent. (See Appendix B) (All participants who agreed to participate completed the entire process.) The five open-ended questions (Appendix E) were then asked and if the women responded by asking for clarification of a particular question, the question was repeated and they were told to say whatever came to mind. Following the interview, the young women were given a demographic sheet (Appendix F) and two questionnaires to complete (HVS and MHLC); all of which were completed and returned before the participant left the psychologist's office.

The interviews took place over a seven week time period from mid-March to mid-May, 1986. All of the interviews took place in the
psychologists' office at a large urban medical center except for one of the interviews which took place in the woman's home.

Analysis of Data

Health Value Scale

The value for this scale was determined through a median split of the sample distribution. If the individual ranked "health" as number one or two, the value placed on health was considered "high". If the individual ranked "health" as number three to ten, the value placed on health was considered "low".

A number of analyses were performed with the Health Value Scale. An analysis of variance was calculated to test for possible differences between the two groups in the value placed on health and the level of education. A two-way t-test was performed to determine possible differences between the experimental and control groups regarding marital status and the value placed on health. A two-way t-test was performed to evaluate possible differences in ethnicity and the value placed on health.

Multidimensional Health Locus of Control

In evaluating the MHLC, a Pearson correlation was performed separately for the two groups. This was calculated with the experimental group on age of participant, length of mother's diagnosis, and internal, chance and powerful others locus of control. A Pearson correlation was performed with the control group on age, internal, chance and powerful others locus of control.
Interviews

The structured interviews were evaluated by frequency ratings and percentages. This was calculated for each of the responses given by the thirty women.
CHAPTER IV

RESULTS

This study addressed women's cognitions and behaviors relating to a maternal breast cancer history as an outgrowth of three null hypotheses:

1. There is no difference in the value placed on health between women with a maternal history of breast cancer and a control group.

2. There is no difference in the awareness of risk for breast cancer to self between the women with a maternal history of breast cancer and the control group.

3. There are no differences demonstrated in health behaviors to minimize the risk of breast cancer between the daughters whose mothers have breast cancer and a control group.

Thirty women completed a demographic information sheet, self-report measures regarding health attitudes: Health Value Scale (HVS) and the Multidimensional Health Locus of Control (MHLC) and completed a structured interview about susceptibility to disease risk factors (with diabetes, heart disease and cancer), the practice of health behaviors and self-behaviors viewed as destructive to health. Results of the demographics, questionnaires and interview responses were completed by all 30 women and are given below.
Table 2

Demographic Information for All Participants

<table>
<thead>
<tr>
<th></th>
<th>Experimental N = 15</th>
<th>Control N = 15</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>28 years</td>
<td>25 years</td>
</tr>
<tr>
<td>Range</td>
<td>15-35 years</td>
<td>15-37 years</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>11 (73)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>Black</td>
<td>4 (27)</td>
<td>4 (27)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>9 (60)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>Married</td>
<td>6 (40)</td>
<td>4 (27)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In high school</td>
<td>2 (13)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>High school</td>
<td>1 (7)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Two years college</td>
<td>3 (20)</td>
<td>6 (40)</td>
</tr>
<tr>
<td>Four years college</td>
<td>4 (27)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Graduate school</td>
<td>5 (33)</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Length of Mother’s Diagnosis</strong></td>
<td></td>
<td>15 100</td>
</tr>
<tr>
<td>Mean</td>
<td>6.4 years</td>
<td></td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>4.4 years</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1-15 years</td>
<td></td>
</tr>
<tr>
<td><strong>Stage of Mother’s Breast Cancer</strong></td>
<td></td>
<td>15 100</td>
</tr>
<tr>
<td>Stage II</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Stage IV</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

*With one mother in each stage having two daughters who participated in the study.

As can be seen in Table 2 the women ranged in age from 15 to 37 years with a mean age of 25 years. Table 2 compares the various population characteristics of the two groups. The groups were well balanced except for a trend of having more education in the experimental group.
The age of the participants' mothers, who had a history of breast cancer ranged from 35-65 years with a median age of 54 years. The length of time that the mothers had been diagnosed with breast cancer ranged from 1-15 years with the mean number of years living with breast cancer being 6.4 years.

The stage of the mothers' breast cancer at the time the study was conducted included: five mothers with Stage II and eight mothers had Stage IV disease. One mother in each of the two stages had two daughters participating.

At the time the study was conducted seven of the mothers were receiving either chemotherapy or radiation therapy for their breast cancer. Six of the mothers were receiving no treatment at the time of the study, but had received either chemotherapy or radiation therapy in the past for their diseases. All mothers had received prior surgery.

The occupations of the women in the experimental group included: two students in high school, two in college, two attorneys, two teachers and one each a photographer, a jeweler, a pediatric audiologist, a respiratory therapist, an office manager, an educational consultant, and a legal secretary.

In the control group the occupations included: two high school students, four college students, four secretaries, two attorneys, and one each a medical technologist, a research technician, and a media network coordinator.
Analysis of the Health Value Scale

According to Rotter (1954) and Wallston, Wallston, Kaplan and Maides (1976) the potential for a behavior that leads to reinforcement is directly related to the value that reinforcement has for the individual. So in order to predict health behavior, information is needed concerning the value that individual places on health (Muhlenkamp, Brown & Sands, 1985).

In order to test the first null hypothesis (there is no difference in the value placed on health between women with a maternal history of breast cancer and a control group) the Health Value Scale was evaluated.

This Scale consists of ten values that the subject is asked to rank in order of importance from 1 - 10. In this study the value placed on health is either "high" or "low". This value was determined through a median split of the sample distribution. If the individual ranked "health" as number one or two, the value placed on health was considered "high". If the individual ranked "health" as number three to ten, the value placed on health was considered "low".

In each of the two groups 11 out of 15 women or 73 percent ranked the value placed on health as "high". Therefore no difference was found in the value placed on health between the daughters whose mothers had breast cancer and a control group.
Table 3

Frequency Results for the Health Value Scale

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>22</td>
<td>(73)</td>
</tr>
<tr>
<td>Low</td>
<td>08</td>
<td>(26)</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>100</td>
</tr>
</tbody>
</table>

To further test this hypothesis other variables such as education, marital status and ethnicity were examined for possible differences between the two groups.

An analysis of variance was performed on the HVS and education resulting in an F score of 1.898 (p < 0.142), therefore no significant differences were found in the value placed on health and the education of the women in both groups (N = 30).

An analysis of variance was performed to determine if there were differences between the experimental (N = 15) and control group (N = 15) and education, which resulted in an F score of 0.568 (p < 0.688) yielding no significant differences found between the two groups of women and education.

There were 10 (33%) married and 20 (67%) single women in this study. A 2 way t test was done to determine possible differences between the experimental and control groups regarding marital status and the value placed on health. The result produced a t score of 0.28, yielding a two-tailed (p < 0.78) showing no statistically significant difference.

There were eight Black women (26%) and 22 Caucasian women
represented in the study. A T-test was performed to evaluate possible differences in ethnicity and the value placed on health among the women in both groups ($N = 30$). The T score was 0.12 yielding a two-tailed ($p < 0.905$), resulting in no statistically significant difference between the value placed on health and ethnicity (see Table 4 for summary of HVS).

Table 4

<table>
<thead>
<tr>
<th>Summary of the Results of the Health Value Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental Group ($N = 15$)</td>
</tr>
<tr>
<td>Value</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>High</td>
</tr>
<tr>
<td>Low</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Health Value Scale by Education

Analysis of Variance:

 resulted in an F score of 1.89 ($p < 0.14$), therefore no statistically significant differences were found in the value placed on health and education between both groups.
Health Value Scale by Ethnicity

T Test

T-score of -0.12, a two-tailed (p < 0.90), resulted in no statistically significant difference found in the value placed on health and ethnicity between both groups.

Health Value Scale by Marital Status

T Test

T score of 0.28, a two-tailed (p < 0.78) resulted in no statistically significant differences found in value placed on health and marital status between both groups.

Multidimensional Health Locus of Control

The issue of who is responsible for an individual's degree of health or illness is open to much debate. Many people and physicians believe doctors are primarily responsible; when a health problem arises it is the physician's job to "fix it". Another attitude is that the ultimate responsibility for one's health lies with the individual. Others believe that no one is responsible for health or illness; if one is healthy then one is lucky or has been rewarded by God; if one is sick, then one is ill-fated or has been punished by God (Wallston & Wallston, 1982).

With these observations in mind the Wallstons (1978) developed the Multidimensional Health Locus of Control (MHLC). The MHLC measure beliefs that the source of primary reinforcement for control of health is either internal, a matter of chance, or under the control of powerful others. The
The purpose of the MHLC scales is that one does not end up with a single score indicating internal or external locus of control. Instead one ends up with three scores.

In evaluating the MHLC, a Pearson correlation was performed with the experimental group on (1) the age of participant, (2) length of mother's diagnosis, (3) internal locus of control, (4) chance locus of control, and (5) powerful others locus of control.

The results indicated no correlational relationship in the experimental group between age of participant, length of mother's diagnosis and the three measures (I,C,P) locus of control.

In evaluating the control group, a Pearson correlation was done on age, internal, chance and powerful others locus of control. There appears to be a negative correlation - .6976 (p < 0.004) between age and internal locus of control. It is not clear what this means in this population at this time, however this may be an area for further research.

Structured Interviews

The structured interviews (Appendix E) were conducted by a psychologist who was blind to the conditions of the study and the hypotheses.

To test the second null hypothesis (there is no difference in awareness of risk for breast cancer to self between the women with a maternal history of breast cancer and the control group), Question Three of the structured interview was evaluated. Table 5 demonstrates the results of frequency ratings for this question.
Table 5

**Frequency Results of Responses to Question Three of Structured Interview**

Question Three: Do you believe you are susceptible to diabetes, heart disease or cancer?

<table>
<thead>
<tr>
<th></th>
<th>Experimental Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10 (67%)</td>
<td>Yes 14 (93%)</td>
</tr>
<tr>
<td>(all relate specifically to mothers' breast cancer)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4 (27%)</td>
<td>No 1 (6%)</td>
</tr>
<tr>
<td>Always a chance</td>
<td>1 (6%)</td>
<td>15 (100%)</td>
</tr>
<tr>
<td></td>
<td>15 (100%)</td>
<td>15 (100%)</td>
</tr>
</tbody>
</table>

Ten of the women in the experimental group did acknowledge an awareness of the risk to themselves because of their mother's breast cancer as reported in the structured interview, however one-third (five out of 15) were not aware of the risk to themselves. In the control group, 14 out of the 15 women identified an awareness of risk to either heart disease, diabetes or cancer. The responses to Question One are identified in Table 6.
Table 6

Frequency Results of Responses to Question One of Structured Interview

Question One: Why do you believe people get certain diseases like diabetes, heart disease and cancer?

**Experimental Group (N = 15)**

<table>
<thead>
<tr>
<th>Causes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heredity</td>
<td>13</td>
</tr>
<tr>
<td>Diet</td>
<td>6</td>
</tr>
<tr>
<td>Environment</td>
<td>6</td>
</tr>
<tr>
<td>Smoking</td>
<td>3</td>
</tr>
<tr>
<td>Stress</td>
<td>3</td>
</tr>
<tr>
<td>Preservatives</td>
<td>2</td>
</tr>
<tr>
<td>Unable to control</td>
<td>2</td>
</tr>
</tbody>
</table>

Other causes reported included religion, mental attitude, skin contact, drugs and birth control pills.

**Control Group (N = 15)**

<table>
<thead>
<tr>
<th>Causes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heredity</td>
<td>11</td>
</tr>
<tr>
<td>Environment</td>
<td>7</td>
</tr>
<tr>
<td>Smoking</td>
<td>5</td>
</tr>
<tr>
<td>Diet</td>
<td>4</td>
</tr>
<tr>
<td>Lack of exercise</td>
<td>3</td>
</tr>
</tbody>
</table>

Other causes reported were: stress, religion, preservatives, mental attitude, foods not cooked and unable to control.
In order to evaluate the third null hypothesis (there are no differences demonstrated in health behaviors to minimize the risk of breast cancer between women with a maternal history of the disease and the control group) the results of Questions Two, Four and Five of the structured interview are presented.

Table 7 shows the frequency ratings of Question Two: Do you believe diseases like diabetes, heart disease and cancer can be prevented by changing behaviors? If yes, what behaviors?

Table 7

Frequency Results of Responses to Question Two of Structured Interview

| Question Two: Do you believe diseases like diabetes, heart disease and cancer can be prevented by changing behaviors? If yes, what behaviors? |
|--------------------|------------------|------------------|
|                     | Experimental Group (N = 15) | Control Group (N = 15) |
| Yes                 | 8 (53%)           | 10 (67%)         |
| No                  | 3 (20%)           | 1 (6%)           |
| Maybe              | 4 (27%)           | 4 (27%)          |
| Total              | 15 100%           | 15 100%          |

In the experimental group eight out of 15 (53.3%) of the women reported a definite YES and seven out of 15 (46.6%) of the women reported NO or MAYBE.

This compares with 10 out of 15 (66%) women in the control group who reported YES and five out of 15 (33%) of the women said NO or MAYBE.
The behaviors reported for prevention of heart disease, diabetes and cancer are seen in Table 8. They are listed in order of most frequently reported in each group. In the experimental group, diet (eight) and smoking (six) are the two most frequently reported behaviors to potentially prevent diabetes, heart disease and cancer.

Table 8
Reported Behaviors Given for Prevention - Question Two

<table>
<thead>
<tr>
<th>Experimental Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviors</td>
<td>Frequency</td>
</tr>
<tr>
<td>Diet</td>
<td>11</td>
</tr>
<tr>
<td>Exercise</td>
<td>4</td>
</tr>
<tr>
<td>Stress</td>
<td>4</td>
</tr>
<tr>
<td>Environmental Exposures</td>
<td>3</td>
</tr>
<tr>
<td>Smoking</td>
<td>2</td>
</tr>
<tr>
<td>Weight</td>
<td>2</td>
</tr>
<tr>
<td>Sleep</td>
<td>2</td>
</tr>
<tr>
<td>Check ups</td>
<td>2</td>
</tr>
</tbody>
</table>

Reported once each were: drinking, attitude, BSE, b/c pills, drugs & dress.

Reported once each were: weight, drugs, check ups.
Table 9

Reported Behaviors for Prevention of a Specific Disease

<table>
<thead>
<tr>
<th>Heart Disease</th>
<th>Experimental Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease cholesterol</td>
<td>1</td>
<td>Decrease stress 2</td>
</tr>
<tr>
<td>Decrease stress</td>
<td>1</td>
<td>Foods 1</td>
</tr>
<tr>
<td>Decrease smoking</td>
<td>1</td>
<td>Type A’s 1</td>
</tr>
<tr>
<td>Decrease drinking</td>
<td>1</td>
<td>Exercise 1</td>
</tr>
<tr>
<td>Prevent overweight</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

| Diabetes               | Watch sugar        | 1 Diet 1      |
|                        | Take medication    | 1             |
|                        | Prevent overweight | 1             |

| Cancer                 | Smoking            | 1 Smoking 1   |

The next Table (10) lists the frequency ratings that are reported for Question Four: What behaviors, if any, do you do to keep yourself healthy? They are listed in order of most often reported.

In the experimental group the behaviors most often reported by the 15 women were: diet (eight), exercise (seven) and watching one's weight (four), with only three of the 15 women with a maternal history of breast cancer reporting breast self-examination (BSE).

In the control group the most often reported healthy behaviors included: exercise (13) and diet (nine) with none of the control group mentioning BSE.
Table 10

Frequency Results of Responses to Question Four of Structured Interview

Question Four: What behaviors, if any, do you do to keep yourself healthy?

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Frequency</th>
<th>Behaviors</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>8</td>
<td>Exercise</td>
<td>13</td>
</tr>
<tr>
<td>Exercise</td>
<td>7</td>
<td>Diet</td>
<td>9</td>
</tr>
<tr>
<td>Watch weight</td>
<td>4</td>
<td>Do not smoke</td>
<td>4</td>
</tr>
<tr>
<td>BSE</td>
<td>3</td>
<td>Take vitamins</td>
<td>3</td>
</tr>
<tr>
<td>Do not smoke</td>
<td>2</td>
<td>Get proper sleep</td>
<td>2</td>
</tr>
<tr>
<td>Decrease stress</td>
<td>2</td>
<td>Decrease stress</td>
<td>2</td>
</tr>
<tr>
<td>Take birth control pills</td>
<td>1</td>
<td>Wear proper clothing</td>
<td>1</td>
</tr>
<tr>
<td>Get proper sleep</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3 out of 15 mention BSE    0 out of 15 mention BSE

Table 11 lists the answers to Question Five: Which behaviors do you do routinely that you think might be harmful to your health? They are listed in order of most often reported.

The experimental group reported poor diet (eight), not enough exercise (seven) and stress (four). This compared with the control group who reported most often the unhealthy behaviors of: poor diet (six), five women stated they smoked and lack of sleep (four).
Table 11

Frequency Results of Responses to Question Five of Structured Interview

Question Five: Which behaviors do you do routinely that you think might be harmful to your health?

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Frequency</th>
<th>Behavior</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor Diet</td>
<td>8</td>
<td>Poor Diet</td>
<td>6</td>
</tr>
<tr>
<td>Not enough exercise</td>
<td>7</td>
<td>I smoke</td>
<td>5</td>
</tr>
<tr>
<td>Stress</td>
<td>4</td>
<td>Lack of proper sleep</td>
<td>4</td>
</tr>
<tr>
<td>Lack of proper sleep</td>
<td>2</td>
<td>Around other's smoke</td>
<td>3</td>
</tr>
<tr>
<td>Am overweight</td>
<td>2</td>
<td>Have occasional drink</td>
<td>3</td>
</tr>
<tr>
<td>Drink coffee</td>
<td>1</td>
<td>Stress</td>
<td>2</td>
</tr>
<tr>
<td>Have occasional drink</td>
<td>1</td>
<td>Get angry</td>
<td>2</td>
</tr>
<tr>
<td>Don't take vitamins</td>
<td>1</td>
<td>Am overweight</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Drink coffee</td>
<td>1</td>
</tr>
</tbody>
</table>

Summary of the Results

All 30 women completed the two questionnaires, the Health Value Scale (HVS), Multidimensional Health Locus of Control (MHLC) and a structured interview consisting of five questions concerning susceptibility to disease, risk factors, health behaviors and self-behaviors viewed as destructive to health. All interviews were conducted by a psychologist blind to the hypotheses and conditions of the study. The participants were matched by age, race and level of education.
There was no difference found in the value placed on health between the experimental and control groups with 11 out of 15 women in each group ranking the value placed on health as "high".

Surprisingly, one-third of the experimental group did not report being susceptible to cancer, even though their mothers had been treated for the disease; whereas 14 of the 15 women in the control group answered Yes to being susceptible to heart disease, diabetes or cancer.

When the women were asked which behaviors could reduce risk from disease, only three of the fifteen experimental subjects mentioned breast self-examination (BSE); whereas none of the control group mentioned BSE.

The most frequently cited health behaviors among both groups were diet and exercise. Smoking cessation was the third least frequently reported health behavior among the experimental group, whereas it was the third most frequently cited health behavior among the control group. Behaviors most commonly reported by both groups as being harmful to health were lack of exercise, poor diet, smoking, stress and lack of sleep. No significant differences were found between groups in frequency of such behaviors.

Table 4 gives a summary of the results of the Health Value Scale.
CHAPTER V

SUMMARY, DISCUSSION AND CONCLUSIONS

Summary

The purpose of this controlled descriptive study was to address several issues related to women with a maternal history of breast cancer. This disease is slowly increasing in incidence with 130,000 new cases occurring in 1987, which accounts for one in ten women in her lifetime developing the disease.

The primary risk factors for developing breast cancer include: (1) family history and (2) menstrual and reproductive history. The five year survival rate for localized breast cancer has risen from 78 percent in the 1940's to 90 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 rates and survival.

There are three established methods of early detection for breast cancer: physical examination, mammography and breast self-examination. However at the present time there is a very low frequency of compliance with these three methods especially breast self-examination (BSE).

Using the Health Belief Model as a theoretical base and recognizing the potential severity and chronicity of breast cancer, this study began to address the issues of (1) the value placed on
health, (2) awareness of risk to self for breast cancer and (3) to
determine if this awareness influenced health behaviors aimed at
reducing the risk between women with a maternal history of breast
cancer (N=15) and a control group (N=15) matched for age, race and
education.

The review of the literature includes selected studies
concerning the psychosocial impact of cancer on family members which
included perspectives of spouses and children with specific emphasis
on daughters who have a mother with breast cancer. There is a
description of the methodology including design, subject selection,
instrumentation, procedural details and treatment of data from both
the questionnaires and interviews. The analysis of data was presented.
The limitations of the study, a detailed discussion of the results,
conclusions and implications for counseling and future research will
follow.

**Limitations of the Study**

The most significant limitations of this study include the
small sample size and the largely middle class population so the
results should not be generalized to all women with a maternal history
of breast cancer.

Another area of limitation is with the structuring of the
interview questions. Several of the questions were too broad. For
example, more information would have been gained by asking separate
questions regarding risk for heart disease, diabetes and cancer. In
order not to bias the responses to the questions, there was no question specifically addressing the issue of breast self-examination, although, in retrospect, it might have been more useful to do so.

Another limitation of this study is that it necessitated using self-report measures since there was no nonintrusive way of observing health behaviors (i.e., performing exercise, following proper diets and practicing breast self-examination). To observe these behaviors was beyond the scope of this study, therefore self-report measures were used. When self-report measures are used a "halo" effect must be considered. That is presenting oneself in the best light. Considering this effect, subjects might be exaggerating their reported health behaviors. This makes the infrequency of their reports even more profound.

DISCUSSION

The concept of health as a value is one that has been surprisingly underutilized in health research. This is especially true in the area of health prevention as it relates to cancer. Researchers have frequently assumed that all people place a very high value on health. However, when looking at preventive health behaviors, "where health actions are undertaken in an asymptomatic state for the purpose of preventing illness and remaining healthy" (Kasl & Cobb, 1966) the value placed on health may not be high. Lau, Hartman & Ware, (1986) conclude that health as a value should be an integral part of any social science study of health behaviors.
However these same authors suspect that when the disease or symptoms are very life-threatening, the value placed on health will be uniformly high and therefore possibly of little use to researchers. The findings of this study dispute Lau, Hartman & Ware's assumption.

This study found that 73 percent of women living with a life-threatening disease (their mother's breast cancer) placed a uniformly high value on health. However, it is surprising that only 73 percent and not 100 percent of this "at risk" population would have placed a high value to health. In fact, exactly the same percentage of the control population (73 percent) placed a high value on health. These findings call into question the comments of Lau, Hartman & Ware (1986) as this study was unable to demonstrate any heightened value placed on health between the control group and the experimental group, even though their mothers have a life-threatening disease. Therefore the first null hypothesis, that there is no difference found in the value placed on health between the women with a maternal history of breast cancer and the control group, is not rejected.

In further evaluating possible differences between the values placed on health, there were no statistically significant differences found in educational background, age, ethnicity or marital status among all women. In fact, interestingly, the four women in the experimental group who placed a low value to health were in the two highest categories of educational background: one had completed four years of college and three had completed graduate school.
One possible explanation is that individuals who are better educated may feel more in control of their health and therefore not as concerned about it. However checking this point against scores on the MHLC revealed that only one of the experimental subjects had a higher than average Internal Locus of Control score.

In the control group, of the four women who placed a low value to health, two were currently in high school, one had completed high school and one had completed graduate school, overall these four women are slightly less educated than those in the experimental group.

However, classifying this information as being of little use or unimportant to researchers is in dispute. The issue of the value placed on health is a new area of study in this "at risk" population to a potentially life-threatening disease such as daughters with a mother with breast cancer. Can one assume that just because there is a high value to health, that this "at risk" population will be aware of their risk, which will lead to health behaviors that will minimize this risk? As this study indicates, the answer to that question is possibly no, which raises questions of assumptions that have been made by health educators that "of course women at high risk for breast cancer will place a high value to health". This finding of the study suggests this concept is far more complicated than was first assumed.

As was previously discussed, 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. It can not be assumed that being at risk and being aware of this risk are one in the same.
Methodologically, this study asked general questions about health risks to diabetes, heart disease and cancer. In the control group, fourteen out of fifteen (93 percent), answered yes in a general way. That is, they felt susceptible to any or all of these diseases.

Interestingly, when asked the same general question, ten out of fifteen (65 percent) of the women in the experimental group focused on being susceptible specifically to breast cancer. Despite this, it was disappointing to find that five out of the fifteen (33 percent) did not report being at risk to breast cancer specifically or to diabetes or heart disease.

Based on this finding, the second null hypothesis is not rejected, that there is no difference in awareness of risk for breast cancer to self between the women with a maternal history of breast cancer and the control group.

Several possible questions are raised concerning the finding that one-third of the experimental group did not recognize an awareness of risk to themselves for breast cancer.

1. Have they not been educated about their risk?

2. Is there discussion with their mothers about the issues of breast cancer?

3. Are their mothers too uncomfortable about the topic? Specifically, do they feel guilty about the possible genetic predisposition to their daughters?

4. Is denial the main coping mechanism being used by both mothers and daughters regarding specific issues of breast cancer?
Once again the conclusion is drawn as to the complex nature of this entire area of value of health and awareness of risk specifically for women coping with a maternal history of breast cancer.

This finding of a vague or limited knowledge of the risk to breast cancer is consistent with the limited literature on the subject. In discussing breast cancer risk, thirty-nine women with a maternal history of the disease were interviewed by Kelly (1980) who reported that the women's knowledge about the magnitude of their risk was quite vague. Twenty (51 percent) said their risk was much higher than average, four of these twenty felt quite certain they would get breast cancer. Twelve (31 percent) said their risk was average and two (5 percent) maintained that they were at less risk than the average woman. Those who thought their risk to be average or lower said they had decreased their risk by such means as diet, positive thinking or being fortunate enough not to resemble their mothers.

In a study by Rosenfeld, Caplan, Yaroslavsky et al (1983) all of the eight girls with a maternal history of breast cancer interviewed reported uncertainty about the causes and inheritability of the disease. These studies reinforce the suggestion that not enough education is taking place to heighten awareness of risk to women with a maternal history of breast cancer.

In assessing knowledge about breast cancer, Question One of the structured interview gives some interesting data (See Table 6). In answering this question (Why do you believe people get certain
diseases like diabetes, heart disease and cancer?), heredity was the most frequent cause reported in both the experimental (13 out of 15) and the control (11 out of 15) groups, which supplies a base for the level of knowledge about causes for diabetes, heart disease and cancer.

One limitation to this question is that causes were not associated with a specific disease. Therefore, it is difficult to evaluate the full depth of knowledge about the causes the women attribute to diabetes, heart disease and cancer.

In singling out one of the diseases in Question One, Linn, Linn and Stern (1982) studied beliefs about causes of cancer in one hundred twenty patients with late-stage cancer and compared the beliefs of patients without the diagnosis, matched for age, gender and hospitalization. The authors found that people with cancer had less strong beliefs about the causes of cancer than did the control group, even when causes such as smoking and having lung cancer were probably associated with the development of their disease.

To evaluate the third null hypothesis (there are no differences reported in health behaviors to minimize the risk of breast cancer between women with a maternal history of the disease and a control group), a discussion of Questions Two, Four and Five of the structured interview will follow.

Question Two: Do you believe diseases like diabetes, heart disease and cancer can be prevented by changing behaviors? If yes,
what behaviors? Table (7) reveals the frequencies and percentages of the responses given by the thirty women.

Of interest are the behaviors reported by subjects for prevention of specific diseases. It appears that the educational promotions in recent years for heart disease have paid off. The women reported more responses for this disease than either diabetes or cancer. In fact, the responses for diabetes and cancer should be "an eye-opener" for health educators.

Questions Four and Five of the structured interview address the healthy and harmful behaviors practiced by the participants. (See Tables 9 & 10 for the results.) These responses are somewhat difficult to interpret and certainly one must be cautious in drawing conclusions from these responses.

In discussing Question Four, eight out of the fifteen women in the experimental group answered "diet" as a practiced healthy behavior and yet in Question Five, eight out of the fifteen women report having poor diet as an unhealthy behavior. In the future more specific questions may elicit more detailed information.

However, the most important response gathered from Question Four concerns the preventive behavior of breast self-examination (BSE). When subjects were asked which behaviors could reduce risk from disease, only three of the fifteen (20 percent) of the experimental group mentioned BSE; whereas none of the control subjects mentioned BSE.
Inspite of 73 percent of the women placing a high value to health and 67 percent reporting a susceptibility to breast cancer, it was disappointing to find only 20 percent reporting BSE as a healthy behavior practiced. This low frequency is surprising given these women's experiences with their mother's health problems. The overall frequency of BSE citation in this study is consistent with the frequency rates found in the literature (ACS, 1980; Kegeles & Grady, 1982).

Value of Breast Self-Examination

There is a great deal of discussion in the literature regarding the value of BSE, incidence and barriers to its practice, in addition to new and improved ways to increase and maintain the practice of BSE. Because studies of BSE report low rates of practice and irregular use of the procedure, questions have been raised concerning its value.

Advocates of BSE point out that the practice is cheap, easy to learn and perform, and is always available. In addition, it requires no personal sacrifice other than approximately five minutes per month and has no inherent risks, except perhaps giving women a false sense of security.

In a study of over 2000 women with cancer of the breast, findings by Huguley & Brown (1981) suggest that, "far from being given a false sense of security by failure to discover a lump themselves, women who do BSE are more likely to make use of mammography and
regular screening physical examination by physicians and thus are more likely to discover early cancers which by themselves they cannot feel and are less likely to be caught unawares with a large tumor" (Huguley & Brown, pg.995, 1981).

Their data demonstrated that women who practice BSE and developed breast cancer were in fact more likely to have smaller tumors and earlier stage disease, and consequently have better prognoses. Their study found that women who practiced BSE were more likely to consult a physician without delay but this promptness does not account for the earlier stage because even when delay was one month or less women who practiced BSE had earlier disease (Huguley & Brown, 1981).

Although their data do not prove a causal relationship, they do demonstrate a correlation between the performance of BSE and the early discovery of breast cancer. BSE is not the final answer, but it is a significant step forward in the continuing struggle towards early detection for breast cancer.

Despite widespread publicity about the value of early detection, many women still do not practice breast self-examination. The American Cancer Society recommends that BSE be performed monthly by all women over the age of twenty. However many studies confirm this study's findings that too few women especially those in high risk groups are not performing BSE.

In the United States, for example, Stillman (1977) found that in a sample of well-educated women 35-50 years of age, only 40 percent
practiced BSE with any regularity. Other studies have shown much lower rates: a study by the American Cancer Society (ACS) reported that fewer than 15 percent of American women regularly perform BSE; the percentage rose to 27 percent by 1978 (ACS, 1980).

A 1973 Gallop survey found that while 77 percent of the sample had heard of BSE, only 18 percent reported monthly practice. A follow-up study six years later by the National Institutes of Health (NIH) again reported a low practice rate of 29 percent. According to Kegeles & Grady, (1982), perhaps only 18-20 percent of the eligible female population habitually perform BSE, and even some of these women may not be performing it correctly.

A number of factors have been identified in many different studies attempting to explain the gap between knowledge and practice: ignorance of the importance of BSE; fear and anxiety; lack of knowledge about the technique of BSE; lack of confidence in one's ability to perform BSE; not perceiving a risk to breast cancer; difficulty in remembering each month and too young to get breast cancer (Hirshfield-Bartek, 1982; Kelly, 1979; Trotta, 1980).

Applying the Health Belief Model (HBM), the framework for this study, to BSE would suggest that given an appropriate cue (i.e. fear, lack of knowledge, etc.), the practice of BSE should be enhanced by (1) the recognition that one is susceptible to breast cancer, (2) by the perception that the consequences of getting breast cancer are severe and (3) belief that performing BSE is efficacious (Alagna & Reddy, 1984).
Stillman (1977) and Trotta (1980) utilized the HBM to quantify attitudinal factors which influence women to perform BSE. Stillman could not draw the correlation between perception of susceptibility to breast cancer and belief in the benefit of BSE to the practice of BSE, but concluded that other barriers such as embarrassment, religious upbringing and prior medical history affects behavior. There are conflicting results in the literature regarding high risk groups and performing BSE. One would assume that individuals at high risk for breast cancer would be especially vigilant in monitoring their physical status. Both Trotta (1980) and Stillman (1977) analyzed data from a separate group of women with a prior history of either breast lumps or breast cancer. This group reported fewer barriers to practice, had a higher perceived susceptibility to disease and greater beliefs in the benefits of BSE. In turn they performed BSE more frequently (Hirshfield-Bartek, 1982).

However it is unwise to make this assumption and generalize to all women who are at risk for the disease. A study by Mulvihill, Safyer and Bening (1982) examined the preventive health behaviors of high risk women who were also members of families genetically predisposed toward breast cancer. While half of the subjects chose prophylactic mastectomy (having the breast removed before cancer had a chance to develop), the other half chose instead to be monitored closely for symptoms. Their monitoring regimen included monthly practice of BSE, baseline mammography by age 25, a repeat mammogram every two years till age 40, and yearly mammography after that. At
follow-up the investigator found that none of the individuals in the high risk group were following the recommended regimen (Mulvihill, Safyer & Bening, 1982). This study supports the notion that making assumptions is not a wise practice especially concerning individuals at risk for breast cancer.

The finding of this present study that only three out of the fifteen women (20 percent) with a maternal history of breast cancer mentioned the practice of BSE as a behavior to do to keep oneself healthy should alert health psychologists as to the crucial role they can play in health care education. Major emphasis should be placed on recruiting high risk women into health-screening programs and enhancing compliance of BSE, mammography and physical examination. How best to implement this goal is the basis for future research.

Education of Breast Self-Examination

Several studies have already attempted to devise better ways of education and maintenance of BSE. Trotta (1980) concluded that the use of personal interaction, either one-to-one teaching which had more influence on frequency of practice; or group teaching which more favorably influenced thoroughness, is an important variable in the approach to education. The second variable identified as significant for influencing compliance is barriers to action. The study indicated that the fewer the barriers reported by the women the more frequently and thoroughly they performed BSE.
However attempts used to teach BSE have not always been successful. A number of studies have attempted to test different methods of BSE instruction or educational programs. Edwards (1980) found that modeling alone when compared with modeling plus guided practice was as effective in changing BSE practice. A study by Marty (1983) reported that subjects exposed to modeling and guided practice indicated more positive attitudes about the benefits of BSE and a high frequency of practice of BSE when compared with exposure to pamphlets on breast cancer and BSE, or a facilitator who discussed breast disease and modeled BSE.

A new and different approach to education of BSE was reported by Rose, Fore, Rachide et al (1980) which they taught more than 900 men in a community about breast cancer detection for their wives/partners. However no data were reported about changes in BSE practice in their wives/partners.

Although many studies have promoted the concept that knowledge of BSE is not enough, mass dissemination of information designed to increase knowledge of BSE techniques is the present method of choice in many health campaigns including those sponsored by the ACS to promote BSE.

The relationship between self-confidence about performing BSE and proficient technique is noteworthy because it suggests that instruction in BSE can be improved by including strategies to enhance a woman's confidence in performing BSE in an efficient and thorough fashion (Alagna & Reddy, 1984).
In a recent study Meyerowitz & Chaiken (1987) reported on a new approach to BSE education, again with emphasis on the woman's self-confidence. They found that women who read a pamphlet stressing the negative consequences of not performing BSE showed more positive attitudes, intentions and behaviors compared with women in the other three conditions which were (1) a gain-frame pamphlet, (2) a no-arguments pamphlet, or (3) the women received no pamphlet (control group). The authors stress the need for long-term follow-up when investigating the practice of BSE. Their findings indicate the need for health care professionals to be aware that "postinstructional good intentions do not translate into long-term behavior change without a discussion of the negative consequences of not performing BSE" (pg. 508).

Few researchers would dispute the need for procedures and techniques that will lead to earlier detection and treatment of breast cancer. The disappointing results of BSE campaigns need not be interpreted as suggesting that BSE is of no value. Rather, BSE can be regarded as a necessary but not sufficient condition for early detection and treatment (Owens & Ashcroft, 1986).

One of the most encouraging reports in the literature is from Pennypacker, Goldstein and Stein (1983). The authors described an extensive study in which they developed and validated a technology for instructing BSE that is reported to be "as aggressive a screen as mammography while lacking the inconvenience, expense and risk" (Pennypacker, Goldstein & Stein, 1983, pg. 309).
This present study and others previously mentioned should alert health educators to place emphasis on recruiting women, especially women at high risk for breast cancer, into health-screening programs. These programs need to promote and enhance (1) compliance of BSE, (2) prompt action should an abnormality be found, (3) mammography and physical examination by a physician. Implementing this complex goal is the basis for future research.

Conclusions

The results of the Health Value Scale (HVS) found that seventy-three percent (11 out of 15) women in each group ranked the value placed on health as high, therefore this study found that there was no difference in the value placed on health between the experimental and control groups. To further assess this question two-way t-tests and Analysis of Variance were performed on the HVS with education, ethnicity and marital status. (See Table 4 for a summary of results). There were no differences found in the value placed on health and education, ethnicity and marital status between the daughters with a maternal history of breast cancer and the control group.

The structured interview responses to Question Three were used to assess the second null hypothesis: no difference was found in awareness of risk to self between the women with a maternal history of breast cancer and a control group.
Methodologically, the study asked general questions about susceptibility to heart disease, diabetes and cancer. In the control group 14 out of 15 women answered YES to this general question about risk to self.

Interestingly, when asked the same general question, 10 out of 15 women in the experimental group focused specifically on being at risk for breast cancer. Surprisingly, one-third (5 out of 15) of the women in the experimental group did not report being at risk to breast cancer, even though their mothers had been treated for the disease.

To test the third null hypothesis: no differences were reported in health behaviors to minimize the risk to breast cancer between the women with a maternal history of the disease and a control group, Questions Two, Four and Five of the structured interview were evaluated.

With Question Two: Do you believe diseases like heart disease, diabetes and cancer can be prevented by changing behaviors? If yes, what behaviors? it appeared that the women were better able to give information for heart disease than for diabetes and cancer (See Table 7 for results).

Question Four of the structured interview asked: What behaviors, if any, do you do to keep yourself healthy? Only 3 out of 15 (20 percent) of the women in the experimental group reported BSE as a healthy behavior, whereas none of the women in the control group mentioned BSE.
Currently there is no known cause of breast cancer, nor are there any means of preventing it. Prognosis is dependent upon the stage of disease at the time of treatment, therefore hope for improvement in survival with present therapy depends upon earlier diagnosis. Mammography has been demonstrated to be effective as a screening method but cost-benefit ratio is in question. Breast self-examination is inexpensive and safe and could conceivably be done by nearly all women if they were adequately educated about the technique and motivated to perform it monthly (Huguley & Brown, 1981). All three recommended methods: physical examination by a physician, mammography and BSE are at present the key to early detection.

The most frequently cited health behaviors among both groups were diet and exercise. Smoking cessation was the third least frequently reported health behavior among the experimental group; whereas it was the third most frequently cited health behavior among the control group.

According to the responses of Question Five, behaviors most commonly reported by both groups as being harmful to health were lack of exercise, poor diet, smoking, stress and lack of sleep. No significant differences were found between the groups in frequency of such behaviors. This frequent reporting of exercise and diet may be due to the success of recent health education campaigns directed at reducing heart disease.

With respect to Question One of the structured interview: Why do you believe people get certain diseases like diabetes, heart
disease and cancer? heredity was the most frequently cited cause in each group (See Table 6 for results). For future studies it might be more informative to ask for more specific causes for each of the specific disease.

In looking at the Multidimensional Health Locus of Control (MHLC) by using a Pearson correlation the study found no corrolational relationships in the experimental group between age, length of mother's diagnosis and the three measures of locus of control: internal, chance and powerful others.

In the control group a Pearson correlation found no corrolational relationship between age, internal, chance and powerful others locus of control. Using this measure attempted to give a better understanding of the locus of control for women with a maternal history of breast cancer. Future studies may want to place more emphasis on this issue in order to better understand how locus of control influences values on health and motivation to practice health behaviors.

Overall the importance of this preliminary study is that it began to look at issues of value of health, awareness of risk, and to determine health behaviors practiced to minimize the risk in women with a maternal history of breast cancer. A controlled study looking at these issues had never been previously done on this population. The value of this study is that it raises more questions concerning assumptions that have been made which need further scientific exploration.
The findings of this study demonstrate that (1) issues of value placed on health, (2) susceptibility and knowledge of risk factors and (3) knowledge and motivational issues of practiced health behaviors are far more complex than health educators have assumed. This study disputes the literature that values placed on health are predictive of behavior. Inspite of 73 percent of the women placing a high value on health and 67 percent reporting susceptibility to breast cancer, it was disappointing to find that only 20 percent of the women in the experimental group reported BSE as a health behavior to practice. It is unwise to assume that if an individual places a high value to health, they will more likely perform preventive health behaviors.

This finding agrees with a conclusion of Weinstein (1984) that individuals may be capable of keeping their thoughts about their behaviors and their vulnerability to a disease in separate mental compartments (Weinstein, 1984). This conclusion leads into the subject of how better to educate those at high risk for certain diseases like breast cancer.

**Implications for Future Research and Counseling**

Although sample size limits the strength of conclusions which can be drawn from this preliminary study, the findings raise many questions and supplies a foundation for more extensive future research. The value of this controlled descriptive study is that general questions were asked and the findings give new specific
directions. (1) In the past, research has looked at the issues of value placed on health far too simplistically. This study raises the question of developing a new measure to assess the concept of the value placed on health; not just as a Yes or No or ranking, but addressing more complex details of (a) how individuals define health and (b) reasons for ranking health as high or low.

(2) Future research needs to refine terms, develop more sophisticated concepts and avoid making certain assumptions, i.e., that health value by itself predicts the performance of preventive health behaviors.

This study identified an at risk population (daughters of women with breast cancer) and raised many questions regarding awareness of risk to breast cancer and health behaviors practiced aimed at reducing the risk. Specifically, (1) In what ways are health care providers educating this at risk population? (2) How is this education being assessed for its effectiveness?

Kelly (1980) reported that only one subject could remember being given specific breast cancer risk information from her physician. Many subjects spontaneously said they'd like more information about breast cancer risk and possible causes. They felt increased information would diminish their anxiety (Kelly, 1980).

**Future Directions**

Several possible directions for further research might include:
(1) To correlate coping styles of women with breast cancer and their daughters coping styles. For example, how are the mothers and their daughters similar and/or different in their approach to seeking information, compliance with follow-up practices, and compliance toward routinely practiced health behaviors, i.e. BSE.

(2) To look at the issue of denial as the possible coping mechanism used by the daughters, which might explain their not being aware of their susceptibility to breast cancer.

(3) To correlate health behaviors and coping behaviors practiced by women with breast cancer and the health behaviors practiced by their daughters. Are the mothers coping so well that the daughters are misled about the potential severity of breast cancer?

(4) Specifically addressing this study, several next steps could be looked at such as doing in-depth interviews with the daughters and the control group to reach more detailed information about:
   - knowledge of breast cancer,
   - look at the women who did "not fit", i.e. those who placed a "low" value to health, those not aware of their risk to breast cancer and those that did not report BSE as a health behavior to be practiced.

(5) To design intervention studies, directed at this high risk population, which educate about risk factors; motivate and sustain health behaviors; and identify individual difference effects.

(6) The next study design should be methodologically more complex for example, (1) using a larger sample size; (2) looking at
sub-groups of women whose mothers have a good versus poor prognosis; (3) looking at those women who are sick with their treatments versus those who are not.

Health psychologists need to focus on these questions raised and prepare more sophisticated studies and educational programs. The educational programs should stress risk factors when teaching illness prevention and look at what methods might be most efficient and effective to achieve this goal.

Counseling needs of women with a maternal history of breast cancer is a whole new area for health psychologists to enter. In addition to counseling for the emotional concerns about their mother's illness, adult and adolescent daughters would undoubtedly benefit from a counseling service that provides:
- accurate information about breast cancer in general with special emphasis on risk factors and health behaviors to practice to minimize their risk.
- understanding the most effective ways to educate, motivate and sustain health behaviors that match each individual style of coping by the daughters.
- understanding of the particular barriers each daughter may have that prevents the routine practice of health behaviors.
- and to assess individual coping styles as healthy versus unhealthy for each individual daughter, understanding and respecting various coping methods.
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APPENDIX A
THE PSYCHOLOGICAL IMPACT OF MATERNAL HISTORY

OF BREAST CANCER

PILOT STUDY SUMMARY

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CPHE
Breast cancer, the most common type of cancer, affects one out of ten American women during their lifetime (ACS, Facts & Figures, 1987). Although breast cancer continues to be one of the major causes of cancer death among women, the five-year survival rate for localized disease detected early is approximately 90 percent (ACS Facts & Figures, 1987).

The principle risk factors for breast cancer include (1) family history and (2) 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.

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). BSE is a simple, safe and inexpensive procedure that has been shown to play an important role in early diagnosis of the disease. Because of the key role in early detection BSE should be practiced by all women especially by those at risk for the disease.

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. Therefore, it seemed timely to test several hypotheses concerning this at risk population.

The hypotheses to be tested included:

(1) There is no difference in the value placed on health between daughters whose mothers have breast cancer and a control group.

(2) There is no difference in the awareness of risk to self for breast cancer between women with a maternal history of breast cancer and a control group.

(3) There are no differences between health behavior practiced to minimize this risk between daughter with a maternal history of breast cancer and a control group.

In preparation for testing these hypotheses a small pilot study was done in order to test the structured interview questions that would be asked to a study population. Specifically the pilot study was done to determine several factors including: clarity of the questions, comprehensiveness, ease of obtaining responses and to gain an approximate length of time that the interview would take to conduct.

Method

Subjects

Participants included ten women and one man between 25 and 36 years of age. The ethnic background of the individuals included three
Black women, six Caucasian women, one Hispanic woman and one Caucasian man. All the participants worked in the same office as this investigator. Their occupations included a nurse, business manager, medical secretaries and receptionists.

Procedure

This investigator interviewed all the individuals in their work setting and took anywhere from five to twenty-five minutes.

Results and Discussion

All eleven participants answered all of the questions. During one of the interviews one woman admitted to having a mother with breast cancer.

Responses to Question One: Why do you believe people get certain diseases like diabetes, heart disease and cancer?

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<td>Diet</td>
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<tr>
<td>Lifestyle</td>
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<tr>
<td>God</td>
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<tr>
<td>Environment</td>
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</tr>
<tr>
<td>Punishment</td>
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<td>Overweight</td>
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Responses to Question Two: Do you believe diseases like diabetes, heart disease and cancer can be prevented by changing behaviors? If yes, what behaviors?

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<td>Stress</td>
<td>2</td>
</tr>
</tbody>
</table>

Responses to Question Three: Do you believe you are susceptible to any of these diseases? If yes, why?

<table>
<thead>
<tr>
<th>Responses</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heredity</td>
<td>4</td>
</tr>
<tr>
<td>I smoke</td>
<td>3</td>
</tr>
<tr>
<td>Overweight</td>
<td>1</td>
</tr>
<tr>
<td>Birth control pill</td>
<td>1</td>
</tr>
</tbody>
</table>

Responses to Question Four: What behaviors, if any, do you do to keep yourself healthy?
Two people reported practicing no behaviors to keep themselves healthy.

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>5</td>
</tr>
<tr>
<td>Exercise</td>
<td>4</td>
</tr>
<tr>
<td>Quit smoking</td>
<td>3</td>
</tr>
<tr>
<td>No caffiene</td>
<td>1</td>
</tr>
<tr>
<td>No drinking</td>
<td>1</td>
</tr>
</tbody>
</table>

Responses to Question Five: Which behaviors do you do routinely that you think might be harmful to your health?

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>I smoke</td>
<td>6</td>
</tr>
<tr>
<td>Poor diet</td>
<td>4</td>
</tr>
<tr>
<td>Overweight</td>
<td>2</td>
</tr>
<tr>
<td>Not enough exercise</td>
<td>2</td>
</tr>
</tbody>
</table>

In general, all but one individual understood all of the questions without difficulty. Several of the individuals needed extra probing or rewording of the question to respond. All of the responses corresponded with the answers expected of this investigator. It appeared that the questions were understandable and generated appropriate responses and took place in an acceptable time frame.

In evaluating the responses it appears that there is a desperate need to better educate those working in this investigator's work setting, which is disappointing since this is a medical oncology office. Evidence for this conclusion is that six out of the eleven
interviewed still smoke, with one believing she was susceptible to cancer because she took birth control pills. Question Three did illicit the desired response from one woman who admitted to a maternal history of breast cancer, which was not known by this investigator before asking her to participate.

In summary, the pilot study provided some interesting responses to the five questions. Each of the participants were very open and sincere in their responses. On the basis of these responses to this pilot study no revisions were made for the interview questions.
I. an adult (or legal guardian of a minor), have been invited to participate in a study of Impact of Maternal Breast Cancer on Young Women under the direction of Bonnie H. Taylor, RN, BS in which I voluntarily consent to participate.

The implications of my voluntary participation in this medical study, its nature, duration and purpose, the methods and means by which it is to be conducted, and the inconvenience and hazards which may be expected have been thoroughly explained to me by ____________________________.

I have read and understand all written materials which have been provided to me further describing the study and its potential risks and benefits to me.

I have been given an opportunity to ask any questions I wish concerning this study and all such questions have been answered to my complete satisfaction. I understand that I may terminate my participation in this study at any time without affecting the level of my medical care. I also understand that my participation in this study may be terminated at any time if in the opinion of my personal physician or the director of the study this is in my best interest. If I have any further questions, problems or questions about my rights as a research subject, I should contact the above named director of the study.

(If not applicable, check box). I certify that, to the best of my knowledge, I am not pregnant at this time. I agree that if I become pregnant during the course of this study I will notify the above named director of the study.

I understand that the information gathered in this study (including medical records) may be reviewed by the sponsor and appropriate government agencies, including the U.S. Food and Drug Administration (21 CFR Part 50.25 (a) (5)), when authorized by statute and regulation. I further understand that my identity will be kept confidential and no identifying information will be released or published.

I understand that in the event of injury resulting from this study, there is no compensation available from the Medical Center for such injury and that I will obtain any necessary medical care for such injury in the same manner in which I obtain any other medical care. (This notice is printed here pursuant to Federal regulations 21 CFR Part 50.25 (a) (6) and (7) and 45 CFR Part 46.116 (a) (6) and (7)). I understand that in the case of injury resulting from this study, I should contact the Office of Risk Management at (312) 942-7828.

I understand that the director of the study will inform me of significant new findings developed during the course of the study which may affect my willingness to continue to participate in the study.

Subject's signature and date

Signature of Parent or Guardian (when applicable)

I was present during the explanation referred to above, as well as the subject's opportunity for questions, and hereby witness his or her consent to participate in the study.

Witness signature and date

NOTE: Please type or print name below signature line. This consent form not valid without the Human Investigation Committee approval stamp. Signed copies of this form must be: a) retained on file by the Principal Investigator, b) deposited in the subject's medical record, and c) be given to the subject.

Attach subject information sheet to this form.
SUBJECT INFORMATION SHEET

Because health professionals (nurses, psychologists, 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 their health especially related to their 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 twenty minutes) and be briefly interviewed by a psychologist. 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 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 interview 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 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 have received a copy.

Volunteer's Signature & Date (or person authorized to consent for subject)

Investigator's Signature & Date

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

Witness's Signature & Date
HEALTH VALUE SCALE

Below you will find a list of ten values listed in alphabetical order. We would like you to arrange them in order of their importance to you, as guiding principles in your life.

Study the list carefully and pick out the one value that is the most important for you. Write the number "1" in the space to the left of the most important value. Then pick out the value that is second-most important to you. Write the number "2" in the space to the left. Then continue in the same manner for the remaining values until you have included all ranks from 1-10. Each value will have a different mark.

We realize that some people find it difficult to distinguish the importance of some of these values. Do the best that you can, but please rank all 10 of them. The end results should truly show how you really feel.

A COMFORTABLE LIFE (a prosperous life)
AN EXCITING LIFE (a stimulating, active life)
A SENSE OF ACCOMPLISHMENT (lasting contribution)
FREEDOM
HAPPINESS (contentedness)
HEALTH (physical and mental well-being)
INNER HARMONY (freedom from inner conflict)
PLEASURE (an enjoyable, leisurely life)
SELF-RESPECT (self-esteem)
SOCIAL RECOGNITION (respect, admiration)
APPENDIX D
MHLC Form A

This is a questionnaire designed to determine the way in which different people view certain health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you think you should believe or how you think we want you to believe.

1. If I get sick, it is my own behavior which determines how soon I get well again.  
   1 2 3 4 5 6

2a. No matter what I do, if I am going to get sick, I will get sick.  
   1 2 3 4 5 6

3. Having regular contact with my physician is the best way for me to avoid illness.  
   1 2 3 4 5 6

4. Most things that affect my health happen to me by accident.  
   1 2 3 4 5 6

5. Whenever I don't feel well, I should consult a medically trained professional.  
   1 2 3 4 5 6

6. I am in control of my health.  
   1 2 3 4 5 6

7. My family has a lot to do with my becoming sick or staying healthy.  
   1 2 3 4 5 6

8. When I get sick, I am to blame.  
   1 2 3 4 5 6

9. Luck plays a big part in determining how soon I will recover from an illness.  
   1 2 3 4 5 6

10. Health professionals control my health.  
    1 2 3 4 5 6

11. My good health is largely a matter of good fortune.  
    1 2 3 4 5 6

12. The main thing which affects my health is what I myself do.  
    1 2 3 4 5 6

13. If I take care of myself, I can avoid illness.  
    1 2 3 4 5 6

14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.  
    1 2 3 4 5 6

15. No matter what I do, I'm likely to get sick.  
    1 2 3 4 5 6

16. If it's meant to be, I will stay healthy.  
    1 2 3 4 5 6

17. If I take the right actions, I can stay healthy.  
    1 2 3 4 5 6

18. Regarding my health, I can only do what my doctor tells me to do.  
    1 2 3 4 5 6
(1) Why do you believe people get certain diseases like diabetes, heart disease and cancer?

(2) Do you believe diseases like diabetes, heart disease and cancer can be prevented by changing behaviors?

(3) Do you believe you are susceptible to any of these diseases?

(4) What behaviors, if any, do you do to keep yourself healthy?

(5) Which behaviors do you do routinely that you think might be harmful to your health?
APPENDIX F
DEMOGRAPHIC INFORMATION SHEET

NAME

ADDRESS

CITY

ZIP CODE

RACE

MARITAL STATUS

NUMBER OF BROTHERS

RELIGIOUS PREFERENCE

NUMBER OF SISTERS

DATE

BIRTHDATE

EDUCATIONAL BACKGROUND

Please check highest level attained.

☐ high school  ☐ college  ☐ graduate school

OCCUPATION

☐ Please check box if interested in receiving the group results of this study.

☐ Please check box if you have any questions regarding this study. I will be glad to telephone you.

Thank you,

Bonnie Taylor, R.N.
Approval Sheet

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

Dr. Gloria J. Lewis, Director
Associate Professor and Chairperson,
Counseling and Educational Psychology, Loyola

Dr. Marilyn Susman
Assistant Professor,
Counseling and Educational Psychology, Loyola

Dr. Katherine A. Billingham
Assistant Professor
Rush University

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

The thesis is therefore accepted in partial fulfillment of the requirements for the degree of Master of Arts.

November 21, 1988
Date

Gloria J. Lewis
Director's Signature