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Breast self-examination and the mastectomy patient

Gail Pieper
San Jose State University

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BREAST SELF-EXAMINATION AND THE MASTECTOMY PATIENT

A Thesis

Presented to

The Faculty of the Department of Nursing

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

By

Gail Pieper

May, 1996

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ABSTRACT

BREAST SELF-EXAMINATION AND THE MASTECTOMY PATIENT

by Gail Pieper

This thesis identified types of educational information provided to women about breast self-examination (BSE) and explored the attitudes and beliefs of women who have had mastectomies regarding cancer and the performance of BSE. A retrospective design was used to gather data from women who had mastectomies (N=50). The subjects were acquired from the mailing lists of a community hospital and a unit of the American Cancer Society in central California. The data collection tool sought women's responses in order to provide information that can be applied to health care delivery in continuing to provide education to women with mastectomies.

The data indicate that most women are performing BSE, felt that there were benefits to their performance and that the types of educational information provided were helpful. Suggestions for further research were recommended.

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Chapter 1

INTRODUCTION

Breast cancer affects one out of every nine women and is a leading cause of death for women in the United States (American Cancer Society, 1991, p. 9). When breast cancer is detected at an early stage, survival increases (Kurtz, Given, Given, & Kurtz, 1993, p. 252). Breast self-examination (BSE) is also recognized and recommended as a breast screening tool for early detection of breast cancer. It is described "as a safe, low-cost, non-invasive, self-screening test" (Nettles-Carlson, Field, Friedman, & Smith, 1988, p. 41). When breast cancer is detected at an early stage, treatment is more successful (National Cancer Institute, 1989, p. 4).

BSE is also encouraged and recommended as an important component of follow-up care after a mastectomy. Women who have had breast cancer are at higher risk for recurrence of breast disease, and performance of BSE is an important way of discovering any changes that may occur in order to detect recurrence at an early stage (National Cancer Institute, 1989, p. 4). Alagna, Morokoff, Bevett, and Reddy (1987) state that older women and women that have a family or personal history of breast disease are at the greatest risk for developing

breast cancer. Because of these factors, they further state that it is important to recognize the factors that affect BSE performance.

The research by Taylor, Lichtman, Wood, Bluming, Dosik, and Leibowitz (1984) and Grover, Amsei, Baishem, Kulpa, and Engstrom (1983) are among the few studies conducted regarding BSE among mastectomy patients. Further research needs to be done in order to better assess the population's needs in order to provide improved patient outcomes. Since BSE is recommended after a mastectomy, the types of educational information provided and the attitudes and beliefs that women have regarding cancer and the performance of BSE needs to be studied.

Although studies vary, performance of BSE by women ranges between 14-40% (Lauver, 1989). Many different explanations for this varying performance have been attributed to such reasons as attitudes and beliefs, psychosocial support, teaching methods, types of instructional information provided, motivation, threat of illness, and benefits of performance. Despite these varying reasons, studies have not determined what specific factors contribute to low performance of BSE (Glenn & Moore, 1990; Nettles-Carlson et al., 1988; Alagna et al., 1987).

Problem

Stein and Zera (1991) state that "until the age of 54, the leading cause of cancer-related deaths in women is breast cancer " (p. 938).

Sawyer (1986) states that "early detection offers the best weapon against the morbidity and mortality of breast cancer. Breast self-examination (BSE) is one health-promoting activity associated with early breast cancer detection" (p. 4).

BSE is recommended by the National Cancer Institute (NCI) and the American Cancer Society (ACS), and according to Lierman, Kasprzyk, and Benoliel (1991), is "an effective means of early detection of breast cancer" (p. 46). Despite this recommendation, only a small percentage of women perform BSE on a monthly basis (Lauver, 1989; Wyper, 1990).

Individuals who have had a mastectomy are at high risk for recurrence of the disease. Women with a previous history of breast disease are among those considered high risk. "Women with a history of primary breast cancer have a three to fourfold increase in risk for primary breast cancer in the contralateral breast" (Kelsey & Gammon, 1991, p. 155). Studies have shown that BSE performed by the individual or through physical examination is accountable for most discoveries of the

recurring breast cancer (Del Turco et al., 1994, p. 1593).

Purpose of the Study

The purpose of this study was to seek information from female mastectomy subjects to explore the performance of BSE in relation to the type of educational information provided about BSE. Current literature and research indicate that performance of BSE is an important tool in early detection and prevention of breast disease.

Research Questions

What type of educational information was provided to women that have had mastectomies? What are the attitudes and beliefs of women that have had mastectomies regarding cancer and the performance of BSE?

Definition of Terms

For the purpose of this study, the following definitions applied:

1. Breast Self-Examination is a health promoting technique that enables women to examine their breasts in order to discover any abnormal changes that may assist in the early detection of breast cancer.
2. Mastectomy is the "surgical removal of the breast" (NCI, 1989, p. 23).
3. Barriers are things or events that prevent BSE performance.

4. Recurrence is the "reappearance of cancer in the same site (local), near the same site (regional), or in other areas of the body (metastatic)" (NCI, 1989, p. 15).

5. Cancer is a "term for more than 100 diseases in which abnormal cells divide without control. Cancer cells can spread through the bloodstream and lymphatic system to other parts of the body" (NCI, 1993, p. 33).

6. High Risk is "something that increases a person's chance of developing a disease" (NCI, 1993, p. 37).

7. Early Detection is "finding and treating cancer early in order to have more treatment choices and better chances for recovery" (NCI, 1993, p. 4).

8. Support Groups are a mechanism for individuals to share an experience or disease that they have in common. The individuals meet to share their feelings and concerns as well as discover ways to find new information and handle their problems (NCI, 1989, p. 12).

9. Oncology Program is a method of delivering cancer education and support to individuals that have cancer and to their families or significant others, as well as providing health promotion, prevention and detection services/activities for the population at risk.

10. Educational Information is information that is provided regarding a mastectomy, recovery, BSE and breast cancer through written materials, instruction by a health care professional, videos or other educational means.

Design

Participants in the study who have had a mastectomy may have had some knowledge regarding BSE before surgery. These participants may have also received additional information and instruction following their mastectomies. Therefore, this study examined the types of educational information the participant received, demographic information regarding the participants and their breast histories, and data about the participant's performance of BSE.

Frequencies and percentages were utilized to summarize the information collected from the questionnaires that the participants completed. The information collected should offer insight into the types of educational information provided and the attitudes and beliefs that women have regarding cancer and the performance of BSE after a mastectomy. The information collected may identify problems, strengths, or opportunities for improvement regarding the type of educational information that may or may not have been provided after a mastectomy.

Summary

Considering the importance of the performance of BSE in the early detection of recurring breast disease, individuals that have had mastectomies were surveyed to gather data regarding the education provided and the attitudes and beliefs of the participants about cancer and the performance BSE. Many variables may account for the performance or lack of performance of BSE in the subjects studied. These variables were reviewed and considered as they pertain to the performance of BSE. In general, performance of BSE is low considering the awareness and publicity of breast cancer in women over the last several years. Since mastectomy patients are at risk for recurrence of breast disease, it is important to study performance of BSE in these individuals.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

The importance in performance of BSE in women with mastectomies has been established. Performance of BSE is a positive health behavior, but compliance with performance of BSE has been a continuous problem with women of all ages. Many studies have been based on women's non-compliance with BSE performance. In order to best understand determinants and predictors of health behavior in performance of BSE in women with mastectomies, the Health Belief Model (HBM) was used to study educational information in BSE.

Conceptual Framework

The conceptual framework selected for this study is based upon the Health Belief Model (HBM). This theory is the most widely used and studied in its relationship to BSE, and according to Champion (1991), "has had the greatest influence on research related to predicting BSE behavior" (p. 733). This theory helps to explain reasons for performance or nonperformance of BSE and also demonstrates components that are valuable when analyzing the compliance with performance of BSE in women who have had mastectomies. This theory and the studies based upon this model also indicate important information that can be utilized in nursing practice, health promotion programs and education to further enhance BSE performance

among women with mastectomies.

In the study by Wyper (1990), the HBM was used to determine why the public did not utilize screening tests to detect disease at an asymptomatic stage. Since its development, the HBM has undergone many changes, but according to Mikhail (1981), an individual's action regarding a health condition depends upon the psychological readiness of the individual related to the perceived benefits of the action weighed against the barriers to the action (p. 67). Wyper also refers to the study by Rosenstock (1974) where an individual's perceived susceptibility and severity are related to and dependent upon knowledge (p. 421).

Rutledge and Davis (1988) best explain the HBM in this way:

In this model, it is the subjective experience of the individual that determines whether that person will engage in a certain health behavior.

In its simplest form, the HBM consists of two main constructs: perceived threat of illness, and perceived benefit of some health action in reducing the threat. When both perceived threat and perceived benefit of action are high, the likelihood of performing the action is high. (p. 175)

Included in this ideology are high motivation towards good health and cues or prompts that trigger action (Rutledge & Davis, 1988, p. 175). Walker and Glanz (1986) include in their description of the HBM some of the variations and expansions that have been included in BSE studies which include "BSE

knowledge and instruction factors, general preventive health behaviors, and attitudes toward medical care" (p. 171).

Review of Literature

Many studies have been done on the performance of BSE in women; yet it is not clearly understood what components increase practice of BSE. The findings of these studies have been incorporated into different educational or informational methods that encourage practice and performance of BSE. It is important to understand and study the reasons behind performance of BSE, because it continues to be one of the most effective low-cost and convenient methods of early detection of breast cancer (Walker & Glanz, 1986, p. 169). The studies of the relationship between the concepts of HBM and BSE help provide valuable information that has been incorporated into the educational information that has been provided to women to encourage BSE practice.

Rutledge and Davis (1988) based their study of the HBM on the concept that an individual's experience is subjective and determines certain health behaviors. Their study assessed "BSE learning experience, beliefs, and knowledge of BSE" (p.175). Items that were measured in the study were from an adapted HBM that included perceived seriousness of disease, perceived susceptibility, perceived benefit of action, barrier to action, general health motivation and specific non-HBM variables. The non-HBM variables included

support from family or friends and physician interest in BSE performance. The study showed that the seven predictors supported the HBM in regards to BSE behavior (Rutledge & Davis, 1988, p. 175). Implications of the study validate the importance of including concepts such as susceptibility or seriousness of breast cancer, discussion of specific barriers that deter performance, lack of confidence in the ability to perform BSE, and support or involvement from a significant other in the BSE teaching method. Two other variables in the study that were significant in promoting a regular habit of BSE performance were the physical involvement and inclusion of reminder cues (p.178).

In the study by Wyper (1990), HBM variables were combined into “threat of breast cancer and net perceived efficacy of BSE to ensure performance in relationship to frequency and thoroughness” (p. 421). The two variables that explained the variance of BSE performance were “susceptibility and barriers” (Wyper, 1990, p. 427). Wyper (1990) stated that “the most consistent finding is the significant negative relationship between barriers and all measures of BSE” (p. 427). Wyper further concludes that seriousness of the disease is a poor predictor of BSE performance in that it has been utilized in a preventive model. Seriousness is a subjective interpretation based on experience of the individual (p. 427). In the study by Taylor et al. (1984), BSE performance was investigated in women with a diagnosis of breast cancer. The study

showed that the performance of BSE in women with breast cancer was 43%, which did not vary significantly from BSE performance in women in the general population (p. 2528). The study by Alagna et al. (1987) showed similar results in women at high risk for breast cancer, where BSE practice was not greater when compared to women with a low risk for breast cancer (p. 29).

Calnan and Moss (1984) demonstrated BSE performance was correlated to the variable of perceived cost and benefits of BSE. Women were less likely to practice BSE if they did not perceive any benefits in performance (p. 206). Some of these determinants (benefits) of BSE performance were personal belief in susceptibility to cancer as well as a perceived threat (Walker & Glanz, 1986, p. 170). Perceived benefits include ability to discover a lump at an early stage, thus decreasing the morbidity and mortality of breast cancer (Champion, 1991, p. 737). Other determinants that influence BSE performance are social influence to perform BSE, personal motivation, positive attitude and perception of the importance of BSE, confidence in skill of BSE practice, previous performance/practice of BSE, and knowledge and education regarding BSE (Calnan & Moss, 1984; Lierman & Powell-Cope, 1994; Kurtz, 1993; Walker & Glanz, 1986; Lierman, 1991).

Many studies have demonstrated the multiple barriers that have a negative effect on BSE performance. As stated by Champion (1991), "women who perceive more barriers to BSE are the least likely to

practice it" (p. 737). Walker and Glanz (1986) found that a small amount of fear would not motivate a woman to perform BSE. A lot of fear could inhibit the performance of BSE. Women are fearful that they may discover breast cancer (p. 170). Kurtz (1993) stated that barriers to BSE practice include:

lack of breast self-exam knowledge and skill, doubts about self-efficacy or ability to perform breast-examination, doubts about the efficacy of breast self-examination in detecting abnormalities and reducing risk, forgetfulness, lack of a strong physician recommendation, misunderstanding of recommended frequency. (p. 252)

Other barriers identified by Champion (1991) include embarrassment in performance of BSE as well as problems with remembering to practice BSE (p. 737). Lierman (1991) also found that women who were infrequent performers of BSE felt that BSE wasted their time, and they had a tendency to procrastinate or believed that BSE was unimportant if there was no familial or personal history of breast cancer (p. 58).

Although few studies have been done on women who are high risk for cancer, some important information has been found that can be utilized in the education that is provided to high risk women in relationship to performance of BSE. The study by Alagna et al. (1987) showed that women who have an increased perception of the severity of breast cancer practiced BSE less. Alagna et al. suggested that women needed to have BSE

encouraged and emphasized, needed to be informed regarding the severity of breast cancer without increasing the perceived threat, and needed to have BSE instruction provided to them. Women need to be reassured that practicing BSE will increase their chance of survival (p. 45).

Demographic data in the studies of BSE also provided information that is useful in providing educational information to various populations of women. In the study done by Taylor et al. (1984), it was found that younger women practiced BSE more often than older women. They also pointed out that "older cancer patients are less likely to seek out information about their cancer care and are more likely to adopt a passive patient role concerning their care than are younger patients" (p. 2531). Fulton (1991), in a study on screening behavior, noted that women with a socioeconomic disadvantage were less likely to receive preventive care and were less likely to use breast cancer screening (p. 418). Champion (1991) found in her study of behaviors associated with breast cancer detection that "BSE behavior did not correlate significantly with demographic variables such as age, marital status, socioeconomic status, and race" (p. 737).

Summary

Women who have had mastectomies are at high risk for recurrence of breast cancer. BSE is an early detection practice that increases the chances of survival for this population of women. BSE practice, despite this knowledge,

remains low and not completely understood. Many studies have been done utilizing the Health Belief Model to help better understand barriers to performance and determinants for infrequent or frequent practice. After reviewing the many variables that are involved in human behavior, continued research needs to be done in order to provide and develop education regarding BSE to women with mastectomies.

Chapter 3

METHODOLOGY

Design

A retrospective design was used to explore the types of educational information provided to women who have had mastectomies and the attitudes and beliefs that these women have about cancer and the performance of BSE. Data were collected during the months of July and August 1995 from 113 questionnaires mailed to women who had mastectomies at a hospital with a dedicated oncology unit and program or who were on the mailing list from a local unit of the American Cancer Society. Control groups and interventions were not used in the study.

Subjects/Setting

Subjects in the study were a convenience sample acquired from the mailing lists of a community hospital and a unit of the American Cancer Society in central California. Fifty women, a 44% return rate, responded to the questionnaires. The sample included women in the age ranges of 22-30 years to 61 years and above. Prior to mailing, efforts were made to eliminate any duplication of individuals on the mailing lists or any individuals that may have expired since the lists were acquired. Despite these efforts, one unanswered questionnaire was returned by the husband of a

female who died during the study.

All participants in the study were informed of confidentiality, anonymity, benefits and risks of the research through an agreement letter that was mailed with the questionnaire (Appendix A). Participation in the study was voluntary. A returned questionnaire indicated consent to participate in the study. Consent to participate in the study was explained in the letter and indicated with a completed questionnaire.

Human Subjects Approval

Approval to use human subjects was obtained from the community hospital, first from the Nursing Research Committee (Appendix B) and subsequently from the Institutional Review Board of the hospital (Appendix C). The Board of Directors of the hospital then gave permission for the study (Appendix D). Permission was also requested and granted from the local unit of the American Cancer Society (Appendix E). Following these permissions, approval was sought and obtained from the Institutional Review Board, Human Subjects, of San Jose State University (Appendix F).

Data Collection/Analysis Procedures

In July 1995, the Breast Self-Examination Questionnaire, a consent letter, and a stamped self-addressed return envelope were mailed to the women on the mailing lists of the participating institution and agency. The mailed material was copied on brightly colored paper, cheerful stickers were applied to the

envelopes and a piece of candy was sent along in the envelope to encourage participation.

Data collection by mail was selected because of the convenience and ease the method provided. This method of data collection also provided privacy for individuals in material that covered sensitive and personal information. No interviewing or observation was necessary, thereby decreasing bias and maintaining objectivity. Frequencies and percentages were utilized to summarize the data collected.

Instruments

The data collection instrument gathered information from the participants regarding the type of education provided about breast self-examination and the attitudes and beliefs about cancer and the performance of BSE. The tool was developed by the researcher incorporating information from a literature search, education, and experience in nursing practice over the last 20 years. The tool's readability statistics calculated by Flesch-Kincaid was 9.4 grade level (Grammatick for WordPerfect, 1994) and by SMOG Testing was 10th grade level (Doak, Doak, & Root, 1986). The researcher has been a nursing director of an oncology unit and program for the for the past 5 years and is currently an oncology certified nurse.

The instrument utilized in this study was a 18 item close-ended questionnaire (Appendix G). Ten of the questions utilized fixed-response items.

The Likert scale format was utilized incorporating “strongly agree,” “agree,” “disagree,” and “strongly disagree.” The customary fifth response, “undecided,” was omitted to encourage the respondent to select an answer. The respondent still had the option to skip or leave blank the question. The remaining seven questions gathered demographic data regarding the participant, thereby identifying any trends or patterns.

Current studies and research were utilized in the tool development. The content of the instrument was reviewed by a master’s prepared oncology nurse specialist with extensive education and clinical experience in advanced practice regarding the care and education of the patient experiencing and facing cancer. The instrument was also reviewed by a master’s prepared nurse with a background in education of families in various clinical and non-clinical environments and who is currently working as a nurse and patient educator in a community based hospital with an active oncology unit and program. The instrument was also reviewed by a university professor with a background in instrument preparation and development.

The 18 items on the questionnaire provided various types of information for the researcher. Items 1 and 8 addressed the individual’s comfort level in performing breast self-examination. Items 3 and 5 dealt with the understanding of the educational material provided in relationship to the importance and benefit of performing breast self-examination. Items 2 and

10 questioned if the education the participant may or may not have received was helpful and sufficient.

Items 4 and 9 indicated the individual's personal attitude or belief regarding personal and societal responsibility toward health maintenance, prevention, and detection. Anxiety and fear of recurrence were questioned in items 6 and 7 to investigate if these emotions hindered or encouraged the performance of breast self-examination.

Demographic information regarding the participants in the study was collected in items 11 through 18. Items 11 and 18 identified data regarding the age and the formal educational level of the individuals in the study. Items 12 and 15 identified if the mastectomy was unilateral or bilateral and how much time had elapsed since the surgery was completed. Item 13 addressed the current frequency of performance of breast self-examination. Items 14 and 17 identified the source of the educational material and the type of educational material regarding breast self-examination.

The methodology for gathering data from the participants in the study was effective. Fifty individuals completed the questionnaire that was mailed providing an adequate sample size for analysis of the findings and interpretation of the data. The findings and interpretation will provide information about women with mastectomies regarding their performance of BSE and the attitudes and beliefs they have about cancer and performance of breast self-examination.

Chapter 4

FINDINGS

The purpose of this study was to identify the types of education provided to women about BSE and the attitudes and beliefs of women who have had mastectomies regarding cancer and the performance of BSE. Performance of BSE is a health promotion behavior that is an effective measure for early detection and prevention of breast cancer and provides an opportunity to combat the morbidity and mortality of breast cancer.

Sample Characteristics

One hundred and thirteen women who had mastectomies and who were on the mailing lists from a community hospital and a unit of the American Cancer Society in central California were asked to participate in the study. Fifty participants that returned completed questionnaires, for a return rate of 44%.

The characteristics of the sample, including age, location of the mastectomy, performance of BSE, learning about BSE, discovery of breast disease, type of information received about BSE, and level of education, are presented in Table 1. These data were collected from items 11-18 on the questionnaires.

In Table 1, Item 11 asked for the participant's age. No participants were

Table 1
CHARACTERISTICS OF THE SAMPLE (N = 50)

Age of the Participants	<u>n</u>	%
Under 21	0	0
22 - 30 years	2	4
31 - 40 years	1	2
41 - 50 years	11	22
51 - 60 years	16	32
61 years and above	20	40
Location of Mastectomy	<u>n</u>	%
One side	42	84
Two sides	7	14
No response	1	2
Performance of BSE	<u>n</u>	%
Never	5	10
Once a month	19	38
More than once a month	16	32
More than 5 times a year	5	10
Less than 5 times a year	5	10
Learning About BSE	<u>n</u>	%
At the doctor's office	23*	46
From the American Cancer Society	15*	30
At the hospital	4*	8
Other	14*	28
No response	1	2
No information	1	2
Elapsed Time Since Mastectomy	<u>n</u>	%
Six months or less	7	14
Seven months to 23 months	8	16
Two years	3	6
More than two years	30	60
No response	2	4

*Represents more than sample size due to more than one response to question

Table 1 (cont.)
CHARACTERISTICS OF THE SAMPLE (N = 50)

Discovery of Breast Disease	<u>n</u>	%
My performance of BSE	25	50
Doctor performance of BSE	5	10
Mammogram	10	20
No response	2	4
Husband's discovery	1	2
Multiple response	7	14
Type of Information	<u>n</u>	%
None	3	6
Pamphlets/materials from the hospital	16*	32
Pamphlets/materials from the doctor's office	21*	42
Video from the hospital	2*	4
Video from the doctor's office	2*	4
Demonstration by health care professional at the hospital	6*	12
Demonstration by health care professional at the doctor's office	13*	26
Demonstration by health care professional in my home	0	0
Other	17*	34
Level of Education	<u>n</u>	%
High school graduate	9	18
One year of college or more	20	40
College graduate	11	22
Master's degree/ PhD	8	16
Graduate level work without degree	2	4
Other	0	0

*Represents more than sample size due to more than one response to question

under the age of 21 years. Two participants were in the range of 22-30 years (4%), and one participant was in the 31-40 year range (2%). Eleven participants were in the 41-50 year range (22%), and 16 participants were in the 51-60 year range (32%). The largest number of participants were 61 years and above, which represents 40% of the population.

Item 12 on the questionnaire asks participants to describe the location of their mastectomy. Forty-two of the participants (84%) responded with one side, and seven participants (14%) responded with two sides. One participant (2%) did not respond to the question.

Item 13 asked the participants in the survey how often they performed breast self-examination. Five women (10%) responded that they never performed BSE. Nineteen women (38%) perform BSE once a month, and 16 women (32%) perform BSE more than once a month. Five women (10%) responded that they performed BSE more than 5 times a year, and five women (10%) responded that they performed BSE less than 5 times a year.

Of the five women that never perform BSE, three of the women had bilateral mastectomies, one had a unilateral mastectomy on one side and a lumpectomy on the other side, and one woman had a unilateral mastectomy. Two of the 5 women were given no information and did not understand the importance of BSE after a mastectomy. Three of the women did not feel comfortable with their performance of BSE. Four of the 5

women responded that they discovered their breast disease from their performance of BSE. One of the 5 participants wrote in that she relies on her physician's performance of BSE every 6 months, and one woman wrote in that she had no breast tissue left, but that even if she did, she probably would not perform BSE due to the "fear factor."

Item 14 on the questionnaire asked the participants how they learned about BSE. Eight participants circled more than one response for their possible answers for a total of 58 responses to Item 14. The data represent a larger number of responses because of this factor. Areas where multiple responses were indicated are represented with an asterisk.

Twenty-three participants (46%) responded that they learned about BSE at the doctor's office. Fifteen women (30%) learned about BSE from the American Cancer Society, and four women (8%) learned about BSE from the hospital. Fourteen women 28% gave other sources for learning about BSE. Written responses for learning about BSE included magazines, "many different areas," mammogram center, mammogram tech, TV, high school health class, nurse's talk at a local organization, women's health education class, readings, nurses' training, mother, and a human sexuality course. One participant (2%) wrote that she received no information. It can be inferred from this data that there are many different areas and sources of learning about BSE learning about BSE that a woman is exposed to and has the opportunity to

learn about. Of the 50 participants, 98% have received information about BSE.

As shown in Table 1, Item 15 asked the participants how much time had elapsed since their mastectomy. Seven women (14%) responded that their mastectomies had been 6 months or less. Eight women (16%) had their surgeries within 7 months to 23 months. Three participants (6%) responded that it had been 2 years since their surgery, and 30 participants (60%) responded that it had been more than 2 years since their mastectomy. Two participants (4%) did not respond to the question.

Item 16 asked the participants in the survey how they discovered their breast disease. Twenty-five (50%) women responded that they discovered their breast disease by their performance of BSE. Ten participants (20%) responded that their breast disease was discovered through a mammogram. Two participants (4%) did not respond to the question. One woman wrote that her husband discovered her breast disease. Seven participants (14%) answered by circling more than one answer as to how they discovered their breast disease. Of the women that had multiple responses to their discovery of breast disease, 6 out of the 7 women discovered their breast disease from their own performance of BSE and a mammogram, 2 indicated that the discovery was made from the physician's performance of BSE in addition to their performance, and one discovery of breast disease was made by the

physician's performance and a mammogram.

Item 17 asked the participants to identify all types of information they received regarding BSE. There were a total of 80 types of information identified by the 50 participants. Three participants (6%) stated that they received no information regarding BSE. Sixteen participants (20%) responded that they received pamphlets or written materials from the hospital. Twenty-one (26%) participants answered that they received pamphlets or written materials from the doctor's office. Two participants (4%) answered that they watched a video from the hospital, and two participants (4%) answered that they watched a video from the doctor's office. Six participants (12%) responded that BSE was demonstrated to them by a health care professional at the hospital. Thirteen participants (26%) responded that BSE was demonstrated to them by a health care professional at the doctor's office. No participants responded that BSE was demonstrated to them by a health care professional in their home. Seventeen participants (34%) responded that other methods or types of information were utilized for BSE. Other responses written in by the participants included information and demonstration at a women's club meeting, information from the American Cancer Society, information from magazines, information from a program offered to reach to recovery volunteers, information from the mammogram center, information from a video from the American Cancer Society, information from television, and information from a

a visiting nurse at her company. However, it can be inferred that women receive various types of information about BSE from a multitude of sources and that the information is available through many different methods.

Item 18 asked the participants what the highest level of education was that they achieved. Nine participants (18%) answered that they were high school graduates. Twenty participants (40%) responded that they had 1 year of college or more, and 11 participants (22%) responded that they were college graduates. Eight participants (16%) responded that they had a master's degree or PhD. Two participants (4%) wrote in that they had completed graduate level education without receiving a degree. It seems unlikely that this sample represents only high school or college graduates. No one with less than a high school education completed the questionnaire.

Participants' Attitudes and Beliefs Regarding Breast Self-Examination and Educational Information

Table 2 shows the data gathered from items 1-10 on the questionnaire mailed to the participants. Items 1, 2, 3, 5, 7, 8 and 10 question participants' attitudes and beliefs regarding BSE. Item 1 asks the participants if they felt comfortable with their own performance of BSE. Fifteen participants (30%) strongly agreed, and 19 participants (38%) agreed for a total of 68% that felt comfortable with their own performance of BSE. Twelve participants (24%) disagreed, and one participant (2%) strongly disagreed for a total of 26% that

Table 2
FREQUENCY DISTRIBUTION OF PARTICIPANTS' ATTITUDES
AND BELIEFS (N = 50)

Comfort with Own Performance of BSE	<u>n</u>	%
Strongly agree	15	30
Agree	19	38
Disagree	12	24
Strongly disagree	1	2
No response	3	6
More Information About BSE	<u>n</u>	%
Strongly agree	2	4
Agree	7	14
Disagree	23	46
Strongly disagree	14	28
No response	4	8
Importance of BSE After Mastectomy	<u>n</u>	%
Strongly agree	32	64
Agree	13	26
Disagree	1	2
Strongly disagree	2	4
No response	2	4
Health Care Professionals for Follow-up and Detection	<u>n</u>	%
Strongly agree	8	16
Agree	11	22
Disagree	10	20
Strongly disagree	20	40
No response	1	2

Table 2 (cont.)
FREQUENCY DISTRIBUTION OF PARTICIPANTS' ATTITUDES
AND BELIEFS (N = 50)

No Benefits in BSE After Mastectomy	<u>n</u>	%
Strongly agree	0	0
Agree	2	4
Disagree	32	64
Strongly disagree	14	28
No response	2	4
Concern That Breast Cancer Will Reoccur	<u>n</u>	%
Strongly agree	15	30
Agree	27	54
Disagree	7	14
Strongly disagree	1	2
BSE Presents a Threat	<u>n</u>	%
Strongly agree	6	12
Agree	19	38
Disagree	11	22
Strongly disagree	13	26
No response	1	2
Comfort With Doctor/Nurse Performance of BSE	<u>n</u>	%
Strongly agree	4	8
Agree	22	44
Disagree	8	16
Strongly disagree	15	30
No response	1	2

Table 2 (cont.)
FREQUENCY DISTRIBUTION OF PARTICIPANTS' ATTITUDES
AND BELIEFS (N = 50)

Too Much Emphasis on Mastectomy		
or Breast Disease	<u>n</u>	%
Strongly agree	3	6
Agree	3	6
Disagree	26	52
Strongly disagree	18	36
Educational Information About BSE Helpful		
	<u>n</u>	%
Strongly agree	11	22
Agree	34	68
Disagree	0	0
Strongly disagree	2	4
No response	3	6

did not feel comfortable with their own performance of BSE. Three participants (6%) did not answer the question.

Of the 13 participants that did not feel comfortable with their own performance of BSE, all 13 agreed or strongly agreed that they felt more comfortable with a doctor's or nurse's performance of BSE. Four of the 13 participants indicated that their highest educational level completed was high school, 7 participants answered that they had 1 year of college, one participant was a college graduate, and one participant had a master's degree/PhD.

Item 2 asked participants if they needed more information about BSE.

Two participants (4%) strongly agreed, and seven participants (14%) agreed that they needed more information about BSE. Twenty-three participants (46%) disagreed and 14 participants strongly disagreed that they needed more information about BSE. Four participants (8%) did not respond to the question. It can be inferred from the responses that 74% of the participants felt that they had received enough information regarding BSE. Of the 18% who felt that they needed more information, 5 responded to question 1 that they did not feel comfortable with their own performance of BSE.

Item 3 asked the participants if they understood the importance of BSE after their mastectomies. Thirty-two participants (64%) strongly agreed, and 13 participants (26%) agreed, for a total of 90% who understood the importance of BSE after a mastectomy. One participant (2%) disagreed, and two participants (4%) strongly disagreed that they knew the importance of BSE after a mastectomy. Two participants (4%) did not respond.

Item 5 asked the participants if they believed no benefits exist in the performance of BSE after a mastectomy. No participants answered that they strongly agreed. Two participants (4%) agreed that there were no benefits in BSE after a mastectomy. Fourteen participants disagreed (28%), and 32 participants (64%) strongly disagreed, for a total of 90% that felt that there were benefits in the performance of BSE after a mastectomy.

Item 7 asked the participants if they felt that the performance of BSE

presented a threat of discovering a lump. Six participants (42%) strongly agreed, and 19 participants (38%) agreed, for a total of 50% that felt that BSE did present a threat in discovering a lump. Thirteen participants (26%) disagreed, and 11 participants (22%) strongly disagreed, for a total of 48% that felt that the performance of BSE did not present a threat of discovering a lump. One participant (2%) did not respond to the question. One participant stated that she had a fear of metastasis, and one participant crossed off the word "threat" and wrote in "fear" of discovering a lump.

Item 8 of the questionnaire asked the participants if they felt more comfortable if the doctor or nurse performed BSE. Four participants (8%) strongly agreed, and 22 participants (44%) agreed, for a total of 52% that felt more comfortable if a doctor or nurse performed their BSE. Fifteen participants (30%) disagreed, and eight participants (16%) strongly disagreed, for a total of 46% that did not feel more comfortable with a doctor's or nurse's performance of their breast self-exam. One participant (2%) did not respond to this question.

Item 10 asked the participants if the educational information provided about breast self-examination was helpful. Eleven participants (22%) strongly agreed, and 34 participants (68%) agreed, for a total of 90% that felt that the educational information about BSE was helpful. No participants disagreed that the educational information about BSE was helpful. Two participants strongly disagreed (4%), and three participants (6%) did not respond to the question.

Items 4, 6, and 9 ask the participants about their attitudes and beliefs regarding cancer. Item 4 asked the participants if they felt that physicians, nurses, or other health care professionals were responsible for their follow-up and detection of any reoccurring breast disease. Eight participants (16%) strongly agreed, and 11 participants (22%) agreed that health care professionals were responsible for their detection and follow-up. Twenty participants (40%) disagreed, and 10 participants (20%) strongly disagreed, for a total of 60% that felt that health care professionals were responsible for their follow-up and detection.

Item 6 asked the participants if they were concerned that breast cancer would reoccur. Fifteen participants (30%) strongly agreed, and 27 participants (54%) agreed, for a total of 84% that were concerned that breast cancer would reoccur. Seven participants (14%) disagreed, and one participant (2%) strongly disagreed, for a total of 16% who stated that they were not concerned that breast cancer would reoccur. One of the participants that disagreed wrote in that she was more worried about metastasis.

Item 9 asked participants if they felt that too much emphasis was placed on discussing their mastectomies or breast disease. Three participants (6%) strongly agreed, and three participants (6%) agreed, for a total of 12%. Twenty-six participants (52%) disagreed, and 18 participants (36%) strongly

disagreed, for a total of 88% that did not feel that too much emphasis was placed on discussing their mastectomies and breast disease.

Performance of BSE and Elapsed Time Since Mastectomy

Figure 1 shows the participants' performance of BSE as compared to elapsed time since their mastectomy. Data were gathered from items 13 and 15 of the questionnaire that was mailed to the participants. Data from item 13 and item 15 are displayed in Table 1. For seven of the participants whose surgery was 6 months or less, four participants (8%) responded that they performed BSE once a month, one (2%) responded more than once a month, and one participant responded more than five times a year. One participant (2%) responded less than five times a year, and no participants responded that they never performed BSE. Forty-two of these women had mastectomies on one side, which may indicate that they were performing BSE on the opposite side and or on the mastectomy side. It is unknown if they were performing BSE on the side of their mastectomies.

Participants responded that the elapsed time since their mastectomies was 7 months to 23 months. Two participants (4%) responded that they performed BSE once a month, one (2%) responded more than once a month, two participants (4%) responded more than five times a year, and one (2%) responded less than five times a year. Of the three participants that responded 2 years for the elapsed time since their surgery, two (4%) responded

Figure 1
PERFORMANCE OF BSE AND ELAPSED TIME SINCE MASTECTOMY

1 = Six months or less 2 = Seven to 23 months 3 = Two years
4 = More than 2 years

that they performed BSE once a month, and one (2%) responded more than once a month.

The majority of the 29 (58%) responses came from participants that had more than 2 years of elapsed time since their mastectomies. Three (6%) of the participants responded that they never performed BSE. Ten (20%) participants performed BSE once a month, and 11 (22%) performed BSE more than once a month, for a total of 42%. Two (4%) participants responded that they performed BSE more than five times a year, and three (6%) of the participants responded that they performed BSE five times a year.

The data in Figure 1 indicate that regardless of the length of time since surgery, 38 participants (78%) perform BSE more than five times a year, and 33 participants (66%) perform BSE at least once a month. Five participants (10%) never perform BSE, and five participants (10%) perform BSE less than five times a year, for a total of 20%. Of the participants that never perform BSE, three had bilateral mastectomies. It is unknown why these women do not perform BSE, but explanations may be related to lack of knowledge regarding recurrence of breast cancer, reliance on physician performance of BSE, or lack of knowledge regarding the technique of BSE performance after a mastectomy.

Summary of Findings

The findings of the study indicate that most of these women who had mastectomies received information about BSE from many different sources.

These women received this information through various methods of instruction. Most of these women felt that the information they received about breast self-examination was helpful. The study also found that the breast disease of the participants was discovered through multiple methods; the significant method of discovery was the woman's own performance of BSE.

Findings from the participants' attitudes and beliefs showed that these women felt that there were benefits from the performance of BSE after surgery and that they understood the importance of BSE after a mastectomy. Most of the women were concerned that their breast cancer will reoccur. It was also found that although the majority of women felt comfortable with their own performance of BSE and felt that they were responsible for follow-up and detection of their breast disease, some of the women felt uncomfortable with their own performance of BSE and felt comfortable with the doctor's or nurse's performance of BSE. The findings also showed that 80% of women who have had mastectomies reported that they regularly perform BSE. This a significant difference in the practices reported for women in the general population.

Chapter 5

DISCUSSION

The summary, conclusions, scope, limitations and recommendations from the study of breast self-examination and mastectomy patients will be discussed in this chapter. The purpose of this study was to identify the types of educational information provided to women about BSE and the attitudes and beliefs of women who have had mastectomies regarding cancer and the performance of BSE.

Implications for nursing practice in the hospital and office setting regarding educational information also will be addressed. The conceptual framework selected for this study was based upon the Health Belief Model (HBM). This theory is based upon readiness to learn and perceived benefits of the action to be taken in relationship to the barriers to the action (Mikhail, 1981).

The data collection tool used in the survey was a questionnaire mailed to women who had mastectomies that were on mailing lists from a community hospital and a chapter of the American Cancer Society in central California. The purpose of the questionnaire was to look at women's responses about performance of BSE and educational information in order to provide helpful information that can be used by health care professionals as they provide education to women with mastectomies.

Conclusions

Fifty participants responded to the questionnaires that were mailed to 113 women. The results showed that 72% of participants were 51 years and above. This is consistent with the research by Stewart and Foster (1989) that women over the age of 50 years represent close to 70% of the diagnosed breast cancer. Twenty-eight percent of the remaining participants were between 22 and 50 years of age. Stein and Zera (1991) state that "until the age of 54, the leading cause of cancer-related deaths in women is breast cancer" (p. 938). Breast cancer as a disease begins to increase between 35-40 years, increases at a faster rate until 50 years, and then continues to increase but more slowly after the age of 50 years (Kelsey & Gammon, 1991; Dienger & Llewellyn, 1991). The importance of early detection, diagnosis, and treatment remains significant regardless of age as "breast cancer is the leading cause of cancer-related death in women in the United States" (Hortobagyi & Buzdar, 1995, p. 199).

Findings regarding performance of BSE demonstrate 70% of women perform BSE at least once a month, and 10% perform BSE more than 5 times a year. Research indicates that in general the performance of BSE in the general population varies from 14-40% (Lauver, 1989). The study done by Taylor et al. (1984) found "that as few as 43% of women practice BSE following the diagnosis of a malignant breast tumor" (as cited in Dienger & Llewellyn,

Since the participants' responses in this study indicate a higher percentage performing of BSE, several implications can be made. Studies indicate that frequency of performance of BSE does not imply quality, proficiency, or accuracy of the technique. The studies further show that women are using improper technique (Haughey et al., 1988; Newcomb et al., 1991; Dienger & Llewellyn, 1995; & Lauver, 1989). One questions if the participants in this study are practicing BSE utilizing the proper technique as recommended by the American Cancer Society. Dienger and Llewellyn (1995) found that "experts emphasize that in order for BSE to be an effective early detection mechanism, the technique should be performed proficiently" (p. 360).

Other factors that may have influenced the performance of BSE with the participants in this study include fear, vulnerability, personal control, age, prior practice, health behaviors, confidence in performance, social support, type of education received, readiness to perform or learn, attitude and beliefs, benefits of performance, personal motivation, established schedule for performance and perceived severity (Lierman et al., 1991; Alagna et al., 1987; Owen & Long, 1989; Wyper, 1990; Worden et al., 1987; Taylor et al., 1984). One factor that may have had a significant influence upon these women was the social support that many of participants may have had because of their contact with a community hospital with an active cancer program that

has ongoing breast cancer support groups or the American Cancer Society's Reach to Recovery Program. Three women mentioned that they were Reach to Recovery volunteers.

Sixty-eight percent of the participants felt comfortable with their own performance of BSE, 90% understood the importance of BSE after their mastectomies, 90% of the participants did not feel that there were no benefits in BSE after a mastectomy, and 88% of the participants did not feel that there was too much emphasis on their mastectomy or breast disease. These responses positively support some of the factors that influence the performance of BSE and may have been perceived as benefits to the action of a health behavior, as described by Mikhail (1981) when describing concepts of the Health Belief Model.

In addition 50% of the participants also responded that they discovered their own breast disease. Taylor et al. (1984) report that the majority of breast cancer is self-detected and that many of the tumors cannot be identified with mammography.

Questions 6 and 7 ask about the fear of recurrence and threat of discovering a lump. Eighty-four percent of the participants were concerned that breast cancer would recur, but only 50% of the participants felt that BSE presented a threat of discovering a lump. It is not known why the others did not feel that there was a threat. Fletcher, Morgan, O'Malley, Earp and Degan (1989)

state “when BSE is practiced, the woman must be able to detect a lump suspicious of cancer if present and to determine the absence of suspicious lumps” (p. 207). Two participants had crossed out “threat” and had written in “chance.” One participant wrote in “fear of metastasis.” Therefore, one may deduce that some participants may have a greater fear of metastasis. Others may have a positive attitude, while others may deny or avoid acknowledging the threat of recurrence.

Other explanations can be drawn from the study by Taylor et al. (1984) that identifies individuals who see health outcomes under personal control and therefore engage in positive health habits. These individuals may also fall into the group of those that are confident, have a strong sense of support, are personally motivated, and have a positive attitude regarding their health outcomes.

Findings relating to the type of educational information and learning about BSE show that the doctor's office was identified by the participants as the primary source of learning and information. The hospital and the American Cancer Society were also identified as significant areas for obtaining information and learning. Dienger and Llewellyn (1995) refer to the study by Bennett et al. (1990) where “instruction in BSE, regardless of teaching method used, increases baseline knowledge and frequency of BSE

performance" (p. 362). Nettles-Carlson and Smith (1988) report that various methods of BSE instruction were evaluated (pamphlets, films, models and classes) showing that content varied, and overall results of these teaching methods did not demonstrate that one was better than the other. Most of the participants experienced one or more of these teaching methods. On the other hand, the study by Trotta (1990), showed "the most frequently reported sources of information about BSE were individual physician instruction and pamphlets" (p. 13).

The study by Nettles-Carlson and Smith (1988) states that personal instruction promotes regular practice of BSE. Trotta (1980) also reported that "subjects who had been taught person-to-person instruction tended to practice the most frequently, but those that experienced group teaching tended to be more thorough" (p. 13). In this study of breast self-exam and the mastectomy patient, 38% of the participants received a demonstration from a health care professional.

Owen and Long (1989) also refer to "a variety of methodologies, such as organized group learning, printed educational material, and practice sessions to teach the BSE technique, help women to gain confidence in their ability to practice breast self-examination" (p. 153). The study by Rutledge and Davis (1988) found that there is a significant relationship between learning methods, confidence, and BSE behavior.

All the participants in this study had a high school education or higher. It was interesting to note that the majority of the participants had a college degree or higher. Fletcher, Morgan, and O'Malley (1989) found that most studies indicate that educational level increases the performance of BSE.

Most participants in the study (90%) indicated that the educational information they received about BSE was helpful. Seventy-four percent felt that they did not need more information about BSE. Although not indicated in the questionnaire, those seeking more information (18%) may not have known the significance of recurrence of cancer after a mastectomy, may not have received enough information to instill confidence, or may not have received any information at all.

Findings also indicate that although most (60%) of the participants in the study felt that they were responsible for their own follow-up and detection, some participants indicated that they felt doctors and nurses were responsible for their follow-up and detection. Dienger and Llewellyn (1995) reported that Champion (1987) "found that women who were taught BSE by physicians or nurses were more likely to perform BSE than women who learned BSE from other means" (p. 361).

Scope and Limitations

Little is known about the performance of breast self-exam and the mastectomy patient. This study was useful in that it explored data regarding

performance of breast self-exam, attitudes and beliefs, and educational information that is provided to mastectomy patients. The study provides data that estimates or indicates current practices, beliefs, and tendencies of this population. The scope of the study was limited to 50 women who had mastectomies; their names were obtained from mailing lists at a community hospital and a chapter of the American Cancer Society.

The study was limited by the use of the convenience sampling method. Participants in the study were on the mailing lists of a community hospital with a cancer program and the American Cancer Society. These women may have been more likely to receive information regarding breast self-examination, educational materials regarding mastectomy, and opportunities to receive support and educational programs than those in the general population. The findings cannot be generalized to the general population of women with mastectomies. The sample had no Spanish-speaking women, nor is it known what ethnic groups were represented in the sample.

Another limitation of the study may have been the tool/questionnaire. Questions on the tool may have been confusing when responding to the Likert scale format. Readability may have been difficult for those that did not respond. Some of the questions may have caused anxiety, and they may have been avoided in order not to cause additional anxiety. Some women may have been in the advanced stages of their disease or may have been undergoing

treatment. Some of the respondents indicated that their surgeries had been less than a year before, and depending upon treatment modalities and stage of the disease, others that did not respond may not have been ready to participate in this study.

A third limitation in this study was that information collected did not include data that measured proficiency of breast self-examination. Research indicates that proficiency is necessary in order to detect the various changes in a woman's breast tissue. Information should also have been collected in regard to the women's previous performance of BSE before their mastectomy. Lauver (1989) found that although information on BSE is sufficient to promote BSE frequency, health professionals should evaluate the woman's previous BSE performance in order to promote thoroughness of BSE.

This study is also limited by the self-report method used in the mailed out questionnaires. It is possible that some participants may have selected answers that they felt were socially desirable. The anonymity provided in the study should have minimized this possibility. Self-report in the performance of BSE limits reliability and validity when observation of performance may have provided more true and accurate information (Wyper, 1990, p. 426).

Another limitation in the study was the use of the word mastectomy. Recent changes in surgical practices include lumpectomies that provide

breast conservation. Some of the women did not answer certain questions because of the word “mastectomy,” while others crossed it out and inserted “lumpectomy.”

Recommendations

Several recommendations can be made from the findings of this study. Further studies involving different ethnic groups, as well as the Spanish-speaking populations, would identify if educational materials and information are available and distributed. More extensive research needs to be applied to the general population in various areas of the country to find out if information is available and utilized.

Further studies should explore the quality and presentation of the information. BSE instruction should be standardized by such agencies as the American Cancer Society and the National Cancer Institute.

It is recommended that women should receive a demonstration by a health care professional about BSE after a mastectomy. Guidelines such as those developed by the Breast Health Awareness Advisory Committee, Ohio Division, following a lumpectomy or mastectomy (Breast Health Awareness Advisory Committee, Triple Touch, 1995) should be incorporated into the instruction. Evaluation of a woman's prior practice habits as well as performance skills need to be incorporated into the teaching methodologies.

More studies need to be conducted on women with mastectomies evaluating "women's BSE performance skills in assessing the relationship of BSE practice and stage of disease at diagnosis" (Haughey et al., 1988, p. 318). In addition, studies need to be conducted on these women's long term survival rates, incorporating barriers to and perceived benefits of performing of BSE.

Implications for Nursing

Nurses need to be aware of the importance of BSE after a mastectomy, need to learn the various barriers to learning, make educational materials available, and schedule a demonstration of BSE by a health care professional. Doctors and nurses need to be aware of the importance they hold as health care providers for the educative components in health care. The public expects health care professionals to provide the necessary education as part of their health care regimen. Since doctors' offices, hospitals, and the American Cancer Society have been identified as the most probable places of learning BSE, the professionals in these areas should work together to incorporate and implement effective teaching methods and follow-up.

Nurses should incorporate into their teaching methods the positive and supportive aspects of learning that have proven to be effective in the promotion of BSE. These methods need to be standardized as guidelines for the health care professionals to follow as they implement teaching methods

for women with mastectomies and lumpectomies. As stated by Alagna et al. (1987), health care professionals need to stress the importance of BSE, need to be instructed on the technique, and encourage patients to perform BSE as a health promoting or, indeed, life saving activity.

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APPENDIX A

Consent Letter

School of the Applied Arts and Sciences • *Department of Nursing*
One Washington Square • San José, California 95192-0057 • 408/924-3130 • FAX: 408/924-3135

AGREEMENT TO PARTICIPATE IN RESEARCH

Responsible Investigator: Gail Pieper

Title of Protocol: Breast Self-Examination and the Mastectomy Patient

Dear Research Participant:

A study is being conducted by a registered nurse, Gail Pieper, to learn if the type of educational information about breast self-examination provided affects the performance of breast-examination after a mastectomy. You have been selected to participate because of your affiliation with an Oncology Program, support group, or Reach to Recovery Program.

If you decide to participate, the researcher will ask you to complete a 18 question survey by circling the answers that most closely resemble your opinions and beliefs. There are no right or wrong answers, and all the survey information will remain confidential and participants will remain anonymous. After completion of the questionnaire, please return the information in the self-addressed and stamped envelope that has been provided.

Participants may feel anxiety when reading questions regarding educational information that may not have been provided or available. Participants may also feel anxiety when questioned or reminded of the possibility of reoccurring breast disease.

Subjects who choose to participate may feel satisfaction in that they have contributed to nursing research by sharing their information regarding their breast disease.

The results of the study may be published, but no information that could identify the participants will be included. Participants will receive no compensation for their contribution to the research.

If you should have any questions regarding the research, they may be addressed by contacting the principal investigator, Gail Pieper, at (408) 455-1078. Any further questions or complaints about the research, subjects rights, or research-related injury may be presented to Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research, at (408) 924-2480.

Your decision not to participate in the study will not affect service of any kind to which you are entitled. If you choose to participate, you may withdraw at any time without prejudice to your relations with San Jose State University or any other participating institutions or agencies.

Thank you for participation in the study.

*Your returned questionnaire implies consent to participate in this study and acknowledgement that you have read and understand your rights as provided in this agreement letter.

APPENDIX B

Approval from the Nursing Research Committee

SALINAS VALLEY
MEMORIAL
HOSPITAL

Neighbors Who Care

Date: April 10, 1995
To: Gail Pieper
Subj: Approval for Nursing Research Activity

The Nursing Research Committee has reviewed your research proposal and has approved the proposal for implementation from our view point.

Judy Snyder, RN, MS
Chair - Nursing Research Committee

A District Hospital
450 East Romie Lane
Salinas, California 93901
(408) 757-4333

APPENDIX C

Approval from the Institutional Review Board

May 26, 1995

Gail Pieper, RN
Oncology Unit
Salinas Valley Memorial Hospital

Re: Study: "Breast Self-Examination and the Mastectomy Patient"

Dear Mrs. Pieper:

The Institutional Review Board (IRB), at its May 24, 1995 meeting, approved your request to conduct the above referenced study with patients in the oncology unit of Salinas Valley Memorial Hospital, as well as the patient consent form to be used.

This recommendation will be forwarded to the Board of Directors at their June 1995 meeting, for their approval.

Ninety days following commencement of the study, a progress report must be forwarded to the IRB. (Sample enclosed.)

Enclosed for your information is a copy of the "Procedures for Protection of Human Subjects - Responsibilities of Principal Investigators".

Sincerely,

Thomas German, M.D. *en*
Chairman
Institutional Review Board

A District Hospital
450 East Romie Lane
Salinas, California 93901
(408) 757-4333

APPENDIX D

Approval from the Board of Directors

For: PIEPER, GAIL	From: CAROL M. NOVAK
Fri 06/16/95 10:36 am	Taken by: NOVAK, CAROL M. (1707)

THE BOARD OF DIRECTORS, AT ITS 6/15 MEETING, APPROVED YOUR PARTICIPATION IN THE BREAST SELF-EXAM POST MASTECTOMY STUDY, AS RECOMMENDED BY THE IRB.

CAROL

APPENDIX E

Approval from the American Cancer Society

DATE: May 15, 1995

TO: Gail Pieper

SUBJECT: Approval for Nursing Research Activity

The Salinas Valley Unit of the American Cancer Society has reviewed your research proposal and has approved the proposal for implementation from our viewpoint.

Nancy Hardy
Nancy Hardy
Cancer Control Manager

APPENDIX F

Approval by Human Subjects Institutional Review Board

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San José, California 95192-0025 • 408/924-2480

TO: Gail Pieper
21001 Country Park Road
Salinas, CA 93908

FROM: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies & Research

DATE: June 15, 1995

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Breast Self-Examination and the Mastectomy Patient"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Serena Stanford, Ph.D., immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

APPENDIX G

Questionnaire

The purpose of this survey is to determine if there is a relationship between the type of education provided and the performance of breast self exam after a mastectomy.

There are no right or wrong answers. Please circle the answer that best describes how you feel. It is important for you to answer all the questions on the form.

All the survey information will remain anonymous and will be reported only as group data.

Example:	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I feel comfortable with my performance of breast self exam.	1	2	3	4
2. I need more information about breast self exam.	1	2	3	4
3. I understand the importance of breast self exam after my mastectomy.	1	2	3	4
4. Physicians, nurses, or other health care professionals are responsible for my follow-up and detection of any reoccurring breast disease.	1	2	3	4
5. There are no benefits in the performance of breast self exam after a mastectomy.	1	2	3	4
6. I am concerned that breast cancer will reoccur.	1	2	3	4
7. Performing breast self exam presents a threat of discovering a lump.	1	2	3	4
8. I feel more comfortable if doctor or nurse performs	1	2	3	4

my breast exam.

9. Too much emphasis is placed on discussing my mastectomy or breast cancer.	1	2	3	4
10. The educational information provided about breast self-examination was helpful.	1	2	3	4

Please circle the most accurate answer on the following questions:

11. Age in years:

- a. Under 21
- b. 22-30
- c. 31- 40
- d. 41-50
- e. 51-60
- f. 61 and above

12. My mastectomy was on

- a. One side
- b. Two sides

13. I currently perform breast self exam

- a. Never
- b. Once a month
- c. More than once a month
- d. More than 5 times a year
- e. Less than 5 times a year

14. How did you learn about breast self exam?

- a. At the doctor's office
- b. From the American Cancer Society
- c. At the hospital
- d. Other (please specify) _____

15. How long has it been since you have had your mastectomy?

- a. Six months or less
- b. Seven months to 23 months

- c. Two years
- d. More than two years

16. How did you discover your breast disease?

- a. My performance of breast self exam
- b. Doctor performance of breast exam
- c. Mammogram

17. Please identify the type of information you received regarding breast self exam. Circle all that apply.

- a. None
- b. Pamphlets or written materials from the hospital
- c. Pamphlets or written materials from the doctors office.
- d. Video from the hospital
- e. Video from the doctors office
- f. Demonstration by a health care professional at the hospital
- g. Demonstration by a health care professional at the doctors office.
- h. Demonstration by a health care professional in my home.
- i. Other (please describe) _____

18. Please identify the highest level of education completed.

- a. High School Graduate
- b. One year of college or more
- c. College graduate
- d. Master's degree/PHD
- e. Other (please describe) _____