



Breast self-examination practices in women who have had a mastectomy
by Carole H Crowell

A thesis submitted in partial fulfillment of the requirement for the degree of Master of Nursing
Montana State University

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Abstract:

Research findings indicate that breast cancer mortality has not decreased significantly in the past decade. While research continues on the development of more effective therapies, techniques for early detection are presently receiving greater attention. The use of breast self-examination (BSE) has been emphasized in the media and professional literature but little emphasis has been placed on BSE for women who have had a mastectomy. The purposes of this study were to determine if women who have had breast surgery do breast self-examination and to describe barriers that block this behavior. An assumption was made that women who have had surgery for breast cancer do not examine their remaining breast tissue and scar site.

A qualitative study was conducted using a grounded theory approach to explore and describe behavior of women who have had a mastectomy. Analytic strategies used for data analysis were the constant comparative method, theoretical sampling, open coding, memo writing, and recoding. A convenience sample of twelve informants was selected from a mastectomy support group located in a rural community in Montana. BSE was viewed as a health-promoting behavior and was found to relate to certain variables of Penders (1987) Health Promotion Model.

Findings of this study indicate a majority of women perform BSE after their mastectomy but most do not examine their scar site. A facilitator to the performance of BSE was encouragement by a physician. A perceived benefit was finding a lump early, perceived seriousness was related to fear of recurrence, and a perceived barrier was forgetting.

A major finding of the study was the informants did not view themselves susceptible to breast cancer because there was no history of breast cancer in their family.

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A thesis submitted in partial fulfillment
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of
Master
of
Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

June, 1990

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VITA

Carole Crowell was born the daughter of Paul and Cecelia Harry on January 4, 1935. She received her secondary education from Colestock High School, Titusville, Pennsylvania. She received a Diploma in Nursing from Buffalo Deaconess Hospital and a Bachelor of Science in Nursing from the State University of New York at Buffalo.

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ACKNOWLEDGEMENTS

I would like to acknowledge my Grandmother Leona Bauer for the inspiration to work with women who have had breast cancer. My grandmother died of breast cancer at age 46, and I never knew her.

I would also like to express thanks for the expertise and support from Dr. Barbara P. Rogers. Dr. Roger's help made this thesis a reality.

Finally, I would like to thank some special individuals who also contributed their direction, guidance, and encouragement:

Dr. Jan Buehler
Dr. Helen Lee
Dr. Robert Fellenz
My husband Allen and family
Friends and classmates

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ABSTRACT

Research findings indicate that breast cancer mortality has not decreased significantly in the past decade. While research continues on the development of more effective therapies, techniques for early detection are presently receiving greater attention. The use of breast self-examination (BSE) has been emphasized in the media and professional literature but little emphasis has been placed on BSE for women who have had a mastectomy. The purposes of this study were to determine if women who have had breast surgery do breast self-examination and to describe barriers that block this behavior. An assumption was made that women who have had surgery for breast cancer do not examine their remaining breast tissue and scar site.

A qualitative study was conducted using a grounded theory approach to explore and describe behavior of women who have had a mastectomy. Analytic strategies used for data analysis were the constant comparative method, theoretical sampling, open coding, memo writing, and recoding. A convenience sample of twelve informants was selected from a mastectomy support group located in a rural community in Montana. BSE was viewed as a health-promoting behavior and was found to relate to certain variables of Penders (1987) Health Promotion Model.

Findings of this study indicate a majority of women perform BSE after their mastectomy but most do not examine their scar site. A facilitator to the performance of BSE was encouragement by a physician. A perceived benefit was finding a lump early, perceived seriousness was related to fear of recurrence, and a perceived barrier was forgetting. A major finding of the study was the informants did not view themselves susceptible to breast cancer because there was no history of breast cancer in their family.

CHAPTER 1

INTRODUCTION

One out of every ten women in the United States will develop breast cancer in their lifetime. The incidence of breast cancer is second only to lung cancer in women, with an estimated 15,900 new cases in the United States in 1990. Breast cancer incidence rates have increased one percent a year since the 1970s. An estimated 44,000 women will die of breast cancer in 1990 (American Cancer Society, 1990). This mortality rate reflects those women who did not survive the primary occurrence of breast cancer as well as those women who had a recurrence of breast cancer.

Tumors resulting from breast cancer may take eight to ten years to reach a size that is detectable by mammography or palpation. According to Buzdar (1989), micrometastatic deposits of tumor may develop locally or in systemic locations during this growth period. This concept of early metastatic activity lends support to Clark & McGuine's (1989) findings that twenty-five to thirty percent of patients with negative axillary lymph nodes will have a recurrence of breast cancer and will die of the disease.

Recurrence of Breast Cancer

The majority of recurrences of breast cancer are within the first three years after treatment for women who had negative lymph nodes and the first two years for women who had positive lymph nodes. Recurrences have the potential to be treated and cured but if cure is not possible, the objective of the treatment is to control the disease. Cure and control are possible only if the recurrence of breast cancer is detected at an early stage (Case, 1984).

Survivorship

The chances of surviving breast cancer are related to the stage of disease at diagnosis, yet the rate of early detection is only fifty percent (Nettles-Carlson, 1989). Early detection of breast cancer is necessary for survival. The five-year survival rate for localized breast cancer is ninety percent, sixty-eight percent for regional spread, and eighteen percent for distant metastases.

Although breast cancer is not currently preventable, studies suggest that breast self-examination (BSE) may result in the detection of small tumors at an early stage and thus contribute to an increased survival time (Rutledge & Davis, 1988). Foster et al. (1987) reported a positive relationship between BSE and the early detection of breast cancer. Hartman & Celentano (1983) found that women who regularly practice BSE were more likely to find their tumors than those whose tumors were found by accidental discovery.

The success of BSE is dependent on achieving a high acceptance rate for women in performing this procedure regularly, utilizing a correct technique (Calnan, Chamberlain, & Moss, 1983). A Gallop Poll conducted in 1984 estimated that only twenty-seven percent of American women practice BSE monthly. In a more recent study, Rutledge and Davis (1988) found that only fifteen percent of women practiced BSE monthly or more often.

A woman who has breast cancer is three times more likely to develop a second primary mammary carcinoma than her counterpart in the general population is to develop her first breast cancer (Moffat, Ketcham, Robinson, Legaspi, & Irani, 1988). Laughter et al. (1981) found little or no emphasis on learning and performing regular BSE for post-mastectomy patients, even though this could result in the discovery of early-stage breast cancer in the remaining breast. A woman who has had surgery for breast cancer is at risk for developing a recurrence of breast cancer at the scar site as well as in the remaining breast tissue.

Laughter et al. (1981) also noted that BSE literature does not reflect the importance of breast cancer patients examining their mastectomy scars for signs of recurrence. Current literature and research also do not reflect the importance of women examining the remaining breast tissue and scar site after surgery for breast cancer. The importance of continuing BSE, including examination of the

scar site and surrounding breast tissue, is not included by the Montana Division of the American Cancer Society Reach for Recovery programs presented throughout the state.

Statement of the Problem

The focus of this study was arrived at after this researcher studied "The Breast Module" at M. D. Anderson Hospital and Tumor Institute in Houston, Texas in 1985. The content presented included the fact that women who had a mastectomy were at increased risk to develop a recurrence of breast cancer in the scar site. Subsequently after developing and working in the Breast Health Clinic in a rural Montana community, the question arose as to whether women who had had a mastectomy knew how to examine their scar sites and furthermore, whether they did BSE.

In reviewing previous literature and closely following the literature for the past five years, no published studies have been located that address the subject of the examination of the scar site by women who have had surgery for breast cancer. Statistics indicate that women overall have a low adherence rate for performing BSE. The question arose as to whether removal of a breast for cancer changes the behavior of women and if the statistics are different for this population.

Purpose of the Study

Breast self-examination is a psychomotor task that should be utilized by women who have had surgery for breast cancer. The purposes of this study were to determine if women who have had breast surgery do breast self-examination and to describe barriers that block this behavior.

Relevance to Nursing

In her 1931 textbook of nursing, Harmer said, "the purpose of nursing is to care for, to cure, to educate the sick and to prevent disease". Today, the purpose of nursing remains essentially the same; however, nurses are assuming a greater responsibility for health promotion and disease prevention. Nurses have the unique opportunity to promote better health among individuals, families, and communities (Pender, 1987). Nurses who work in the hospital or community setting have a responsibility to teach women how to do breast self-examination (Phipps, Long, & Woods, 1987). Cancer screening services in communities would be improved if nurses assumed responsibility for teaching breast self-examination during routine office visits of asymptomatic women (Nettles-Carlson, 1989).

The role of the nurse in the early detection of breast cancer has become increasingly important (White, 1986). Findings of a study by the National Cancer Institute (U.S. Department of Health and Human Services, 1983) indicated

that there is increased acceptance of performing breast self-examination if women are taught by a nurse.

Effectiveness of teaching regarding BSE will depend on the ability of women to learn and practice the skill. An understanding of the barriers a woman may have to performing BSE will assist the nurse to develop teaching strategies to increase acceptance of this health promoting behavior in women who have had surgery for breast cancer.

Assumptions

Current modalities of treatment for breast cancer focus on immediate postoperative care, wound care, rehabilitation of the affected arm, coping with the stress from a change in body image, as well as follow-up radiation and chemotherapy. There appears to be little emphasis placed on methods for detection of recurrence of breast cancer. Few women are taught techniques for examination of their scar site, even though they may be instructed on examining the remaining breast.

The following assumptions are inherent in this study:

1. Women who have had surgery for breast cancer do not examine their remaining breast tissue and scar site.
2. Failure to examine the breast and scar site are the result of lack of knowledge and barriers.
3. Barriers to practicing BSE can be identified.

Definitions of Terms

1. Breast Cancer: A malignant growth that develops in breast tissue from selected cells that undergo change and initiate an abnormal process of uncontrolled growth.
2. Breast Self-Examination: The technique of assessing one's breasts by inspection and palpation to detect abnormal changes and/or breast cancer.
3. Recurrence: A malignant growth that occurs in remaining breast tissue after the treatment and supposedly cure from the initial cancer.
4. Barriers: Behaviors that block the performance of BSE.

CHAPTER 2

REVIEW OF LITERATURE

Breast cancer is a disease of women, as less than one percent of all breast cancers occur in men (Entrekin, 1987). Breast cancer is also a disease of aging and with an aging population, more women are at risk for breast cancer than ever before. American women are at a higher risk to develop breast cancer than women in most parts of the world today (Berg, 1984).

The best hope for recovery from breast cancer lies in early treatment, which is made possible by early detection. Current knowledge of breast cancer does not allow for prevention, only early detection and treatment. Breast self-examination is recommended as a screening behavior to complement professional exams and mammography as a method of detecting early breast cancer.

Etiology of Breast Cancer

The underlying cause of breast cancer is unknown but hereditary and environmental factors are implicated in its development. Hereditary cancer occurs in nine percent of all cases of breast cancer; a daughter of a mother or father who carries the gene has a fifty percent greater chance of developing the disease. A strong implication for a genetic

link exists when cancer develops premenopausally or if the woman's mother, sister, aunt, or grandmother developed cancer in both breasts. Women in these high risk families can be tested for the enzyme glucamate-pyruvate transaminase (GPT) that travels in tandem with the altered gene (Case, 1984).

Another genetically determined trait associated with breast cancer is wet ear wax. The glands that produce ear wax are apocrine glands, as are the breasts. Women with wet ear wax have a fifty percent greater likelihood of developing breast cancer than women with dry ear wax (Case, 1984). Breast density has also been cited as a cancer risk factor and high density breasts are a common finding in tall women (Saftlas, 1989).

Oncogenesis may contribute to the development of breast cancer. Oncogenes are genes that are believed to cause cancer; the human gene pool has over one hundred oncogenes that have been identified. These genes formed during embryogenesis are modified and altered to achieve a specific function (Bullock & Rosendahl, 1984). Proteins encoded by oncogenes function abnormally and cause the transformation of a normal cell into a cancer cell (Hunter, 1984). Once the cancer cell has been formed, oncogenes may regulate proliferative processes and enhance the expression of other genes and oncogenes. Oncogenes may be altered and initiate the process of carcinogenesis by chromosome rearrangement

due to inherited cellular fragility, chemical carcinogens that change oncogene structure, radiation that mutate oncogenes, and insertional mutation by a virus (Ziegfeld, 1987). Researchers recently photographed the first retrovirus linked to breast cancer (Al-Summidaire, 1987).

Further evidence for the role of oncogenes in breast cancer was reported by Gusteron et al. (1988). These researchers detected the c-erb B-2 oncogene in benign and malignant breast disease. The c-erb B-2 oncogene is a normal cellular gene found on chromosome 17. Over expression of c-erb B-2 is being investigated in relation to its role in the pathogenesis or prognosis of a breast cancer.

Risk Factors

Research continues on the underlying causes of breast cancer but more recently the focus has been on associated risk factors (Dupont & Page, 1985). Risk factors are markers that occur with unusual frequency in women who develop breast cancer. Having one or more risk factors does not mean a woman will develop breast cancer; it does mean that she is at a greater risk statistically (Case, 1984). Only fifteen percent of women with breast cancer have a known risk factor. The four general categories of risk factors that have been identified are hormonal, personal history of cancer, diet, and lifestyle.

Hormonal Risk Factors

Certain hormones produced by the body can enhance breast tumor growth. The two hormones for which responsiveness of breast tumors can be tested are the ovarian hormones estrogen and progesterone. The adrenal glands produce androgens and after menopause the body converts these into a form of estrogen (Case, 1984).

The levels of estrogen and progesterone are highest during the child bearing years and decline after menopause. A woman can have prolonged hormonal stimulation from early menarche (before age twelve) and late menopause (after age fifty). Women who have never had children or who have had their first child after age thirty are at risk from prolonged hormonal stimulation. Obese women are also at risk as a result of the estrogen found in adipose tissue.

Personal History of Cancer

If a woman has had breast cancer in one breast, she is at a fifteen percent greater risk to develop breast cancer along the scar site or in the opposite breast. Women who have had ovarian, uterine or colon cancer are also at increased risk to develop breast cancer (Case, 1984).

Diet

Epidemiologists have found that in areas with a high incidence of breast cancer the diet is high in fat and animal protein (Case, 1984). The American Cancer Society

(1990) recommends that a woman's diet contain only thirty percent fat.

Low levels of the trace element selenium in the diet have also been linked to breast cancer. Areas with a higher level of selenium in the water, soil, and diet have a lower incidence of breast cancer (Case, 1984).

Lifestyle

Women who have a low tolerance to stress and have difficulty coping with stress are believed to be more vulnerable to breast cancer. Stress creates a higher cortisol level in the body which affects the ability of the immune system to function effectively to suppress or kill cancer cells. In a study of depressed people Sawyer (1989) found a low level of natural killer cells with depression.

A woman's ability to cope with stress may be a factor not only in developing breast cancer but also in how she responds to treatment. A woman's inability to cope with the stress of living and having breast cancer may also put her at risk for a recurrence. Research at the University of Pittsburgh has shown that women who have had strong social support from their husbands cope better after a mastectomy and have an increased survival rate (Fisher, 1989).

A woman's decision to take exogenous estrogens for birth control and to relieve menopausal symptoms may also increase her risk to develop breast cancer. The woman's breast tissue, ovaries, endometrium, and colon are hormonal

sensitive tissues. As reported by Miller (1989) breast cancer is hormonally mediated and estrogens are the prime agent, therefore prolonged use after menopause should be avoided. Findings from a joint study between Sweden and the United States suggested an association between breast cancer and the use of estrogen therapy in post-menopausal women. The study also noted that women who switched to estrogen-progestin combinations after having only used estrogen had twice the risk to develop breast cancer (Bergkvist, 1989).

In a recent study of British women, Pike (1989) concluded that the risk of breast cancer is higher for young women who have taken birth control pills for more than four years. Controversy over women taking exogenous hormones exists. Concluding that research demonstrating a possible link between the use of the pills and breast cancer was inconclusive, the United States Food and Drug Administration released a bulletin in January of 1989 that recommended no changes be made in the use of oral contraceptives (Goodman, 1989).

Pathology of Breast Cancer

Cancer cells are formed through the process of cellular differentiation. Cellular differentiation is subject to an intricate interaction of intracellular and extracellular interplay between oncogenes, and oncogenes and the engendered enzymes. When control genes do not function properly in monitoring the action of structural oncogenes,

cellular differentiation will become pathologic and cancer cells will be formed (McIntyre & Cioppa, 1984).

Classification of Tumors

Breast cancer or adenocarcinomas found in the epithelial tissues of the ducts account for ninety percent of all breast cancers. Five percent of breast cancers are found in the lobules and the remaining five percent are Paget's or inflammatory carcinoma. Breast cancers are further classified as invasive or non-invasive (Case, 1984).

A summary of the different types of breast carcinoma and their prognosis is listed below:

1. Invasive Ductal NOS (Not Otherwise Specified)--Accounts for seventy percent of breast cancers and has a poor prognosis.
2. Tubular Ductal Carcinoma--Represents two percent of breast cancer and has a better prognosis than Invasive Ductal NOS.
3. Medullary Ductal Breast Carcinoma--Constitutes seven percent of all breast cancers and has a better than average prognosis.
4. Mucinous Ductal Carcinoma--Makes up three percent of all breast cancers and has a highly favorable prognosis.
5. Comedo Ductal Carcinoma--Represents five percent of breast cancers and has the most favorable prognosis.

6. Invasive Lobular Carcinoma--Accounts for less than three percent of all breast cancers and has an unfavorable prognosis (Case, 1984).

Lobular and ductal breast carcinomas may also be classified as in situ, referring to their not having invaded adjacent tissue. In situ ductal breast carcinomas are often microscopic and multicentered and are in a preinvasive stage that will eventually evolve into an invasive cancer (Swain, 1989). Lobular carcinomas in situ also connote a high risk of a second primary in situ or invasive breast carcinomas (Moffat et al. 1988).

The diagnosis, treatment, and prognosis of a woman's breast cancer is predicated on the pathologist's determination of tumor type from the biopsied tissue. Just as a woman should seek a second opinion for her treatment options, she should also request that a specimen of biopsied tissue be sent to a major cancer hospital pathology laboratory for verification of tumor classification.

Metastasis

Breast cancer cells undergo multiple changes to become metastatic. A tumor cell has an increased ability to grow which could be caused by growth factors produced in the tumor. The environment in which the tumor cells live influences their growth and ability to metastasize. For metastasis to occur, a breast tumor must not only grow, but some of its cells must be able to leave the tumor and burrow

their way into a blood or lymph vessel. A metastatic cancer cell must cross a basement membrane at several points before finding its way back into another tissue (Marx, 1989). The metastatic cancer cell is capable of spreading to any organ but the most common sites of metastasis are the lymph nodes, bones, lungs, liver, adrenal glands, and skin (Ziegfeld, 1987). Case (1984) reported that ten percent of breast cancer patients with metastatic disease develop brain metastases.

Treatment of Breast Cancer

A pretreatment evaluation to determine the most appropriate treatment regimen is completed after tissue biopsy and confirmation of the diagnosis of cancer of the breast. The evaluation consists of preoperative blood work, a bilateral mammogram, chest x-ray and a bone scan. The levels of the biologic tumor markers CEA, HCG, and Ferritin will also be determined if a metastasis of the breast cancer is suspected.

A presumptive clinical staging will also be completed and confirmed with follow-up pathology reports after surgery. Ziegfeld (1987) lists the following as the TNM (Tumor, Nodes, and Metastasis) Classification System currently being used:

1. Stage I: tumor less than 2 cm, axillary nodes negative.

2. Stage II: tumor less than 5 cm, axillary nodes may be positive and fixed, no distant metastasis.
3. Stage III: tumor may be greater than 5 cm, axillary nodes may be positive and fixed, no distant metastasis.
4. Stage IV: any combination of tumor and node involvement with evidence of distant metastasis (p. 111).

A woman with breast cancer should have an active role in the decision making process to determine her treatment. The main options for treatment of breast cancer consists of surgery, radiation therapy, adjuvant chemotherapy, and hormonal therapy.

Surgery

Surgery is the main treatment for breast cancer with the trend today toward more conservative surgical procedures. The most widely used procedure is the modified radical mastectomy where the entire breast is removed. A lumpectomy may be performed if not more than thirty-five percent of the breast tissue is to be removed and the tumor is less than 2 cm in size (Case, 1984).

Radiation Therapy

Primary radiation is combined with a lumpectomy to treat breast cancer. This treatment for breast cancer was

developed in the 1980s. Kurtz et al. (1989) found evidence of local recurrence after a lumpectomy with radiation. In a study of 1593 patients with Stage I and Stage II breast cancer, Kurtz et al. (1989) found that ninety-three percent were free from recurrence at five years, eighty-six percent at ten years, eighty-two percent at fifteen years, and eighty percent at twenty years. Kurtz et al. (1989) also reported that seventy-nine percent of the recurrences were in the vicinity of the tumor bed, but with an increasing time interval, a larger percentage of recurrences were located elsewhere in the breast. A randomized trial is currently underway at the Dana Farber Cancer Institute to determine if adjuvant chemotherapy is more effective preceding or following radiation therapy (Canellos et al. 1988).

Adjuvant Chemotherapy

Adjuvant chemotherapy is used to destroy micrometastatic deposits of breast cancer cells not removed or killed by surgery or radiation. Simmonds et al. (1984) and Rivkin, Glucksberg & Foulkes (1984) have observed that micrometastases are present in most patients at the time of presentation. Blumenschein & Pinnamaneni (1984) maintain that the combined modality for treatment of breast cancer should include both regional (surgery or radiation) and systemic therapy (chemotherapy and/or hormonal therapy).

They observed that adjuvant chemotherapy has a measurable response in metastatic and microscopic breast disease.

Today adjuvant chemotherapy is advocated for women with node-negative breast cancer (Henderson, 1989; Koppa, 1989). The most significant advancement for the treatment of breast cancer in the past decade has been to view breast cancer as a systemic, chronic disease.

Hormonal Therapy

The goal of hormonal therapy is to increase the survival time for a woman with breast cancer. At the time of surgery a tissue specimen of the tumor is sent to the laboratory for an assay to determine the presence of estrogen and progesterone receptors. The results are either a positive or a negative response. Women in which the tumor tissue is positive for estrogen receptors are generally placed on anti-estrogen drugs such as Tamoxifen.

Findings from a randomized, placebo-controlled study of 2,644 women with operable primary breast cancer with negative axillary nodes, suggest that Tamoxifen prolongs the disease-free survival time and reduces the rate of treatment failure at local and distant metastatic sites (Fisher, Constantino & Redmond, 1989). Falkson (1989) found in a Phase III trial of 803 postmenopausal women that the long term use of Tamoxifen delayed the recurrence of breast cancer.

Recurrence

Metastatic breast disease usually spreads to several organ systems. One-fifth of women with metastatic breast disease develop metastasis at only one site. The treatment for recurrence is systemic chemotherapy. The response to systemic therapy is measured in terms of remission. A complete remission is the disappearance of all symptoms and signs of the disease and a partial remission is evidenced by the reduction of the primary tumor or metastatic tumor to half of its original size. The median survival time for metastatic breast disease is two years but many women have survived ten years or more (Case, 1984).

Once having breast cancer a woman is always at risk for a recurrence. Accepted prognostic factors for breast cancer are relatively insensitive to predicting women at risk for a recurrence. Newer tests include identification of growth factor(s) receptors, oncogenes, thymidine labeling index, and measurements of DNA ploidy status by flow cytometry (Clark & McGuire, 1989).

Incidence and Mortality Rates

Breast cancer incidence and mortality rates in the United States and worldwide have increased in women born since 1900 (Wittes, 1989). Incidence rates increase after menopause and death rates from breast cancer are increasing slightly in women fifty years of age or older (Lovejoy, Jenkins, Wu, Shankland, Wilson, 1989). Aging has a strong

correlation with the increasing incidence of breast cancer and as our population ages, the incidence of breast cancer will increase.

The incidence of breast cancer in women is rising at the rate of 1% a year (Silberman, 1988). The incidence of breast cancer has been offset by a slight improvement in survival rates, thus allowing mortality rates to remain fairly steady the past twenty-five years (Case, 1984).

Detection of Breast Cancer

Early detection of breast cancer is necessary for survival. Recommended screening methods include monthly BSE, periodic clinical examinations by a nurse or physician, and mammography (Council on Scientific Affairs, 1989). Age-specific recommendations differ for BSE, clinical examinations and mammography for asymptomatic women.

The American Cancer Society's (1990) guidelines for breast cancer detection are: (a) monthly breast self-examination starting at age 20; (b) professional physical examination of the breast at three-year intervals between the ages of 20 and 40; annually thereafter; and (c) a baseline mammogram between the ages of 35 and 40, followed by annual or biannual mammograms from age 40 to 49, and annual mammograms from age 50 on. Women at higher risk or who have had breast cancer may need more frequent checkups. BSE and clinical examination of the breasts as screening

methods are complementary and should not be substituted for each other (Ziegfeld, 1987).

Mammography

Mammography is an x-ray used to view the internal structures of the breast. The two types of mammography, screen film and xeromammography, each have an accuracy rate of eighth-five percent. Mammography is utilized as an important tool in screening women for early detection of breast cancer and as a diagnostic tool for women who have findings suggestive of breast cancer (Ziegfeld, 1987).

It is now accepted that breast cancer screening in which mammography has a major role, can substantially reduce the mortality rate in breast cancer (Shapiro, 1989). Findings from a randomized clinical trial conducted by the Health Insurance Plan of Greater New York (the HIP study) were the first from a major study that demonstrated a thirty percent decrease in mortality from breast cancer for women who were screened with mammography and a clinical breast examination. In a second large study, the Breast Cancer Detection Demonstration Project (the BCDDP study), the findings indicated a decrease in mortality rates by the use of mammography to detect cancers too small to be palpated by the examiners (Nettles-Carlson, 1989). Shapiro (1989) noted that mammography and clinical breast examination contributed independently to the detection of breast cancers in the HIP and the BCDDP studies. A third of the cases would not have

been detected without mammography and forty-five percent if not for the clinical breast examination.

The early detection of breast cancer by mammography has caused a dilemma in determining protocols for treatment. The problem is further compounded by recent thoughts of breast cancer being a systemic disease.

The cost of mammography varies greatly and is generally not covered by third party insurers. Programs have been developed in some Montana communities which offer mammography at a reduced rate. The most accurate means available for detecting small nonpalpable breast cancers is mammography (Paulus, 1984).

Clinical Breast Examination

Clinical breast examination is the assessment of breast tissue and area lymph nodes by inspection and palpation. Clinical breast examination is usually done by a physician or nurse. Nettles-Carlson (1989) suggests that nurses and physicians could benefit from additional training in correct palpation techniques. Reports of a study of clinical breast examination techniques by Baines, Miller and Bassett (1989) suggested there was no difference between nurse and physician examiners. Clinical breast examination in combination with mammography is the only screening technique with conclusive evidence of increased survival for women with breast cancer (Nettles-Carlson, 1989).

Breast Self-Examination

BSE is a psychomotor and cognitive task in which the techniques of inspection and palpation are utilized by women to detect breast cancer. Ziegfeld (1987) noted that women who regularly practice monthly BSE are more likely to find tumors in an early stage and survive longer. At present three-fourths of all breast cancers are discovered by the woman herself (Case, 1984). All women twenty years of age and older should practice BSE and instruction should start at the high school level.

By performing monthly BSE, a woman can become aware of her own breast structures and identify changes. Women with lumpy breasts or fibrocystic disease can also do successful BSE if they become familiar with their cyclic breast changes in order to detect a palpable mass that persists for more than one menstrual cycle (Hindle, 1989). Eighty percent of lumps found by women themselves are not cancerous. The effectiveness of BSE is dependent on the regular practice and use of correct technique.

Compliance with Breast Self-Examination

Compliance is defined as a behavior, or the extent one's behavior coincides with health care activities. Compliance begins when the individual acquires sufficient knowledge for decision making for behaviors that promote, maintain or restore health (Given & Given, 1989). Multiple studies of compliance with BSE have been reported in the

literature. Howe and Hoff (1983) found that it was difficult to measure the recall bias in a retrospective study of 395 women reporting on BSE practices. Calnan (1984) noted that studies using the Health Belief Model as a conceptual framework to determine compliance with BSE were all conducted retrospectively.

The Health Belief Model, developed by Becker in 1967, focuses on disease prevention and has been used to test hypotheses as to why women do or do not practice BSE. Elements of the Model have been applied to identify a woman's readiness to learn, benefits of BSE, and barriers to the performance of BSE. Calnan and Rutter (1986) examined the use of the Health Belief Model in several studies and observed that it accounted for only a small variance in the relationship between health beliefs and health behaviors.

The Health Belief Model was used as the conceptual framework for many of the studies of compliance with BSE through 1988. A hospital-based study of ninety-three female registered nurses by Cole and Gorman (1984) revealed that non-compliers were more likely to have a maternal history of breast cancer and compliers had more nursing education and were younger. Rutledge (1987) examined factors related to the practice of BSE in 103 women and noted that frequency of BSE was related to high perceived benefits, low perceived barriers and a high self-concept. Lauver and Angerame (1988) found that non-compliance was associated with the

perceived barriers of forgetting, lacking confidence in BSE, fear of finding a lump, embarrassment, and interference with usual routines. Response to a self-report questionnaire of BSE practices by 248 women indicated that the women needed a reminder, encouragement of family and friends, and confidence in ability to do BSE, (Rutledge & Davis, 1988). Physicians interested in BSE compliance was studied for 253 older women using the Health Belief Model (Williams 1988). Findings from this study also revealed an increased compliance with BSE when taught by a physician or nurse.

The above findings have been supported by others who did not use the Health Belief Model as a framework for their study. Nettles-Carlson, Field, Friedman and Smith (1988) found in a randomized trial of 220 women taught BSE by a nurse, that they were significantly more confident of their techniques. The importance of confidence in doing BSE has been identified as an important variable of compliance for performing BSE, (Celentano & Holtzman, 1983; Olson & Mitchell, 1989; Alagna & Ready, 1984; Champion, 1988). A profile of the woman likely to do BSE was developed by Bennett et al. (1983) from interviews conducted with 616 women taught to do BSE using an interactive computer program. They found that the women were more likely to practice BSE if they lived with their sexual partner, had been shown how to do BSE and were confident in their technique.

Compliance vs Adherence

With the increasing emphasis on health promotion and the move to have individuals assume responsibility for their own health, the word compliance is viewed as contrary to the desirable outcome. Compliance has a negative connotation of being externally motivated or doing health related behaviors to fulfill others' expectations. The word adherence is gaining popularity in the literature. Adherence is viewed as positive since it connotes internal motivation of health promotion behaviors.

Health Belief - Health Promotion Models

Breast cancer accounts for more than a quarter of all cancers diagnosed among American women. The mortality rate from breast cancer has remained virtually unchanged (Shapiro, 1989). At present, screening for early detection offers the main possibility for a significant reduction in breast cancer mortality. The recommended screening methods include monthly breast self-examination. Breast self-examination is an inexpensive and noninvasive method to detect breast cancer in an early stage (Council on Scientific Affairs, 1989).

The American Cancer Society in partnership with the National Cancer Institute first advocated breast self-examination approximately thirty-five years ago as a safe, inexpensive, effective way to save lives (Somkin, 1985). Ninety percent of all lumps in the breast are detected by

women themselves (Case, 1984). Women who regularly practice breast self-examination are more likely to find their tumors than those tumors found by accidental discovery or during a routine physical examination (Holtzman & Celentano, 1983). A positive association has been reported between breast self-examination and detecting the cancer at a stage favorable for survival (Somkin, 1985).

In 1989 the media gave extensive coverage to the need for women to examine their breasts monthly for breast cancer. The popular women's magazines, Good Housekeeping, McCall's, Ladies Home Journal and Redbook, all had articles that addressed breast cancer and the need to do breast self-examination. Nova did a public television documentary on breast cancer and a movie was made for television that featured the actress Ann Jillian's battle with breast cancer. The public media has assumed a responsibility for informing women about breast cancer and breast self-examination; however, the rate of women actually doing breast self-examination remains low.

The low rate of BSE has been investigated in studies that have examined different variables as a possible cause. The research studies have shown conflicting results and make it difficult to profile women who perform breast self-examination (Calnan & Rutter, 1986). Many of the early studies used the Health Belief Model which focuses on disease prevention. The model was proposed by Hochbaum and

Rosenstock and modified by Becker to include one's perception of threat from their susceptibility to and the seriousness of disease (Woods, 1989).

Recently a Health Promotion Model was developed that is based on previous work done with the Health Belief Model. The Health Promotion Model was proposed by Pender (1987), a nurse. The model was developed to focus on health promotion and to provide a framework for the study of health-promoting behavior (Phipps, Long, & Woods, 1987).

The Health Promotion Model explains behaviors that are directed to increase an individual's well-being and self-actualization. Individuals play a vital role in determining their own health status, as self-care represents the dominant mode of health care. Individuals make many decisions daily that affect their lifestyle, social, and physical environment. Health promotion behaviors that increase an individual's level of well-being and health potential are viewed as positive, dynamic processes that are an integral part of an individual's lifestyle (Pender, 1987).

The Health Promotion Model is based on social learning theory, which emphasizes cognition in the regulation of behavior. Pender proposed that the likelihood of engaging in health promotion behavior is influenced by cognitive-perceptual factors (Woods, 1989).

Cognitive-perceptual factors are identified in the health promotion model (See Figure 1) as the primary motivational mechanisms for acquiring and maintaining health-promoting behaviors. The cognitive-perceptual factors in the model that influence health-promoting behavior have been identified as (a) importance of health, (b) perceived control of health, (c) perceived self-efficacy, (d) definition of health, (e) perceived health status, (f) perceived benefits of health-promoting behavior, and (g) perceived barriers to health-promoting behavior. Modifying factors are identified within the model as those affecting patterns of health-promotion behaviors indirectly through their impact on cognitive-perceptual factors.

Modifying factors are demographics, biological characteristics, and interpersonal influences. Interpersonal factors include expectations of significant others, family patterns of health care, and interactions with health professionals. Other modifying factors are situational or environmental and behavioral factors. Situational factors include health-promoting options available and ease of access to health-promoting alternatives. Behavior factors include previous experience with health-promoting actions that includes cognitive and psychomotor skills necessary to implement complex health-promoting behaviors (Pender, 1987).

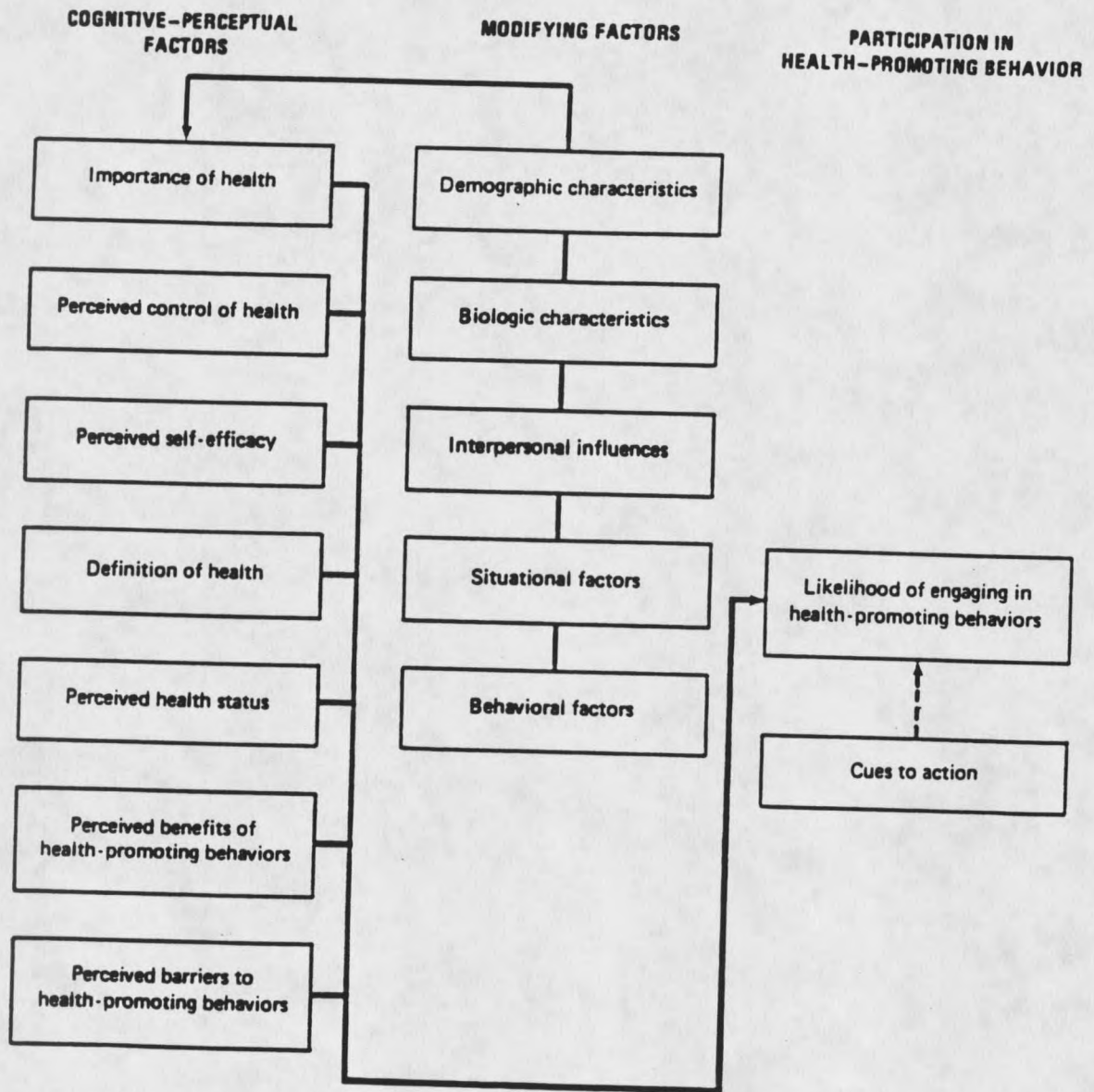


Figure 1. Health Promotion Model (Pender, 1987, p. 64).

Breast self-examination is a health-promotion behavior that combines cognitive and psychomotor skills.

Measurements identifying beliefs and attitudes about breast self-examination are necessary to clarify the relationships between these variables and the frequency of breast self-examination performance (Lauver & Angerame, 1988).

Therefore this study was conducted to identify variables that could block the performance of breast self-examination by women who have had surgery for breast cancer.

CHAPTER 3

METHODOLOGY

Many studies of womens' adherence to breast self-examination (BSE) have used tools designed to measure the influence of health beliefs on performance of this psychomotor skill. The purposes of this study were to determine if women who had breast surgery do BSE and to describe barriers that could block this behavior. A qualitative approach was selected for this study. A description of the research methodology including the research design, selection of informants, data collection tools, protection of human subjects, demographic data, and data analysis techniques is found in this chapter.

Research Design

Previous researchers studying BSE compliance collected data using closed response tools constructed to measure specific concepts. The qualitative approach was chosen for this study in order to allow informants to respond to focused, semi-structured questions. Grounded theory was developed as a methodology to study a substantive area of human experience in which the informants define what is important for the researcher to identify (Spradley, 1979).

The grounded theory methodology was chosen for this study to explain behaviors common to women who have had a mastectomy.

Informants were women who had previously had a mastectomy. This allowed the researcher to understand behaviors from the informants perspective and to see their world from their viewpoint (Chenitz and Swanson, 1986). The informants were interviewed to determine factors that affected their practice of BSE. The data were expressed in words. The qualitative analysis of this non-numerical data allowed for the identification of concepts.

Sample and Setting

The target population was women eighteen years or older residing in Montana who were six months or more post mastectomy. A convenience sample was obtained from a mastectomy self-support group in a small, south central Montana community. A letter was sent to the leader of the support group soliciting names of possible participants. The potential participants were told they were volunteering to participate in a one hour interview to discuss health-promoting behaviors after a mastectomy. Mastectomy support group members who agreed to participate were contacted by telephone to schedule an interview. All were assured of anonymity, confidentiality, and the freedom to withdraw from the interview if they became uncomfortable.

Twelve women were selected to participate in the study. Women who have had complications from wound healing after

the mastectomy, reconstructive breast surgery, or a bilateral mastectomy were excluded from the study.

Data Collection/Instruments

Demographic data were collected through a questionnaire which asked the participant's age, marital status, education, occupation, and date of mastectomy. The participants were then asked focused and semi-structured questions (see Appendix A). This interview method allowed for the acquisition of specific information to be obtained from the informant and at the same time allowed the informants to contribute any information they thought relevant (Woods & Catanzaro, 1988). The interviews were conducted in a private room at a local hospital. All interviews were audio taped and no notes were taken during the interviews.

Protection of Human Subjects

The proposed study was conducted after a favorable review from the Montana State University Human Subjects Review Committee. Human subjects were protected using the recommendations of the Montana State University College of Nursing. No violations in human subjects were found; therefore, approval to use human subjects was given.

A letter was sent to the local mastectomy support group requesting volunteers (see Appendix B) and a list of potential informants was received. Participation in the

study was entirely voluntary. An Introduction to the Study (see Appendix C) was read to each potential informant over the telephone and a forty-five minute interview was scheduled at a time of convenience. At the time of the interview each informant read and signed the Informed Consent Form (see Appendix D).

Demographic Variables and Characteristics

From the list of fifteen potential informants, twelve agreed to participate in the study and on interview signed the Informed Consent Form. One woman was not included in the study because she had had a bilateral mastectomy, another woman had problems with wound healing, and one woman had time constraints.

The ages of the informants ranged from 30 to 77 with the mean age 52. The length of time from their mastectomy varied from 9 months to 13 years with the mean 3.5 years. All of the women had had a modified radical mastectomy and knew the month and year of their surgery. The informants resided in a south central county in Montana at the time of their surgery. The majority of the informants had their surgery performed at a local community hospital.

The majority of the informants had no evidence of breast cancer in their family prior to surgery. One of the informant's mother had a bilateral mastectomy six months after the informant had hers. Another informant had a

maternal aunt with breast cancer and one informant had a sister who died from breast cancer.

Ten of the women are presently living with their spouses and two are widowed. All of the women completed high school, four were college graduates, and three had attended college for one to two years. Five of the women are employed full time, four part time, and three are retired. None of the informants expressed dissatisfaction with their jobs.

Data Analysis

A grounded theory study was done to produce abstract concepts and propositions about their relationships (Chenitz & Swanson, 1986). The grounded theory approach used in this study explored and described behaviors of women who have had a mastectomy. This method was used to account for patterns of behavior which were relevant and problematic (Glaser & Strauss, 1967).

Data collected from the informants were analyzed and separated into parts for the purpose of answering the research question (Wilson, 1985). The two major analytic strategies used in this study were the constant comparative method and theoretical sampling. Other major operations of data analysis used were open coding, memo writing, and recoding.

Constant Comparative Method

The constant comparative method is concerned with generating and plausibly suggesting many categories and their properties for the purpose of establishing underlying uniformity (Buehler, 1982). This method was used to compare incident to incident and category to category as relationships and properties emerged from the data. The continuous process of coding and comparing of responses was used to conceptualize emerging patterns. An example of this process occurred when some of the women stated they did not fear having breast cancer before discovering their lumps because "this couldn't happen to me". Further examination of the data related to the statement revealed that there was no history of breast cancer in their family and therefore they did not consider themselves at risk to develop breast cancer.

Theoretical Sampling

An analytic strategy characteristic of the grounded theory approach is theoretical sampling (Buehler, 1982). Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes the data and decides what data to collect next in order to develop his theory as it emerges (Glaser & Strauss, 1967). The later interviews were influenced by the earlier interviews and as the interviews progressed, questions were added related to wound healing.

Open Coding

The purpose of coding qualitative data is to reduce the bulk of data into concepts and categories that accurately represent the phenomena under study. "Coding in the grounded theory approach is considered open in that categories, concepts, properties of concepts, and relationships between concepts emerged from the data, rather than being preconceived" (Buehler, 1982, p. 122).

The data were coded after each interview was transcribed. All relevant data were underlined and initial, tentative codes were placed in the right hand margin. An initial category identified was fear of recurrence of breast cancer. One woman stated "I don't do breast self-examination because I don't want to find any problems". Another initial category that emerged from the data was a woman showing her mastectomy scar site to her husband.

Memo Writing

Memos are the researcher's written record of data analysis, allowing the researcher to keep a record of and to order the results of the analysis. Memo writing also enables the researcher to know what additional data are needed for the study.

Memos were written to describe how categories and their possible relationships were identified. The memos were coded categorically as the concepts and their properties emerged. For example, memos were written while analyzing

data about attempts of some women to normalize the experience of having had a mastectomy for breast cancer. An example of one woman's attempt to normalize the experience was by wearing her own clothes right after surgery and devising a "purse" for her surgical drain.

Recoding

Recoding occurs in the process of analysis as memos are constantly reanalyzed. Many of the initial codes were eventually recoded as a consequence of the constant comparative method of analysis. For example, an earlier code of fear of recurrence of breast cancer was recoded to perceived seriousness of disease. As the process of recoding was completed, it was found that many of the collapsed categories related to the variables found in Pender's (1987) Health Promotion Model for self-care (see Figure 2).

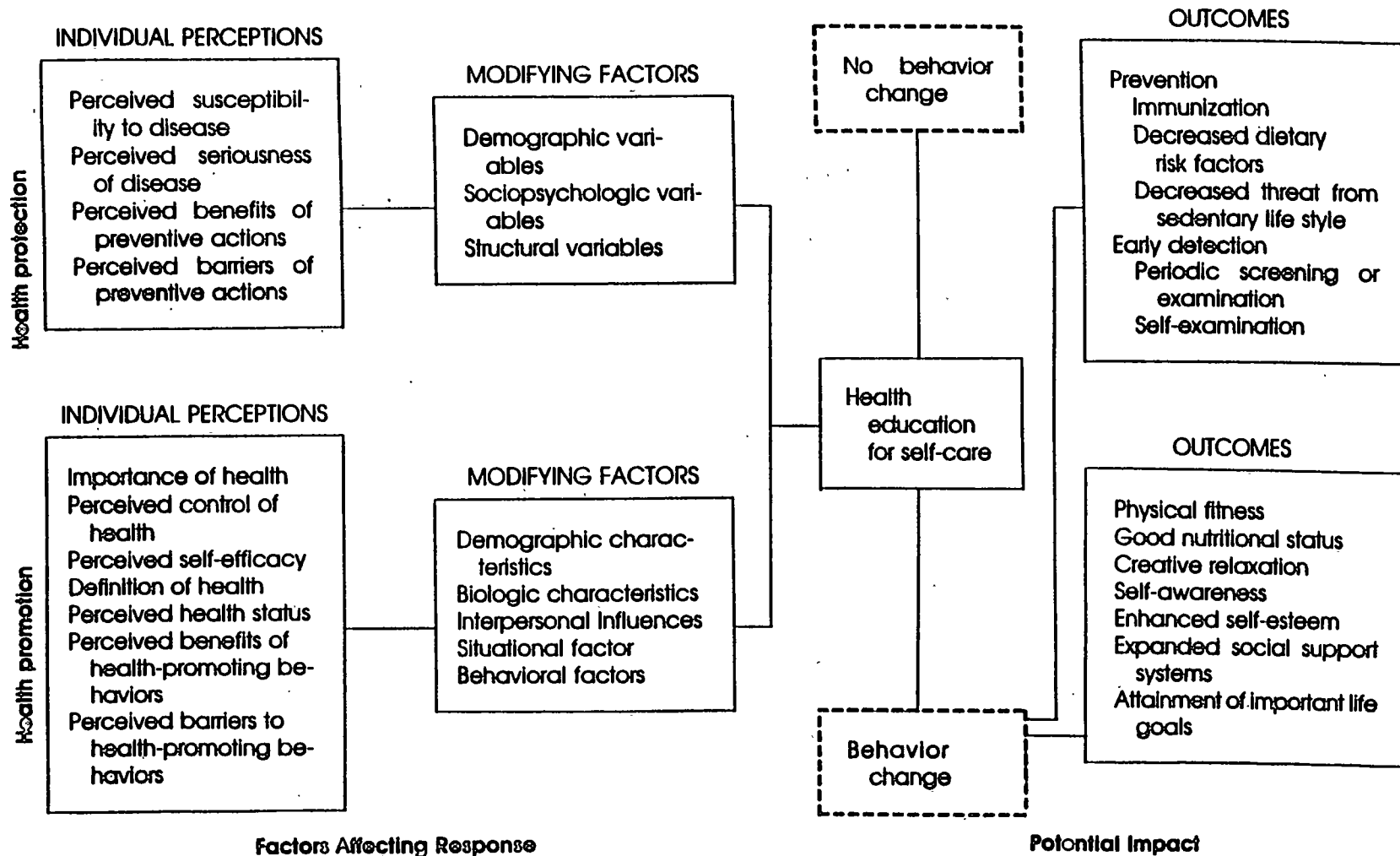


Figure 2. Health Promotion for Self-Care (Pender, 1987, p. 84).

CHAPTER 4

FINDINGS

Qualitative Analysis

The aims of this study were to determine if women who have had breast surgery do breast self-examination and to describe barriers that block this behavior. Women who had had a mastectomy were used as informants and data were obtained through interviews. The purpose of analyzing the qualitative data was to draw inferences about the meaning of the data (Woods & Catanzaro, 1988). A qualitative approach allows the researcher to understand the concerns, actions, and behaviors of the informants. Qualitative analysis provided the framework for the organization and interpretation of findings for this study.

Doing Breast Self-Examination

Breast self-examination (BSE) is the technique of assessing one's breasts by inspection and palpation to detect abnormal changes and/or breast cancer. BSE is a psychomotor and cognitive task that Pender (1987) identifies as a positive outcome of an individual's perceptions of health promotion and health protection behaviors. Self-examination is recognized as a means to detect the occurrence or recurrence of breast cancer.

Before Surgery

The informants were questioned regarding their performance of BSE before surgery and most of the women responded positively and stated they had done BSE. However when asked to describe their frequency of performing BSE the answers varied from "not often;" "rarely;" to "once in a blue moon." The informants were then asked to describe and demonstrate how they did BSE and the responses varied from "when laying down I just felt around;" "generally I just did it in the bath tub, I would lay down and try to circle and feel general areas and under my arms;" "I just feel all the way around;" "sometimes I'd do it in the shower." Most of the women described doing BSE in the shower. Actual demonstrations of BSE did not meet minimal standards of practice as recommended by the American Cancer Society.

When asked who had taught them how to do BSE, the women responded "the nurse;" "the nurse at the doctor's office;" "got it from pamphlets;" "my gynecologist;" "my doctor;" "the doctor showed me how to do it, but I just never did it." The majority of women responded that they learned how to do BSE from their physicians and a few from a nurse. Magazines and pamphlets were the major educational source mentioned by some of the women.

After Surgery

The informants were asked if they were presently doing BSE and they responded with these statements: "I don't now, not that often;" "yes I suppose I am but not as often as I should, I also go to the doctors every three months;" "yes about every two weeks, but its not a true exam all the time, but I do feel the skin over;" "yes once a month;" "yes every day or every other day;" "well no, I don't think I will find a lump;" "sort of, no one has really said anything." One of the informants stated she stopped doing BSE after her surgery because of "fear of finding a lump, I am dying from my breast cancer." At present the majority of women demonstrate adherence to the standards of BSE performance.

Examining the Scar Site

When asked if they examined their scar site as part of their BSE, the informants stated "yes, I just feel and see if it feels all right, one time the nurse said I should follow every rib across, but I don't do that;" "yes, no one showed me how to do it, I just rub the scar with lotion a lot and I think I would know if there was anything there;" "yes, every day I put lotion on it;" "yes, I look at it and feel it, no one told me to do this, I just do it;" "yes I just look at it very carefully and kind of feel along the scar and see if there is anything, I just figured this out myself." The majority of women had not been taught how to examine their scar site but have figured out how to do it on

their own. A few of the women responded negatively as "no, no one has shown me, I really don't know how;" "no I haven't;" "well I have a few times but it just feels so different that I don't."

The above statements revealed that some of the women perform BSE after their mastectomy and some of the women correctly included examination of their scar site but not all the women are doing BSE after their mastectomy nor do all the women examine their scar site. Why do some of the women adhere to recommendations to perform BSE regularly to detect an early recurrence of breast cancer and others do not? The rest of this section will discuss the findings in light of the concepts and behaviors that facilitate or block the performance of BSE.

It was noted during the recoding of data that many behaviors that block or facilitate the practice of BSE were contained within Pender's (1987) Health Promotion Model. The findings of the study therefore will be reported around elements of Pender's (1987) Health Promotion Model for Self-care (See Figure 2). This model was selected to clarify and provide insight into the beliefs and attitudes for the practices of breast self-examination for women who have had a mastectomy for breast cancer. The model assists with determining the women's perception of the cognitive-perceptual factors of health promotion and health protection behaviors.

Facilitators to the Performance of BSE

Facilitators are concepts or behaviors that encourage the performance of BSE. The patterns of behavior that promote the performance of BSE were unique for each of the informants, with common elements identified as well.

Interpersonal Influences

Interpersonal influences are positive or negative actions as a result of an interaction between persons. The informants were questioned regarding sources of encouragement to do BSE. The majority of women stated "yes" they were receiving encouragement to do BSE from their physician and some clarified their answer by saying "my doctor encourages me when I have a checkup;" "I guess every time I have an examination they tell me that." A few of the women responded by stating "no, not since I've had the surgery" and "no, they really haven't." Some women reported receiving encouragement from the Mastectomy Support Group and an informant stated "yes, they talk about doing theirs and maybe that is why more recently I have been checking." A few of the informants also reported receiving encouragement from their husbands, family, friends, and a nurse.

Perceived Benefits

Perceived benefits are the beliefs about the effectiveness of a recommended preventive action and are

important determinants to the performance of that health promoting behavior. All the informants, except one, reported that doing BSE would help them find a lump early. One informant felt by doing BSE she would "only find the lump a week or two earlier;" and another informant expressed "I think more breast cancer is discovered by the person themselves than by anybody else."

Perceived Seriousness of Breast Cancer

The severity of a given health problem is judged by the degree of emotional arousal created by the thought of having the disease or the physical difficulties created by the disease (Pender, 1987). The perceived seriousness of breast cancer was interpreted as being a facilitator to performing BSE after a mastectomy. The fear of recurrence was an emerging theme for this category and it was noted that more of the informants are presently doing BSE after their surgery. One of the women stated that the members of the Mastectomy Support Group are "all scared because we just lost a member of the group." One woman discussed the fact she "is dying from lung metastasis from breast cancer." Another woman expressed the seriousness of having breast cancer and stated "while having chemotherapy and all those tests I was fighting my cancer" but with the discontinuance of treatment feels that now she "is not doing enough to get rid of it." One woman eloquently said "with breast cancer we learn as we go along, you think when they remove your

breast and after your mastectomy everything is over but you find you have to have chemotherapy, bone scans, and be checked so closely every three months."

Blockers to the Performance of BSE

Blockers are perceptions or behaviors that discourage the performance of BSE. During the interviews the informants discussed their reasonings for not performing BSE.

Perceived Susceptibility to Breast Cancer

Perceived susceptibility is expressed as the threat of an illness to an individual (Pender, 1987). This emerged from the data as an important perception for women not performing BSE. Prior to surgery one of the informants stated she did not practice BSE "because no one in my family had ever had breast cancer and I thought it was really kind of silly to do." Another woman stated "it was no big deal because it couldn't happen to me." One woman also said "I really wasn't a candidate for breast or any other kind of cancer since there was none in my family." A theme that arose out of this category as expressed by many of the informants was "I didn't think it could happen to me."

Perceived Barriers

Perceived barriers can take many forms and can be observed as real behaviors that block the performance of BSE. The informants were asked if being busy kept them from

doing BSE. They responded "probably;" "I had five kids, I was busy;" but the majority responded "no" that they were not too busy.

When questioned if they felt comfortable or confident in the technique they used for BSE, the majority of women said "yes." Some of the women responded "I feel confident;" "whenever I did it, I felt like I was doing it right."

When asked if they had a fear of finding a lump the majority responded "no." However, a woman said "I only do BSE periodically because I am afraid I might find something, and if I do it's a whole different ballgame because I have already been told I am dying of cancer."

Some of the women stated that they do not do BSE because the doctor does it. They stated "I go to the doctor every two or three months and I leave it up to the doctor;" "I have been going to the doctor every two months and the doctor has tested me for lumps."

The women were then asked if they felt embarrassed when doing BSE. Most of the women said "no" but one woman said she "felt kind of funny, I guess self-conscious."

Since forgetting was the major reason identified for not doing BSE, the women were then asked if they forgot to do BSE. Responses of the informants were affirmative and varied from "probably forgot because I wasn't in the habit of doing it;" to "I just didn't think about it."

Health Education

Not all women were provided with health education appropriate for a mastectomy or a possible recurrence of their breast cancer. Some women stated they didn't do BSE after their mastectomy because the "doctor didn't tell me to do it." One woman, who has had a recent mastectomy, was told she only needed to have a mammogram every two years and another woman said "I haven't had a mammogram after the first five years." None of the women were told how their scar might be numb or feel different for twelve to eighteen months after their surgery. One woman did not do BSE because her year old scar site felt "weird."

Some of the women indicated that they had fibrocystic breasts and were not told how to examine these normally lumpy breasts. Fibrocystic breast tissue requires a special procedure in order to perform BSE correctly.

Some informants were aware of the signs of breast disease, such as an indentation. One woman stated "it wasn't a lump I found and I didn't worry about it because I couldn't feel anything, I shouldn't say I wasn't worried as I was concerned it was an indentation and I didn't know this was a symptom."

Some of the women expressed frustration with the diagnostic phase of their breast cancer. These women had "felt something" but experienced multiple mammograms and physical exams before their lumps were detected. A few of

the women had indicated that they had tumors under their breast, one woman was told that the irritated area was from her bra; another woman's physician told her "we don't find tumors in that area." While not directly stated, these women seemed to not do BSE because of frustration with the health care system. One woman demonstrated an inaccurate perception of the purposes of BSE and mammograms when she stated "I had mammograms yearly and did BSE but it didn't prevent my breast cancer."

Decision Model

A woman's decision to perform BSE following a mastectomy is based on a multiplicity of variables and factors as previously presented. A model has been developed using elements from Pender's Model (1987) to schematically represent a woman's decision to adhere or not adhere to the practice of BSE (see Figure 3). The decision to adhere to the practice of BSE could be facilitated by interpersonal influences, perceived benefits, perceived seriousness of breast cancer, and health education. Non-adherence to the practice of BSE may be blocked by perceived susceptibility to breast cancer, perceived barriers, and lack of health education. Assessment of behaviors that block a woman's performance of BSE and the development of strategies to overcome these blockers, may assist a woman to make a decision to adhere to BSE. The potential for a behavioral

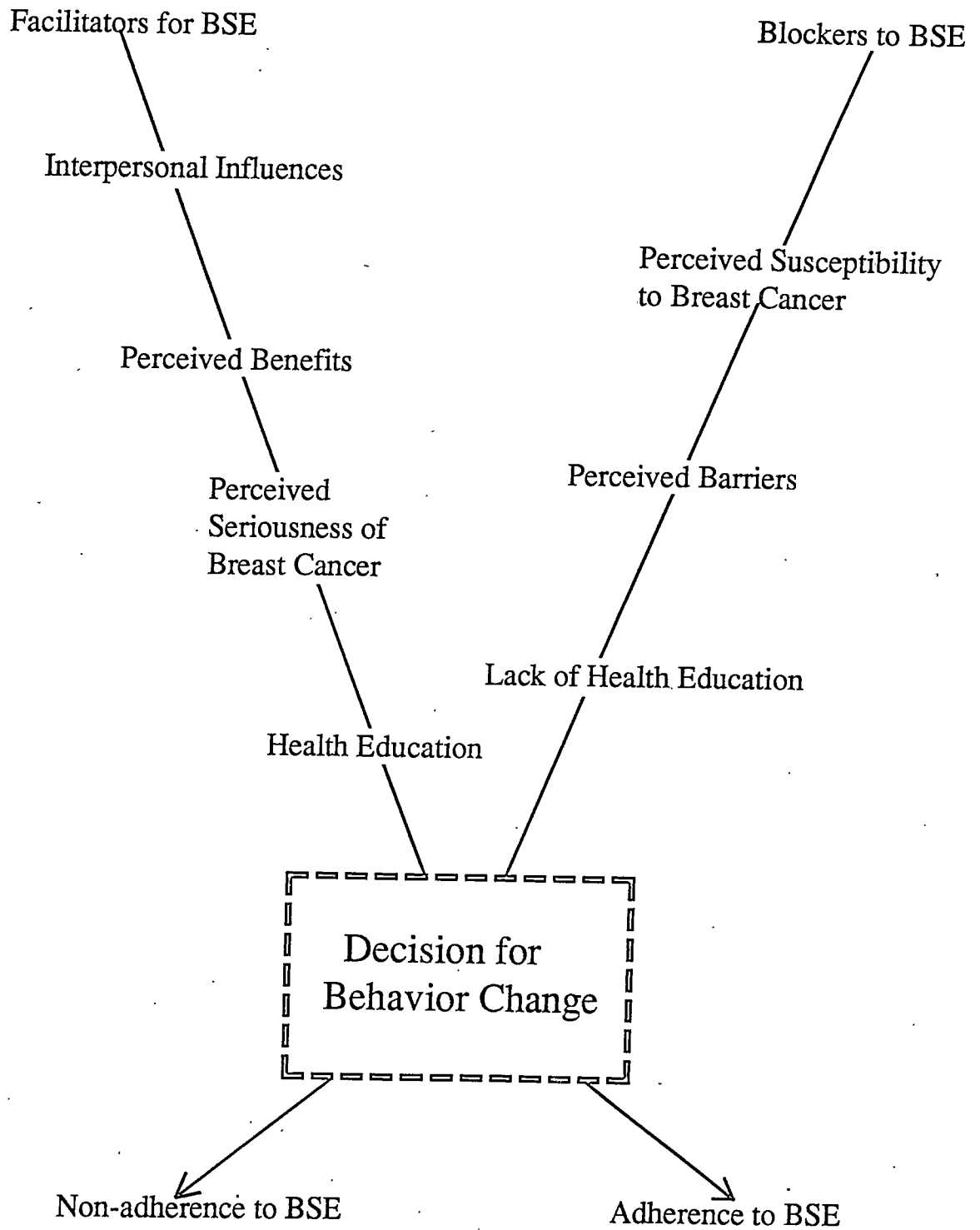


Figure 3. Crowell's Decision Model for BSE.

change will also be strengthened by reinforcing facilitators for BSE. Potential strategies and nursing interventions to modify this behavior will be presented in the last chapter. Two additional concepts or categories not found in Pender's Model (1987) include unburdening and normalizing. Data were obtained because informants wanted to discuss their experiences with breast cancer.

Unburdening

Unburdening is the use of discussion or talking about concerns and worries related to a personal experience. During the initial telephone interview potential informants indicated that they wanted to discuss their experiences with breast cancer; because of this desire it was difficult to get closure on the interview. Many women continued to talk about their experiences even after the tape recorder was turned off. These data were recorded in memos after the completion of the individual interviews.

Concern for Daughters

The women who had daughters were encouraging them to do BSE and get yearly mammograms if of age. All of the women discussed their breast cancer with their daughters except one woman whose daughters are living away from home. One of the women had put a daughter up for adoption and she contacted her daughter's adopted mother to inform her the daughter is at increased risk to develop breast cancer.

Scar Site

All the women indicated that they had shown their husbands their mastectomy scar site within a short period following surgery. The women described their husbands' responses as: "accepted me as I am;" "told me he still loved me;" "told me it didn't bother him." None of the women felt rejected by their husbands after their mastectomy. One woman showed her two sons her scar site following her mastectomy and told them "boobs are important when you are young and dating but there better be something more than that in your relationship because you can loose a boob real quick." Another woman stated "I showed my scar when it was still a fresh wound and healing, I felt more objective about it and I kind of wanted to show it to people and say look what happened and it's doing good."

Body Image

Questions relating to the informants perception of their change in body image were asked of the women half way through the interviews. One woman did not feel any "cosmetic changes from the surgery" but most expressed a loss of a "valued body part." One informant stated she "feels it most in the summertime when I think about my halter tops." Another informant expressed negative feelings about her body since the surgery as "feeling uncomfortable in having other people, even my husband see that part of me." Some of the women are currently considering

reconstructive surgery. One informant stated the loss of her breast "does make a difference even though I look the same to others, it does affect the way I feel about myself and everything."

Normalizing

Normalizing is a coping method used by some of the women to adjust to their mastectomy. A normalizing tactic is to hide an intrusive symptom by covering it with clothes (Strauss et al. 1984). One of the women developed a "purse" like device to support her surgical drain while in the hospital and at home. This allowed the informant to attend a christening two days after her surgery with minimal problems from her surgical drain. Other women found that wearing their own clothes in the hospital also helped them cope with the experience. The search for a prosthesis to replace the missing breast was also a normalizing experience for the informants.

CHAPTER 5

CONCLUSIONS

Discussion

This chapter has been designed to examine the implications of the qualitative analysis of data obtained from interviews of women who have had a mastectomy. The findings as presented in Chapter 4 are based on focused questions asked during interviews with the informants.

Breast self-examination and the variables that block or facilitate this behavior will be discussed as well as the need for women to unburden or discuss their experiences with breast cancer. Lastly, the limitations of this study and implications for nursing will be presented at the end of this chapter.

Performance of Breast Self-Examination

The majority of the informants verbalized that they had not performed BSE before their mastectomy. This adherence rate was lower than the fifteen percent rate reported by Rutledge and Davis (1988). Women who regularly practice BSE can find their tumor in an early treatable stage. Based on the womens' descriptions of tumor size and lymph node involvement, most of the informants were in Stage II and III at the time of their mastectomy. These findings are

congruent with a study by Holtzman and Celentano (1983). The rate of early detection for breast cancer is only fifty percent (Nettles-Carlson, 1989).

Even though the majority of women stated they were doing BSE, when questioned about frequency it was apparent they were not performing BSE on a regular basis. Rutledge (1987) found that frequency of performance was related to high perceived benefits. While the informants were aware of the perceived benefits of finding a tumor early, they were not motivated to practice BSE on a regular basis.

When asked to describe their technique for performing BSE, none of the women were able to minimally meet standards of performance as recommended by the American Cancer Society. Further questioning revealed that these women did not have the knowledge necessary to perform BSE correctly. These findings correlate with those of Haughley et al. (1988) that women who examine their breasts may not be very skillful in performing the procedure, their study findings indicated that women who had been checked on their knowledge of BSE technique showed significantly higher scores on intent, frequency, and proficiency. When doing a physical examination on any woman, health professionals should ascertain if women are using a correct technique when examining their breasts.

Some of the women described difficulty in doing BSE because of their lumpy or fibrocystic breasts. This finding

corresponds with Laughter et al. (1981) that twelve percent of women never perform BSE because they have fibrocystic breast disease. The presence of this disease makes it difficult to determine what lumps are new or significant. Hindle (1989) found that women with lumpy or fibrocystic breasts can do successful BSE if they become familiar with their cyclic breast changes. This is a complicated issue, because if these women are to perform BSE they need to know how to differentiate changes of fibrocystic breasts to those of breast cancer. The technique of BSE should be modified by health care professionals when teaching BSE to a woman with fibrocystic breasts.

The majority of women in this study were taught BSE by a physician and a few by a nurse. This finding agrees with Trotter (1980) findings that women who practiced BSE were taught by a physician. Champion (1988) also found increased compliance in women who had been taught by a physician. Nurses are taught in nursing school how to teach women to correctly perform BSE but evidently they are not teaching this to their clients. One wonders if this is a result of short staffing and the nurses' increased work load in hospitals or did nurses ever teach BSE in the hospital setting?

Some of the informants also cited magazine articles and pamphlets as a resource for learning how to do BSE. This finding is supported by Champion (1988) that individual

physician instruction and pamphlets were the most frequently reported sources of information about BSE. All the women lived with their spouses at the time of their surgery for breast cancer but they did not do BSE. This finding also paralleled that of Champion (1988) who found that marital status did not influence the practice of BSE. This was not congruent with the findings of Bennett et al. (1983) that women were more likely to do BSE if they lived with their sexual partner.

The majority of women were correctly performing BSE after their mastectomy. These findings demonstrate a change in behavior from non-adherence of BSE. This may be due to a fear of recurrence of their breast cancer. The assumption that these women were not examining their remaining breast tissue was incorrect. Most of the women reported doing a cursory examination of their scar site. Very few of the women were taught to examine their scar site correctly. The majority of women did not use a systematic approach to palpate for significant changes on the scar site. This does support the assumption made at the beginning of the study that women who had surgery for breast cancer do not examine the scar site.

Facilitators for BSE

Interpersonal Influences

The majority of the informants reported they were encouraged to do BSE by their physicians. This finding agrees with those of other studies suggesting the physician has a key role in the promotion of breast self-examination (Amsel, Grover, & Balshem, 1988; Rutledge & Davis, 1988; Champion, 1988; Olson & Mitchell, 1989). Some of the women received encouragement to do BSE from their Mastectomy Support Group. The subject of BSE was not approached at every meeting, therefore all the women of the support group did not receive equal encouragement from their peers. A few of the informants also reported receiving encouragement from their family, husbands, and friends. This finding was consistent with other researchers that suggested that soliciting the involvement of significant others may be a source of encouragement and motivation to do BSE (Laughter et al. 1981; Rutledge & Davis, 1988).

Perceived Benefits

All of the informants reported that a perceived benefit of doing BSE was to find a lump early. While finding the lump was not a factor in encouraging the informants to perform BSE before surgery it was an important variable in performing BSE after their mastectomy. Other studies concurred with these findings that higher perceived benefits

of practicing BSE were reported by women with a higher frequency of practicing BSE (Rutledge, 1987; Rutledge & Davis, 1988; Champion, 1988). Williams' (1988) findings did not concur and furthermore she noted that there was a low correlation with perceived benefits and frequency of performing BSE.

Perceived Seriousness of Breast Cancer

The perceived seriousness of breast cancer was viewed in this study as a facilitator for performance of BSE by the informants. No significant relationship was found in studies that examined the frequency of BSE and perceived seriousness of breast cancer (Williams, 1988; Rutledge, 1987; Rutledge & Davis 1988; Champion, 1988). The conflict in findings could be related to the facts that these researchers did not conduct their studies on women who have had a mastectomy nor did they do a qualitative study.

Blockers to BSE

Perceived Susceptibility

Prior to surgery the informants did not view themselves as being susceptible to breast cancer because none of the women in their families had breast cancer. This was interpreted as the women's perceived susceptibility to breast cancer. This finding is consistent with those of Massey (1988), Champion (1988), Rutledge (1987), and William's (1988). Before surgery the informants did not

perceive themselves as susceptible to breast cancer. Dupont and Page (1985) noted more recently that there has been a focus on associated risk factors. Listings of risk factors for breast cancer emphasize that women with a family history of breast cancer are in a high risk category to develop breast cancer. Risk factors are also widely detailed in the media, women's magazines, and the American Cancer Society and National Cancer Institute pamphlets. One wonders if health professionals and others have stressed the importance of known risk factors for fifteen percent of the women who develop breast cancer and not stressed sufficiently that risk factors are not known for the other eighty-five percent of the women. Until all risk factors are known all women must be considered susceptible to breast cancer. Health professionals, the American Cancer Society, and the National Cancer Institute should be made aware of the potential hazards of over emphasizing risk factors.

Perceived Barriers

Forgetting was another major factor identified as a perceived barrier to the performance of BSE. This finding is consistent with those of Rutledge and Davis (1988), Champion (1988), and Lauver and Angerame (1988). A reminder to do BSE that hangs on a shower rod, stickers that go on a calendar or a bathroom mirror could be used as cues or reminders to the women to practice BSE on a regular basis.

Some of the women stated that they do not do BSE because the doctor does it. This finding concurs with the findings of Alguna and Reddy (1984) that the more strongly a woman believed that her health was under the control of health professionals, the less proficient she was at BSE. Health professionals and others should point to the danger of this attitude with respect to the early detection of breast cancer.

The majority of women said they did not fear finding a lump when performing BSE. This finding was also identified by Rutledge and Davis (1988), and Champion (1988). It is interesting to note that doing BSE puts women at risk for detecting a lump. This attitude could be the result of the informants unconscious effort to neutralize or remove the fear of finding a lump while performing BSE.

All but one of the women denied being embarrassed while doing BSE. Williams (1988) study of older women also found embarrassment was not a barrier to BSE. Only a few of the informants felt they were too busy to do BSE. This was not reported as a barrier in other studies (Champion, 1988; Rutledge & Davis, 1988).

Lack of confidence in technique is considered a barrier to the performance of BSE. The majority of informants expressed confidence in their technique used when performing their BSE. Other studies demonstrated a strong relationship of perceived competence with frequency of BSE performance

(Champion, 1988; Lauver & Angerame, 1988; Bennett et al. 1983; Olson & Mitchell, 1989). Health professionals can increase a woman's confidence in her ability to perform BSE by requesting the woman to demonstrate or do a return demonstration of her technique.

An assumption made earlier in the study that barrier to practicing BSE can be identified was proven to be correct. The assumption that failure to examine the breast and scar site are the result of lack of knowledge and barrier was also correct.

Health Education

Lack of health education was a perceived barrier to the women's performance of BSE. Not all women were provided with health education appropriate for having had a mastectomy. Lack of performance by women doing BSE after their surgery may be due to poor education by health professionals about the importance of continuing BSE in the postmastectomy period (Laughter et al. 1981).

Unburdening

The need for the informants to discuss their cancer experience was reflected in their desire to be interviewed by a health professional and belong to the Mastectomy Support Group. This group allows the members to express their feelings about breast cancer with peers. A reason that these informants may wish to continue to discuss their

experience with breast cancer may be related to a lack of opportunity to do so while in the hospital. This may be due to the shortened hospital stay for mastectomy patients and lack of contact with a professional nurse. Even though all of the women professed support from their husbands, there could be a reticence to create worry or stress in their husbands. The local support group provides an outlet for these women to discuss their concerns related to breast cancer but not all towns or communities have support groups. A nurse could be available to attend meetings of a mastectomy support group to periodically provide an additional outlet for the women to unburden their concerns.

Concern for Daughters

The women who expressed concerns about their daughters developing breast cancer should be counseled by a physician or nurse of genetic tests that could determine if their daughters had a predisposition to breast cancer. Although women did not adhere to BSE after their mastectomy, they did promote the regular performance of BSE and yearly mammograms for their daughters.

Body Image

All women except one expressed grief over their lost breast. While the change in body image was not apparent to others, the women still considered this a problem. A few of the women were considering breast reconstruction but others

were concerned that the silicone implant might be carcinogenic.

Normalizing

Normalizing is a healthy coping mechanism that was used by some of the informants to adjust to their experience. This type of behavior should be encouraged by health professionals when helping women to cope with the experience after a mastectomy. The development of a "purse" by one of the informants in an attempt to normalize her behavior has come to the attention of the local hospital and they are considering developing a like device to support the surgical drain for postmastectomy patients. Other normalizing behaviors in women who have had a mastectomy should be investigated.

Recommendations

1. Replication of this study in a smaller rural community and a larger urban area. The two additional areas would provide a total sample more representative for the State of Montana.
2. A follow-up study of nurses in hospitals and office settings of health teaching for women who have had a mastectomy. Findings of this study indicated little involvement of nurses doing health teaching for women who have had a mastectomy.

3. A epidemiological study to determine the rate of performance of BSE by women in Montana who have had a mastectomy. The extent of the problem needs investigation in order to develop teaching strategies and allocate resources.

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APPENDICES

APPENDIX A
INTERVIEW QUESTIONS

INTERVIEW QUESTIONS

1. Did you do breast self-examination before your surgery?
 - (A) How often?
 - (B) Will you describe to me how you do breast self-examination?
 - (C) Who taught you to do breast self-examination?
2. If you were not doing breast self-examination, as best as you can recall, what kept you from doing breast self-examination?
 - (A) Too busy?
 - (B) Not sure how to do breast self-examination?
 - (C) You forget?
 - (D) You feel embarrassed?
 - (E) Fear of finding a lump?
 - (F) Don't feel confident with your technique?
3. Are you presently doing breast self-examination?
 - (A) How often?
 - (B) Do you examine your scar site as part of your breast self-examination?
4. Do you receive encouragement to do breast self-examination from your:
 - (A) Husband?
 - (B) Family?
 - (C) Friends?
 - (D) Mastectomy Support Group?
 - (E) Physician?
 - (F) Nurse?
5. Can you think of anything good or a benefit to you if you practice breast self-examination regularly?
 - (A) Finding a lump early?
6. Are there other things you would like to tell me about your practice of breast self-examination or breast cancer?
7. Have other women in your family had breast cancer?
 - (A) Who?
 - (B) Did that person have it more than once?

APPENDIX B
LETTER TO SUPPORT GROUP

404 Bonner Lane
Bozeman, MT 59715
April 30, 1990

Dear _____:

This letter is a follow-up to a previous telephone conversation we had about asking for 15 members of your mastectomy support group to volunteer for my study. I am studying health promotion behaviors in women who have had a mastectomy.

At this time I am excluding from the study anyone who had problems with wound healing after their mastectomy, a bilateral mastectomy, or reconstructive breast surgery. I would appreciate you forwarding a list of possible voluntary participants to me with their telephone numbers. Thank you.

Sincerely,

Carole H. Crowell, R.N.C.

APPENDIX C
INTRODUCTION TO STUDY

INTRODUCTION TO STUDY

My name is Carole Crowell. I am a registered nurse and a graduate student at Montana State University College of Nursing. I am studying health promotion behaviors in women who have had a mastectomy.

1. When did you have your mastectomy?
2. Have you had one or two breasts removed?
3. Have you had reconstructive breast surgery?
4. Did you have any problems with wound healing after your mastectomy?

If all answers fall within study guidelines I will proceed.

I would like to schedule a 45 minute interview with you at a time of your convenience. This interview will take place in a private room at Bozeman Deaconess Hospital. The study is being conducted at Bozeman Deaconess Hospital as a convenience and the Hospital has no relationship with the study. The interview will be taped and there are no right or wrong answers to the questions you will be asked. The information you will provide will help nurses to know more about health promoting behaviors for a woman who has had a mastectomy.

Any information you provide is confidential and your name or town will not be used in any way in this study. Whether you participate or not, will not effect the health

care you receive now or in the future. Your participation is voluntary and you need not feel obligated to participate.

If you agree to participate in this study, I have a consent form I would like you to sign. You can withdraw from the study at any time, even after you sign the form. The tapes will be destroyed at the end of the study or if you withdraw from the study.

Do you have any questions?

APPENDIX D
CONSENT FORM

INFORMED CONSENT FORM
FOR
BREAST SELF-EXAMINATION PRACTICES IN
WOMEN WHO HAVE HAD A MASTECTOMY

The purposes of this study are to determine if women who have had breast surgery do breast self-examination and to describe barriers that block this behavior.

You will be asked questions in an interview that will be tape recorded. The interview will take place at your convenience in a private room at Bozeman Deaconess Hospital. The interviews will take approximately 45 minutes of your time.

There are no right or wrong answers in this study. I will not pass judgement on what you tell me. If you feel uncomfortable, you are free to not answer questions or end the interview at any time.

Your participation in this study will assist nurses to develop teaching strategies for teaching breast self-examination to women who have had a mastectomy. The information you provide will add to the knowledge nurses have about breast self-examination.

All information that you provide will be kept confidential. The information will be used in a written report (thesis), but your answers will not be connected with your name or your town. After the study is completed, the tape recording will be destroyed.

Your cooperation, time, and interest is greatly appreciated. By signing this form you show your voluntary consent to participate and agree you have been informed about the study.

signature

If you have questions regarding this study, or you wish to discuss any feelings this interview evoked, feel free to contact me at any time.

Thank you.
Carole Crowell, R.N.C.
586-7850 (Home) or
994-3783 (College of
Nursing MSU)

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