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Knowledge, Sources Used and Factors Considered in the Surgical Treatment Decisions of Women With Breast Cancer

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**KNOWLEDGE, SOURCES USED AND FACTORS CONSIDERED IN THE
SURGICAL TREATMENT DECISIONS OF WOMEN WITH BREAST CANCER**

BY

Debra J. Bisel

A THESIS

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ABSTRACT

The purpose of this replication study was to examine how women with breast cancer reached their decision for surgical treatment (Ward, Heidrich and Wolberg 1989). Twenty-one women who met the surgical criteria, i.e. option for Breast Conserving surgery or Modified Radical Mastectomy, completed four surveys 1 to 7 days post operatively. The women were divided into two groups, 13 who had Breast Conserving surgery and 8 who had Modified Radical Mastectomy. The surveys assessed demographic characteristics of the groups, the level of knowledge regarding breast cancer, factors considered important in reaching the decision for surgery and the sources of information used during the decision-making process.

The results of this study were limited due to the small sample size, however several trends were identified. The Breast Conserving group chose that surgery because there was no difference between the two surgeries and felt that the inconvenience of daily radiation treatment was not an important factor in making their decision. The Modified Radical Mastectomy group considered daily radiation treatments to be very inconvenient and the fact that there was no difference between the surgeries to be unimportant. The test of knowledge revealed that both groups had inadequate knowledge and were not significantly different ($t = 2.04$, $df = 8.26$, $p > .05$). The subjects overwhelmingly listed the physician as the most important source of information they used to make their surgical treatment decisions. Further study of how women make their decision for surgical treatment of their early stage breast cancer is needed in order for nurses to apply appropriate interventions as they counsel such women.

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CHAPTER ONE

Introduction

One of the leading causes of death in women is breast cancer with approximately 182,000 new cases diagnosed in the United States during 1995 (American Cancer Society, 1995). Because of the widespread use of mammography, women are diagnosed at an earlier stage (Stage I or II) of the disease (Mansour, 1992). A study performed at the University of Wisconsin-Madison revealed that 53% of women diagnosed with breast cancer were in an early stage of the disease (Wolberg, Tanner, Romsaas, Trump, & Malec, 1987). Treatment for breast cancer requires surgery to remove the lesion, regardless of stage at the time of diagnosis. Typically, the surgery required is a Modified Radical Mastectomy (MRM) for later stage disease and either a simple mastectomy or a Breast Conserving (BC) surgery for the early stages. Clinical trials of women with early stage (Stage I or II) breast cancer have shown that disease-free survival between the Modified Radical Mastectomy (MRM) and Breast Conserving (BC) surgeries with radiation therapy is equal (Fisher et al., 1989; Veronesi et al., 1986; Wolberg, Tanner, Romsaas, Trump, & Malec, 1987). Because many women are in the early stages of the disease at diagnosis, they will be offered a choice of the type of surgery they prefer for their early stage breast cancer.

There is a sense of urgency about the need to make a surgical treatment decision that invokes more stress in an already stressful situation. It is necessary therefore, that health care providers offer comprehensive information about the options and determine

whether patients have understood the information. However, the time from diagnosis to surgical treatment is relatively short, which may affect decision-making abilities and lead to decisions that are later regretted (Valanis & Rumpler, 1985).

The state of Michigan enacted Public Act 195 in 1986. The "Breast Cancer informed consent law" requires Michigan physicians to provide a brochure to all patients who have been diagnosed with breast cancer. The brochure was developed to assist breast cancer patients in understanding surgical treatment alternatives and medical terminology used in the treatment of breast cancer (Michigan Department of Public Health, 1986).

Some women may have doubts about their decision just before surgery and seek positive reinforcement from the nurse. The nurse's role is to provide correct information, assess the impact of the diagnosis on the woman, and to provide the necessary psychological and educational support during this time of stress (Kalinowski, 1991). It is important for nurses to determine whether the information presented has been understood by the patient for the purpose of helping them make informed choices, dispel unfounded fears, and to assess patient-teaching effectiveness.

Ward, Heidrich, and Wolberg (1989) developed a test of knowledge for women with early stage breast cancer to determine if they had adequate information to make an informed decision. These researchers also studied what factors (for example, physical appearance, convenience, fear of recurrence, or dying, etc.) women consider as decisions are being made and the source of any information that was used to learn more about the surgical treatment alternatives. The study design divided women into two groups, those selecting MRM from those electing BC surgery.

The results revealed that there was no difference in level of knowledge between the two groups. The most important factor for those selecting MRM was concern over the efficacy of radiation therapy while those in the BC group were most concerned about body integrity. Those selecting MRM cited physician, family, and friends as the most important sources of information. The BC group identified the physician, the nurse, the family, and the handout provided by the clinic as the most important sources.

There has been limited work by other researchers in this area. Much of the research involves psychological implications of the decision-making process, the percentages of women who chose each type of surgical treatment and a few explanations for informational needs. Therefore, this study will further examine the amount of knowledge, factors considered and sources of information used in the decision making process of women selecting surgical treatment for their breast cancer. This study replicates the research done by Ward, Heidrich, and Wolberg in 1989. The purpose of replicating this research is to provide additional explanations for the nurse who is counseling women with early stage breast cancer.

CHAPTER TWO

Theoretical Framework and Literature Review

Theoretical Framework

Imogene King developed a theoretical framework to describe nursing within the health care system. This interacting systems framework views human beings as existing within personal (individual), interpersonal (groups), and social (society) systems (King, 1981). The focus of nursing is the care of human beings with the goal of helping individuals, groups, and society attain, maintain and restore health (King, 1981).

Following development of the interacting systems framework, King derived the theory of goal attainment, principally from the interpersonal system of her framework. "The theory of goal attainment was developed to describe the nature of the nurse-client encounter" (Fawcett, 1989, p. 121). King (1981) stated . . . "that nurses purposefully interact with clients mutually to establish goals and to explore and agree on means to achieve goals" (p. 142). King's theory of goal attainment provides the theoretical basis for this study. The goal of the nurse-client interaction in this study was to determine how the woman with breast cancer arrived at her decision for type of surgery.

King discussed the metaparadigm concepts of nursing (person, health, environment and nursing) in relation to systems. Person is conceptualized as a personal system from which the nurse obtains information to assist in understanding the individual. It is crucial, according to King (1981), that nurses understand the person as a whole before attempting to understand groups and societies. The personal system for this study is the woman diagnosed with early stage breast cancer.

Health is "a dynamic state of an individual in which change is [a] constant and an ongoing process" (King, 1981, p. 5). "Whereas health is a functional state in the life cycle, [illness is] some interference in the cycle" (Sieloff-Evans, 1991, p. 23). The woman diagnosed with breast cancer has undergone an interference in the life cycle. For the purpose of this study, this interference is breast cancer.

According to King, the environment is the social system such as, family, work, and religious affiliations. The environment can be internal and/or external. The environment of the woman with breast cancer is composed of these same systems of family, work, religious affiliations, and the health care system with which she interacts during her illness. Additionally, the internal and external environment of women with breast cancer may have different influences depending on the individual.

The focus of nursing is the interaction of person with environment. Nurses function to promote, maintain, and restore health with the goal of return to function. Goal setting occurs in every interaction. Nurses teach, counsel and support. These nursing roles apply under both normal and stressful situations. For purposes of this study, nursing is the interaction between the nurse and woman with early stage breast cancer as together they set goals, explore alternatives, and arrive at mutually agreed upon measures to achieve the goals. Within the interaction nurses continuously use the skills of teacher and counselor to assist the woman with breast cancer in making informed decisions regarding surgical treatment options.

King has identified several concepts that make her theory useful for the nurse. Concepts in the theory of goal attainment relevant to this study are: perception,

communication, interaction, transaction, role, stress, and time. Perception is each person's representation of reality (King, 1981). Perception of the impact of the diagnosis of breast cancer on the woman and her environment is important to the decision-making process. For example, suppose the woman decides to have a MRM because she is afraid of recurrence in the breast, even though reassured by the physician that either Modified Radical Mastectomy (MRM) or the less invasive Breast Conserving (BC) surgery would remove all the cancer. This woman has perceived her breast cancer as more life threatening than it truly is. Conversely, a woman who is told that her diagnosis of breast cancer is fatal and that a MRM is the only alternative for her, may insist on BC believing she will not die from her illness, which is her perception of reality. Each woman reacts to the diagnosis of breast cancer based on her perception of how the diagnosis will affect her future life, whether an accurate perception or not.

Communication is "a process whereby information is given from one person to another either directly or indirectly" (King, 1981, p.146). Direct communication occurs during discussions with nurses, physicians, family, friends, and others. Indirect communication occurs through the use of audio-visual materials such as, video tapes, pamphlets, books and magazines. These communications are for the purpose of gathering information related to the diagnosis of breast cancer and often is necessary to choose among surgical treatment options.

Interaction is "a process of perception and communication between the person and environment and between person and person, represented by verbal and nonverbal behaviors that are goal directed" (King, 1981, p. 145). The perception of the woman with

breast cancer, the mode of communication, and the people involved in the communication comprise the interaction process by which the woman with breast cancer decides among surgical treatment options.

A transaction is "observable behavior of [persons] interacting with their environment" (King, 1981, p. 147). The woman with breast cancer interacts with her environment to determine the best type of surgical treatment for her. She does this when she weighs the advantages and disadvantages of surgical treatment options, discusses the options with nurses, physicians, family and friends, and seeks out audio visual/written materials.

A role is "a set of behaviors expected of persons occupying a position in the social system" (King, 1981, p. 147). Numerous roles can be identified for this study, because of the many people a woman seeks out for advice on her surgical treatment options. For purposes of this study, the roles of the woman with breast cancer and the nurse who interacts with her are primary. The woman with breast cancer and the nurse determine a common frame of reference (such as, type of surgical treatment or post operative expectations) as they discuss mutual goals. The role of the woman with breast cancer is to actively seek information from her environment to arrive at her surgical treatment decision. The manner in which she participates, both actively and passively, reflects her role as a decision-maker. The nurse's role is to teach, guide, and counsel and the woman with breast cancer in her surgical treatment decisions. The perception of the woman with breast cancer regarding the role expectation and performance of the nurse and the nurse's

expectation of the woman's role and performance will determine the effectiveness of the transaction.

Stress is "a dynamic state whereby a [person] interacts with the environment to maintain balance for growth, development, and performance. It is an energy response of an individual to persons, objects and events called stressors" (King, 1981, p. 147).

Women are placed in a stressful state when diagnosed with breast cancer. The nurse can help decrease the stress by teaching, counseling and guiding the woman with breast cancer. A goal of the nurse would be to assist the woman with breast cancer in maintaining balance with the environment.

Time is "a sequence of events moving onward" (King, 1981, p. 148). Time is important to the woman with breast cancer as information must be gathered, processed, and acted upon in a relatively rapid fashion. This time factor affects the woman's level of stress and ability to interact and transact in her role as decision-maker.

Figure 1 is a representation of Kings' theory of goal attainment as it relates to this study. The woman with breast cancer and the nurses' perceptions and communications are major factors influencing transactions and mutual goal setting. The woman with breast cancer has perceptions that she communicates to the nurse. The nurse also has a perception of the woman with breast cancer and communicates these to the woman with breast cancer. The resultant perceptions and communication between the woman with breast cancer and the nurse lead to transactions and mutual goal setting.

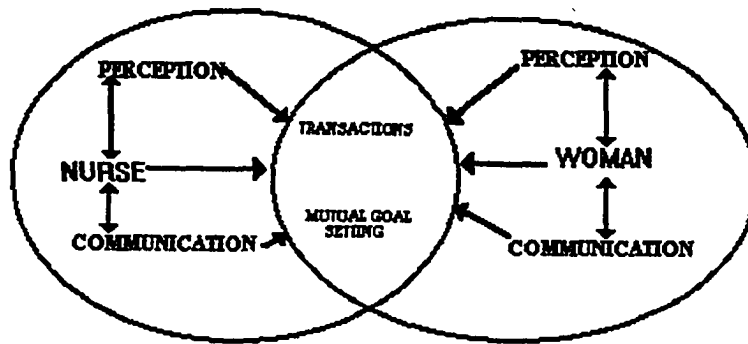


FIGURE 1. Nurse - Woman Interaction

"If behavior is an outcome of perceptions, then human perceptions become the basic data for human interactions and the facts that nurses must gather and analyze if they are to deliver effective nursing care" (King, 1981, p. 47). It is important for nurses to understand the dilemma women face when making surgical treatment decisions for breast cancer. By learning what factors and sources the woman uses and perceptions of the information gathered, nurses will be better able to guide women in their decision making.

Literature Review

The literature abounds on the various aspects of breast cancer and its psychological effect on women. The literature can be categorized into five groups for purposes of this discussion and each will be discussed: 1) making a choice between surgical interventions, 2) informational needs as choices are being made, 3) psychological implications of the choice, 4) factors women consider important to decision making, and 5) knowledge about surgical treatment options.

Making a choice between surgical interventions. Wilson, Hart, and Dawes (1988)

undertook a study that addressed the choice 153 British women made when they were offered the alternatives of Modified Radical Mastectomy (MRM) or Breast Conserving (BC) surgeries for their early stage breast cancer. At the time of diagnosis "one third immediately said that they would have a mastectomy and one third that they would have anything but a mastectomy" (Wilson, Hart, & Dawes, 1988, p. 1168). After further counseling, 35% chose BC and 65% chose MRM. The authors concluded that patients with breast cancer are capable of choosing treatment and do not automatically choose to keep their breast. This study is important to this discussion because it brings into perspective the numbers of women who still elect MRM surgery despite the less disfiguring, equally effective BC surgery.

Pierce (1993) undertook a descriptive study to analyze the decision-making process of women who are faced with surgical treatment for breast cancer. Subjects included 48 women who were interviewed and encouraged to "think aloud" about their decision experience. The results revealed that the amount of information a woman requires to make her decision, places her into one of three categories. The "deferrers" (41%) seemed to be influenced by the "salience" of a particular option. The subjects in this group simply made a decision with no consideration of the treatment options. The "delayers" (44%) were those who considered their options more carefully than the deferrers. The smallest group (15%) were "deliberators" and were characterized as more deliberate and purposeful. This group took charge and felt a personal responsibility for making a quality decision. They took more time and researched their alternatives more

thoroughly than either of the other groups. Pierce (1993) concluded from this study that "each decision-making style has unique characteristics that suggest the need for more individualized interventions and support for patients making difficult decisions" (p. 27).

Chapman, Elstein, and Hughes (1995) reported on a study of the effectiveness of materials for educating patients about treatment options for breast cancer. This study is of limited value because the subjects were undergraduate students who were instructed to make their decision based on the education provided. Because these students were not diagnosed with breast cancer it is difficult to conclude that they would reach the same decision if they were actually faced with the diagnosis.

Informational needs as choices are being made. Three different studies viewed information as a common need in cancer patients. Derdarian (1986) surveyed 60 newly diagnosed cancer patients and learned that these patients had a need for more information about treatment, felt that it was more important to have information regarding treatment and prognosis rather than diagnosis and tests, and that women required more information than men about prognosis. This study used subjects who had cancer (not necessarily breast cancer) and who would not have surgery as part of their treatment plan.

In another study, Messerli, Garamendi, and Romano (1980) asked 77 surgeons and 58 patients to complete surveys regarding informational needs and availability of the information. Patients were asked what information was provided on breast cancer, its treatment and what additional information they would have liked. The physicians were asked about the type and amount of information they provided to patients. The results revealed 86% of newly diagnosed breast cancer patients had unanswered questions

concerning their treatment. Patients wanted written information to help them learn about breast cancer, the different diagnostic tests, and treatments including recovery information. Within the physician group, 78% admitted they did not have written information available for their breast cancer patients. Also, both groups were asked to rank the importance of potentially available resources for help or information. The two groups did not agree on what type of information was needed or on the source of the information. Patients ranked written materials on breast cancer and a list of questions to ask the physician as number 1 and 2 respectively, of nine potential resources for information. Physicians, on the other hand, felt talking with a sensitive, understanding doctor was the best resource (patients ranked this resource as 8). The authors of this study were in a Bachelors of Arts program doing the study as a term project.

Cawley, Kostic, and Cappello (1990) undertook a descriptive study assessing 68 women with breast cancer who chose BC to determine if their physical and psychosocial needs were being met. Physical needs were addressed by a questionnaire that requested information regarding physical discomfort after lymph node removal. Results from this survey determined that 64% experienced some discomfort; 50% of the sample achieved pain relief with medication.

Informational needs were assessed using a questionnaire that sought to determine if the subjects received all the information they felt they wanted before surgery. The source of this information came from the physician and/or the nurse. However, it was unclear if the subjects were asked to list all sources of the information or if they were only given the choice between physician and nurse. No mention is made of written information

or other audio-visual materials that might have been used to learn about breast cancer and follow-up treatment. The findings revealed that 74% felt they had received all the information they wanted about BC before surgery; the physician was the primary source of information. Only 23% of these women received information from nurses.

Psychosocial needs of these subjects were met by family/friends (87%) the majority of time. Of other questions asked, 55% felt the surgery was upsetting, 54% were encouraged to discuss fears and concerns and 14% were visited by someone who had experienced the same surgery. This study was retrospective in nature and the subjects were asked to recall needs they may have had at the time of their diagnoses, at least 2 years previous, limiting its usefulness.

Psychological implications of the choice. Several researchers have analyzed the psychological effect's women with breast cancer experience. Leinster, Ashcroft, Slade, and Dewey (1989) conducted a study using a sample (N = 59) in which 14 of the 59 subjects had benign breast disease and 24 of the remaining 45 patients were not offered a choice of surgical treatment. The study presented data from eight different groups of women which are listed below:

- | | | |
|----|--|------|
| 1. | Trial (random allocation to a mastectomy) | n=2 |
| 2. | Trial (random allocation to a lumpectomy) | n=2 |
| 3. | Mastectomy chosen by subject | n=6 |
| 4. | Lumpectomy chosen by subject | n=8 |
| 5. | Mastectomy the only viable treatment; breast reconstruction not chosen | n=17 |
| 6. | Mastectomy the only viable treatment; breast reconstruction chosen | n=7 |

7. Breast reconstruction n=1
8. Lumpectomy (mastectomy not offered) n=2

Subjects were required to complete a battery of psychological tests to measure depression, anxiety, body satisfaction, social adaptability, self-esteem, marital satisfaction, and concern about appearance, disease, and treatment. Each group was compared with all other groups on scores on each of the tests. The findings were reported in general terms. For example, "generally, none of the patients manifested much depression and anxiety" (Leinster, Ashcroft, Slade, and Dewey, 1989, p. 184) and "none of the analyses found any significant difference in body satisfaction among the groups at any time; the scores approximated those of the normal population" (p. 185). Clearly this study was cumbersome to compare all the groups on all the tests. The most important finding from this study was concern about appearance. Subjects in groups 4 (n = 8), 6 (n = 7), and 7 (n = 1) rated higher on their concern about appearance than did those who chose to be in the randomized surgical treatment or mastectomy only groups.

Margolis, Goodman, and Rubin (1990) provided an analysis of psychological effects of those women making a choice between surgical options. Their results concluded women who elected MRM felt less sexually attractive and more embarrassed about their body image. Moreover, although they had the same frequency of sexual intimacy as their BC counterparts they felt the experience was of poorer quality. In the MRM group (n = 22), 36% felt cured and in good health while 51% would have elected BC surgery if they were given the choice again.

Morris and Royle (1988) determined that those patients not offered a choice between surgical options experienced more depression and anxiety. A total of 30 subjects took part with 20 subjects given a choice of operation (7 chose MRM and 13 chose BC surgery). The 10 remaining participants were not offered a choice. Results suggested that both the patient and her partner exhibited more anxiety and depression when not offered a choice, concluding that choice is more psychologically healthy for both patient and partner. The sample size and inequality of groups limit the usefulness of the study.

Several studies compared the psychological effects of breast cancer between the MRM and BC population. Holmberg, Omne-Ponten, Burns, Adami, and Bergstrom (1989) tested the occurrence of anxiety and depression between 62 patients electing MRM and 37 who chose BC surgery. Data analysis revealed that there was no significant difference ($p > .05$) between the two groups in the amounts of depression and of anxiety.

Psychological consequences of BC surgery were studied by Levy, Herberman, Lee, Lippman, and d'Angelo (1989). A limitation to this study was the methodology used to recruit participants. One group of subjects ($N = 93$) was selected from a pool of patients who were part of a National Cancer Institute (NCI) study looking at outcomes between MRM and BC surgeries. These participants were randomized to BC surgery in the NCI study and thus were not offered a choice of surgery. This group of subjects was compared with a concurrent study in Pittsburgh in which 98 subjects were offered a choice of surgical treatment. The two groups were compared for their level of distress. There was more distress in the subjects who were offered a choice. They also reported a lack of

emotional support from significant others. Factors used in making the choice were not addressed.

Wellisch et al. (1989) evaluated the psychological effects of MRM versus BC surgery in 50 subjects. The impact of breast reconstruction was examined as well. These findings were consistent with those of Lasry and Margolese (1992) regarding fear of recurrence. There is a similar fear among all breast cancer patients, regardless of surgical intervention. Aspects of body image, feelings of femininity and attractiveness, and sexuality (frequency of sexual relations and appearing nude in front of partner) also were assessed in this study. Not surprisingly, the researchers found that those with a MRM had a poorer body image and those who did not have breast reconstruction appeared nude less often.

Deadman, Dewey, Owens, Leinster, and Slade (1989) found that control over surgical treatment choice differs among women with breast cancer. A study of 44 British women for psychological response to breast cancer treatment, found that women with a high concern for appearance were more likely to desire control over their surgical treatment choice. On the contrary, those who have little concern for appearance portrayed more anxiety when given control over surgical treatment choices. The authors concluded that a woman who had lost her breast is more likely to be depressed a year later than a woman who conserved her breast. This study supports the results of Margolis, Goodman, and Rubin (1990) discussed earlier comparing MRM and BC surgeries.

The final study in this category was conducted by Owens, Ashcroft, Leinster, and Slade (1987) to test the informal decision analysis theory for helping patients make

choices in treatment options. Forty-three women were led through a series of value statements, using a decision tree, to arrive at the choice most suited to their psychological well being. The results revealed that concern about appearance is extremely important in the decision about treatment. By breaking the decision into component parts, women were able to identify what additional information was needed. Depression and anxiety around the time of treatment were found to be slight.

Factors women consider important. Margolis and Goodman (1984) studied motives' women had when selecting BC surgery. Overwhelmingly (96%) the participants wanted to avoid feelings of disfigurement, deformity, mutilation, and insult to their femininity. These subjects also were assessed for the meaning of the breast to them. Results revealed that 94% of the women believed the breast was part of their femininity, and 96% felt the breast made them attractive to others. This study did not compare the surgical treatment options and the instrument used to measure the motives was not reported.

Knowledge of breast cancer. The knowledge of treatment options is the final category for discussion. The two studies presented here are discussed in more detail as they more closely represent this study. Wolberg, Tanner, Romsaas, Trump, and Malec (1987) analyzed the decisions of 110 women who were offered the choice between MRM and BC in treatment of their breast cancer. These women underwent a battery of tests before any surgical treatment to determine factors potentially influencing their choice including, psychological distress, breast cancer knowledge, and degree of control over personal health care and maintenance. The findings in this study revealed 53% of the

participants considered suitable for breast conservation surgery elected this treatment. The two groups (MRM and BC) were then compared for their responses on the various tests. Those women who chose MRM demonstrated more anxiety and depression. Those women who elected breast conservation valued their physical appearance more highly. The authors concluded that patients may benefit from psychological intervention when post-operative adjustment is difficult, especially in those who elect MRM, however, post-operative testing was not performed in this study.

Knowledge of breast cancer was tested by Wolberg, Tanner, Romsaas, Trump, and Malec, (1987) using the Breast Cancer Information Test (BCIT). The BCIT is similar to the instrument used in this study. The results, using the BCIT, were not discussed in the published report. The instrument was designed to measure knowledge of breast cancer and its treatment. This same instrument was used in a similar study by Ward, Heidrich, and Wolberg (1989) to determine if women had adequate knowledge about breast cancer. Interestingly, both studies were conducted in the same setting. It is unclear if both studies used the same group of women. One study was performed pre-operatively and the other post-operatively. Comparisons regarding knowledge of breast cancer in the two groups (MRM and BC) cannot be made because the knowledge test results were not reported by Wolberg et al. (1987).

In the Ward, Heidrich, and Wolberg (1989) study, 22 women with early stage breast cancer, given a choice between MRM and BC were interviewed post-operatively to determine the sources of information used in determining the type of surgical treatment, factors they had considered when selecting surgical intervention, and the degree of

participation they desired in decision-making. The women were divided into two groups, those electing BC from those choosing MRM. The two groups were compared on demographic variables (marital status, income, education, and age) and knowledge about breast cancer using the BCIT. The investigators reported that there were no significant differences between the groups in level of knowledge of breast cancer, education, income, or marital status but failed to give statistics. The younger women selected BC surgery more often.

All subjects had been treated through a Breast Problem Clinic which provides the following services: 1) a surgeon describes each procedure (MRM and BC) in terms of risks, benefits, and expected outcome, 2) the patient views a videotape presentation about the two options, 3) the patient receives a handout that compares the two options, and 4) a nurse reviews and discusses this information with the patient. The researchers believed it was important to study women attending the same clinic who were seen by the same surgeon and the same team of two nurses. Therefore, all subjects in this study were offered similar information and neither treatment option was favored by either the surgeon or the nurses.

The subjects were asked to identify sources of information used in arriving at a decision. Those selecting MRM cited physician, family, and friends (in that order) as the most important sources of information. The BC group identified the physician, the nurse, the family, and the handout given by the clinic (in that order) as the most important sources. A data analysis of sources of information used by all subjects revealed people

sources of information ($M = 1.91$, $SD = .89$) were considered more important than were other sources ($M = .86$, $t(22) = 3.43$, $p = .003$).

The results of this study revealed several factors women considered important and helped them to choose their surgical treatment. The most important factor for those selecting MRM was concern over the efficacy of radiation therapy, while those in the BC group were most concerned about body integrity. All subjects believed the three most important factors influencing their decision were fear of cancer recurrence, desire to avoid a second surgery in the future, and physician preference (in that order). The participants wanted to be part of the decision making, with 11 choosing to make the decision solely by themselves and the other 11 wanting to share the decision-making responsibility. A trend was identified that the MRM group wanted the decision to be fully their own and the BC group wanted to share the decision. The majority (91%) of subjects believed they had participated in the decision as much as they desired. The limitations of the study were the small sample size ($N = 22$) and the retrospective nature of the study. The authors defended the retrospective nature of this study with the ethical dilemma of potentially influencing subjects' decisions if interviews had been conducted before the surgical procedure.

There are still many unanswered questions about how a woman with breast cancer selects her treatment including the factors and resources that influence her decision. Despite the numerous studies presented, many are contradictory in their findings and few value the nurse's contribution in assisting women to make choices. It is crucial that women with breast cancer have adequate knowledge to make the choice, are introduced to

the various resources available, and are able to consider all facets of their decision. This is important because the remaining years of their lives will be affected by their decision. This study provides nurses with an insight into these factors and offers nurses valuable information as they teach, guide and counsel women with breast cancer.

Research Questions

The following research questions were addressed:

- (1) What is the level of breast cancer knowledge of women with Stage I or II breast cancer regarding their treatment for early stage breast cancer?
- (2) What sources of information are used by women with early stage breast cancer during the decision-making process for surgical treatment options?
- (3) What factors are considered by women in deciding between modified radical mastectomy and breast conserving surgery?

Definition of Terms

The major concepts for this study are identified and defined below.

Woman with breast cancer. A woman diagnosed with Stage I or II breast cancer having the option for BC or MRM as the surgical treatment of her disease.

Knowledge. The information a woman with breast cancer uses to make a decision between MRM and BC surgeries for early stage breast cancer treatment. The knowledge base of a woman with breast cancer can be tested by an objective measurement tool that provides evidence of the result of both direct and indirect communications.

Sources of information. As a woman with breast cancer proceeds through the decision-making phase of her illness, she may seek information. Sources of information include health care providers, literature, or other people in her environment.

Factors. The woman with breast cancer also will consider various factors that will influence her decision for surgical treatment. Factors under consideration during the decision-making process may include the possible side effects of radiation therapy, another woman's experience with breast cancer or how her support person(s) perceives the options available.

Decision Making. The process a woman with breast cancer uses to make a choice between MRM and BC surgeries. The choice is based on perception and communication of the woman with breast cancer as she transacts and mutually sets goals with the nurse. Once the decision has been made and the surgery completed, transaction and mutual goal setting have occurred.

CHAPTER THREE

Methodology

Research Design

An ex post facto descriptive design was used for this study. This design assists the researcher in describing breast cancer knowledge, factors considered important, and sources of information used by the woman with breast cancer, without any researcher intervention (Polit & Hungler, 1991). Twenty-one women with breast cancer who underwent surgical treatment for their illness, within the prior 7 days, were asked to take part in this study.

Sample and Setting. A convenience sample of 21 women who met the sample selection criteria were used for this study. Subjects were women with Stage I or II breast cancer admitted to a Midwestern metropolitan hospital for breast cancer surgery. Criteria for selecting subjects included:

1. Women with Stage I or II breast cancer that was neither multifocal nor bilateral.
2. Women who have not had a previous contralateral mastectomy.
3. Women choosing BC surgery whose cancer is of a size and in a location such that its excision will leave a cosmetically acceptable breast as determined by the surgeon.
4. Women who were offered the choice of MRM with or without breast reconstruction or BC by her surgeon.
5. Women who are able to read English or who can understand English, if read to.

An additional criterion was imposed by the institutional review board of the hospital that required the surgeon's written permission for potential subjects to be asked to participate. This impaired the ability of the researcher to recruit subjects since attempts to locate the surgeon and gain permission prior to discharge often failed. After 1 year of data collection, 21 women met the selection criteria and agreed to participate in this study. In all, 44 women met the selection criteria identified. Of those 44 women, 19 were not asked to participate because their physician could not be located, 25 were asked to participate, with only four women refusing participation. Of the 21 women, 13 chose BC surgery and 8 chose MRM with three having breast reconstruction.

Instruments

The instruments used in for this study included a demographic data form, the revised Breast Cancer Information Test (BCIT-R), a factor list, and a source of information list.

Demographic Data Form. The demographic data form (see Appendix A) was used to collect data on the demographic characteristics of the subjects. The tool includes the level of education, income, marital status, type of surgery, and number of days between diagnosis and surgery of each subject. This information was used to categorize subjects by level of education, income, and marital status.

Breast Cancer Information Test -- Revised (BCIT-R). The BCIT-R (see Appendix B) is a 19-item, true-false test developed by Ward, Heidrich and Wolberg (1989). This test measures the amount of knowledge regarding breast cancer possessed by women who are recently diagnosed with early stage breast cancer. The title of this test was changed by

replacing the word “test” with the word “survey” in an attempt to minimize the negative connotation the word test can invoke. Two changes were made to the BCIT-R for this study. An additional question was added to assess knowledge regarding Tamoxifen. Secondly, to avoid guessing correctly on statements that the subjects may not know the answers, a "don't know" option was added.

This test has been used twice in different settings (Wolberg, Tanner, Romsaas, Trump, & Malec, 1987; Ward & Griffin, 1990). The first time it was used with patients who had breast cancer and who had a choice of surgical treatment (Wolberg, Tanner, Romsaas, Trump, & Malec, 1987). The second application was expressly designed to examine reliability and validity of the BCIT-R (Ward & Griffin, 1990). Patients, nursing students, and oncology nurses all took the test and each group was compared separately and together to establish both reliability and validity. Content validity was established by asking nurse experts in oncology to examine the test items to determine if they covered the information that women need to make an informed decision. Test questions were revised or eliminated to arrive at the BCIT-R used in the study by Ward and Griffin (1990).

Construct validity was assessed in the second use of the BCIT-R using the known-groups technique (Ward & Griffin, 1990). Three convenience samples expected to have different levels of knowledge about breast cancer were invited to participate in the study: a) senior undergraduate nursing students, b) practicing nurses and c) women diagnosed with breast cancer. The test scores of the three groups differed in variability and in mean percentage correct. The fact that these differences were in the expected direction, gave

support to construct validity. Other factors that assisted in establishing construct validity are:

1. BCIT-R scores were moderately related to the patient's level of education. The higher the education the better test score achieved.

2. There was an inverse relationship between total years in nursing and test score. The longer time in nursing the worse the test score (explained as some nurses practicing with outdated information).

3. A direct relationship between number of years in oncology nursing and test performance was identified. The more years in oncology nursing the better the score (explained by veteran oncology nurses possessing current knowledge).

Reliability coefficient for internal consistency of the BCIT-R for this study using the KR-20 formula, was .83 which is much better than the either of the other two uses of the instrument. A KR-20 using the extra item (number 19) produced a coefficient of .86.

Factor List. A factor list (see Appendix C) was adapted from one used by Ward, Heidrich and Wolberg (1989). This list contains factors that may influence the subject's decision regarding surgical treatment. These factors are based on a literature review of factors women consider when making a choice. Content validity was established by two clinical nurse specialists in oncology. One factor was added to the list (cost of treatment) that was not on the original list based on the recommendation of the original researchers.

Source of Information. The source of information list (see Appendix D) was adapted from one used by Ward, Heidrich and Wolberg (1989). This list includes both "people" sources such as health care providers, as well as literature sources. For this

study, an additional item was added, "another woman with breast cancer". Many women have the opportunity to speak with another woman who has had the same or similar experience. "Expressions", a local support group, accessed through physician referral, offers support to women between the time of diagnosis of breast cancer and treatment.

Procedure

Subjects were recruited from a local hospital. The name of the patient and type of surgery were obtained from the daily surgical schedule. The subject's chart was reviewed by this researcher to determine if sample selection criteria were met. An attempt was made to locate the surgeon to gain permission to approach the potential subject. Only one surgeon refused to allow a patient to participate, however, this same physician later agreed to allow all of his patients who met the criteria to be approached without his prior approval. Patients were approached as potential subjects on the day following surgery.

Explanations to participants included the nature and purpose of the study, potential risks and benefits to the subject, and the time commitment (approximately 45 minutes to complete the instruments). Confidentiality of all demographic and clinical information and test scores were maintained using an identification number assigned to subjects. At any time throughout the data collection period, subjects were allowed to decline to participate. An informed consent was obtained (see Appendix E).

Data collection took place on the first postoperative day if a BC patient, or on the first or second postoperative day if a MRM patient. Every effort was made to test subjects while they were still hospitalized. If this was not possible due to early discharge or day of surgery discharge, as occurred in some of the BC patients, subjects took the

surveys home to complete. A stamped addressed envelope was provided to return the survey. Only two potential subjects declined participation by not returning the surveys. Test administration was performed in the subject's room or at home to women who met the sample selection criteria. To prevent any conflict with potential cognitive issues, the consent and data collection occurred when the subject was without narcotics for at least 4 hours. Administration of all instruments was performed by this researcher. Subjects who had difficulty reading English had the instruments read to them; all others completed the forms personally.

There were several potential risks to the subjects that were identified and therefore plans were made to minimize these risks. Subjects were advised that 1) they had the right to withdraw from the study at any time; 2) may refuse to participate; and 3) refusal would not affect their care while in the hospital or in subsequent treatment.

The purpose of the study and nature of the test may raise questions in the subject's mind about the choice they made for surgery. Each subject had an opportunity to discuss her decision with the researcher or her physician after individual data collection had been completed. Every effort was made to support the subject and the decision she made.

The surgeons who perform the surgeries at the study location were informed of this research. A letter outlining the purpose and nature of the study was sent to them prior to the start of data collection. The researcher also attended the surgery section meeting to further explain the study and discuss the various instruments. All physicians who were in attendance at this meeting supported the proposed research and did not offer any further qualifiers or suggestions. As subjects were enrolled in the study, a form was placed in the

patient's chart (progress notes section) requesting the surgeon to sign an agreement that the individual patient was appropriate for the study. This form also alerted the surgeon to possible questions or concerns the patient may have after completing the surveys.

Some participants became tired during the testing period. The researcher attempted to approach subjects during a convenient time identified by the subject. If fatigue occurred, the testing was halted and resumed at a later time determined by the participant. Several of the BC subjects elected to take the surveys home and mail them back within 1 week. The researcher called those subjects to clarify any questions that may have arisen during completion of the surveys at home..

Subjects also may experience test anxiety if they are unsure of an answer, therefore, all were encouraged to mark the "don't know" option on questions for which they did not know the answer. Finally, confidentiality was maintained by the identification number assigned to each subject and recorded on all response sheets. Names were not used on any forms.

CHAPTER FOUR

Results

Twenty-one women responded to the surveys and therefore comprise the sample group used for this study. Each item on the surveys was assigned a numerical value and entered onto a coding sheet for purposes of computer analysis. Analysis of the data was computed using the Statistical Package for the Social Sciences (SPSS/PC+) software. Data analysis was performed to describe the demographic characteristics of the sample and to answer the research questions. It is important to note that the small sample size was a limitation to data analysis. The results of this study are presented with the demographic characteristics first followed by the results of each research question.

Characteristics of the sample

Table 1 summarizes the demographic characteristics of the two groups. The subjects who chose Breast Conserving (BC) surgery were younger ($M = 55.7$, $SD 7.9$) than those selecting Modified Radical Mastectomy ($M = 63.9$, $SD 13.8$) though the difference was not statistically significant. There was no relationship ($\rho = .41$) between education and group membership of the subjects. However, a trend is noted for the BC group who seemed to have a higher level of education. There was no relationship ($\rho = .02$) between income level and group membership. The subjects marital status was not a significant factor associated with choice of surgery between the groups ($X^2 = 1.64$, $df = 1$, $p > .05$). Subjects had a mean time of 17.9 ($SD 10.3$) days, from the day of diagnosis to the day of surgery, to contemplate their decision between Breast Conserving and Modified

Table 1

Demographic characteristics of breast conserving (BC) and modified radical mastectomy (MRM) groups.

Characteristics	Groups		
	BC (n = 13)	MRM (n = 8)	Total (N = 21)
Age (in years) ^a			
M	55.7	63.9	58.8
SD	7.9	13.8	11.0
Education (frequencies) ^b			
≤ High School	2	5	7
> High School	11	3	14
Income (frequencies) ^c			
≤\$50,000	6	3	9
>\$50,000	5	2	7
Marital Status (frequencies) ^d			
Married	8	7	15
Not Married	5	1	6
Interval between day of diagnosis and day of surgery (in days) ^e			
M	18.2	17.0	17.9
SD	11.7	6.5	10.3

^at (21) = -1.53, p > .05.

^brho (21) = -.41, p > .05.

^crho (16) = -.02, p > .05, Five subjects did not respond.

^dX² (1, N = 21) = 1.64, p > .05.

^et (18) = -.02, p > .05, Three subjects did not respond.

Radical Mastectomy surgeries. There was not a significant difference in time between the groups from day of diagnosis to the day of surgery.

Research Question One

The first research question of this study asked “What is the level of breast cancer knowledge of women with Stage I or II breast cancer regarding their treatment for early stage breast cancer?” To answer this question the subjects were asked to complete the Breast Cancer Information Test - Revised (BCIT-R), a 19-item true-false survey testing general knowledge of breast cancer. The results of the t - test is summarized in Table 2. There was no significant difference between the groups in their amount of knowledge related to breast cancer ($t = 2.04$, $df = 8.26$, $p > .05$). The women in the group selecting Breast Conservation (BC) scored slightly higher ($M = 16.0$, $SD = 2.1$) than those women in the Modified Radical Mastectomy (MRM) group ($M = 11.9$, $SD = 5.5$), on the BCIT-R survey. It should again be noted that due to the small sample size, statistical power might not have been large enough to detect significant results.

Table 2

Data analysis of Breast Cancer Information Test - Revised comparing the breast conserving (BC) group with the modified radical mastectomy (MRM) group.

	Knowledge Score			t	p
	BC (n = 13)	MRM (n = 8)	Total (N = 21)		
M	16.0	11.9	14.4		
SD	2.1	5.5	4.2	2.04	.075 ^a

^a Separate variance estimate.

Research Question Two

The second research question asked “What sources of information are used by women with early stage breast cancer during the decision-making process for surgical treatment options?” The subjects were asked to choose three sources of information and rank them in order of importance in making the decision for type of surgery. Table 3 lists the sources of information and the first and second most important source for each group. Of the 10 choices offered for selection, 10 of 13 in the BC group chose the physician as the most important source while 7 of 8 women who had a MRM chose the physician as the first or second most important resource. The third most important source selected by women was very diverse and not statistically relevant for reporting.

Table 3

Comparison of the rank subjects chose as sources of information between breast conserving (BC) and modified radical mastectomy (MRM) subjects

Source	BC	BC	MRM	MRM
	Rank #1	Rank #2	Rank #1	Rank #2
Handouts	1	1	0	0
Video	0	0	0	0
Doctor	10	0	3	4
Nurse	0	1	0	0
Friends	0	1	1	0
Family	1	1	2	1
Media	0	2	0	0
Medical Books	0	2	0	0
Another Woman	1	4	1	2
Magazine/Newspaper	0	1	0	0
Other	0	0	1	0

Research Question Three

The third and final research question asked “What factors are considered by women in deciding between MRM and BC surgery?” The Mann-Whitney test, a non-parametric test, was used to determine how subjects ranked various factors that affected their decision for surgical treatment. Because the groups being tested are unequal in number the Mann-Whitney test is the procedure to account for these differences. Table 4 summarizes the individual factor (item) with the rank, “R” for each group. Of particular interest were two factors that were significant. The item “Inconvenience of Radiation

Therapy” was ranked 8 by the BC group but 14 by the MRM group ($p = .01$). The other factor was “No difference between the surgeries” which the BC group ranked 13 and the MRM group ranked 7 ($p = .02$). A third factor, that approached significance, indicated a trend that the MRM group knew a family member or friend who had undergone a mastectomy and felt this was very important (ranked as 14) but the BC group did not consider this factor important ($p = .07$).

Table 4

Factors considered important in selecting type of surgery for the breast conserving (BC) group as compared to the modified radical mastectomy (MRM) group

Items	BC	MRM	U	W	p
	(n = 13)	(n = 8)			
	R	R			
Knowing a friend/family with MRM	9.15	14.00	28.0	112.0	.07
Knowing a friend/family with BC	10.58	11.69	46.5	93.5	.68
Knowing physicians preference	10.62	11.63	47.0	93.0	.69
Knowing preference of someone else	9.46	13.50	32.0	108.0	.14
Fear of cancer returning	11.62	10.00	44.0	80.0	.52
Inconvenience of Radiation Therapy	7.92	14.38	17.0	115.0	.01
Fear of Radiation Therapy	9.65	13.19	34.5	105.5	.19
Avoid side effects of Radiation Therapy	10.42	11.94	44.5	95.5	.57
Feel about losing a breast	12.46	8.63	33.0	69.0	.15
How I think my partner would feel	11.42	10.31	46.5	82.5	.68
No difference between the surgeries	13.42	7.06	20.5	56.5	.02
Possibility of breast reconstruction	9.63	10.64	37.5	74.5	.70
Avoid another surgery in the future	9.92	12.75	38.0	102.0	.28
Fear of dying from cancer	9.88	12.81	37.5	102.5	.24
Concerns about loss of arm strength	11.35	10.44	47.5	83.5	.74
Concerns about amount of pain	10.58	11.69	46.5	93.5	.67
Concerns about cost of treatment	12.42	8.69	33.5	69.5	.17

Additional Findings

Several women added comments or other factors they considered important on this portion of the survey in response to the question: “Were there any other factors that influenced your decision for type of surgery that were not part of this list?”

MRM group

- Faith in my surgeons (trust - love - concern) and positive input.
- Excellent facilities.
- Talking with friends who had mastectomies and reconstruction and their satisfaction with the results.
- Knowing of other women who had lumpectomy and did not survive.
- Knowing of other women who had mastectomy and are still alive.
- Christian faith in the Lord watching and having a master plan for each of us.

BC group

- Physician’s advice.
- Stage of the cancer.
- General health good until this diagnosis.
- BC surgery was the easiest and quickest treatment.

In summary, the data analysis, although suggesting several trends, are not of statistical relevance due to the small sample size. Trends suggested that women who selected breast conserving surgery may be younger, may have a higher level of education, and may have more knowledge regarding breast cancer. The MRM group had a significantly higher rank in considering the inconvenience of radiation therapy as important

when compared to the BC group. The belief that there was no difference between the surgeries was the most important (#1) factor influencing the decision of the BC group. Both groups felt the most important sources of information were the physician and another woman with breast cancer. A more thorough discussion of these differences will be found in the next chapter.

CHAPTER FIVE

Discussion and Implications

Discussion

The purpose of this ex post facto descriptive study was to determine how women make decisions for surgical treatment of early stage breast cancer. In discussing the results below it must be noted that the small sample size is a limitation to any conclusions that may be drawn. The discussion will begin with the demographic background of the subjects, a description of the results of each of the research questions, limitations of this study, implications of the results of this study, and, finally, suggestions for further research.

Demographic characteristics There were 21 subjects who participated in this study. Of the eight women who selected MRM, three had concurrent breast reconstruction. The average age of the respondents was 58. The youngest was 41; the eldest 81. Although the age difference between the two groups was not statistically significant ($t(21) = -1.53, p > .05$), the BC group was younger. The average age for the BC group was 56; 64 for the mastectomy group.

Concerning education, the majority of subjects (20) had completed high school. Overall the BC group had a higher level of education, with 11 of 13 women having had some college education, while only 3 of 8 MRM had college level education.

Income level between the two groups was not significantly different with 9 subjects earning \leq \$50,000, and 7 earning $>$ \$50,000. Five subjects did not respond to this question. Most of the subjects were married (15 of 21).

The investigator expected to find a relationship between the amount of time that elapsed from the day of diagnosis to the day of surgery and the amount of knowledge the subjects would have regarding breast cancer. This was to be explained as the longer the time interval, the more knowledge a woman would have. However, there was no difference in the amount of time that elapsed and knowledge scores. Overall the average amount of time between diagnosis and surgery was 18 days.

Research question one. The first research question was asked to determine if women with early stage breast cancer had sufficient knowledge regarding their disease to make an informed decision for type of surgery. Although statistically not significant, there was a trend for the women who selected breast conservation to score slightly higher on the test of knowledge, suggesting that these women may have more knowledge regarding breast cancer.

There were 3 questions on the BCIT - R that bear further discussion. On the question “every woman with breast cancer, regardless of the size or location of the tumor, has an option between having a mastectomy or lumpectomy,” 52% of the subjects believed this to be a true statement. However, this statement is false and may indicate that women with breast cancer (or any woman) have a false impression of surgical treatment options. Another question regarding the necessity of chemotherapy, regardless of the type of surgery, was answered incorrectly by 52% of the subjects. Finally, the last question on the test asked if Tamoxifen prevents recurrence in those tumors high in estrogen. There were 10 subjects (48%) who knew that this was true. However, there were another 10 who stated they did not know the use of Tamoxifen. The responses on these three

questions indicate that women have a need for further information regarding treatment, both surgical and medication management. When comparing the responses to these three questions, it appears as though further education regarding breast cancer treatment (surgery and chemotherapy) and surgical treatment options may require that additional information be presented to women with breast cancer. It is also noteworthy that 2 people scored perfectly on the test, one from each group. The worst score of 3 correct was a woman who had a MRM.

Research question two. The second research question asked for sources of information used while making the decision for type of surgery. Overwhelmingly, the physician was the most important source. The other sources cited by the subjects were another woman with breast cancer, family, friends, and the nurse. Sources such as handouts, books, and the media were cited by 6 of the BC group as the second resource used. None of the MRM group used written material or the media as a source of information. Clearly physicians have the greatest impact on decision-making for these women. It is noteworthy as well that “people” sources were used the most versus printed materials. Ward, Heidrich, and Wolberg (1989) noted a similar finding. These authors draw the conclusion that while there is a move to decrease provision of services in the face of financial constraints, patients rely on interactions with others when making medical decisions. Messerli, Garamendi, and Romano (1980) conducted a study regarding informational needs and availability of the information from both a physician and patient perspective. The results of their study were not supported by the data in this study, because their patients requested more written information. It is disheartening to note that

nurses did not have any influence in providing useful information for women in this study. Nurses were identified more often in the BC as important sources of information in the study by Ward, Heidrich, and Wolberg (1989). This can be explained by the differences between the two study sites. Ward, Heidrich, and Wolberg (1989) conducted their study at a breast cancer clinic where the whole health care team is available in one location. Such a clinic does not exist in this local area. Perhaps the clinic idea should be pursued in an attempt to give women with breast cancer a more consistent and holistic approach for making treatment decisions. The study by Pierce (1993), which examined the decision making of women choosing surgical treatment for their breast cancer, concluded that more individualized interventions and support are needed for the decision-making process.

Several women added their own sources of information as well as comments in this area. One subject who had BC surgery used printed materials to help with her decision. She went so far as to list the bibliography she used. It is also interesting to review the comments she provided throughout the entire survey. She noted that she received a pamphlet from her physician, was told to read it, and then call if she had further questions or required more information. She cited this pamphlet as the most important resource she used and, in fact, did not choose the physician in her top three sources on information. This pamphlet must be given to all women with breast cancer by Michigan state law. No other woman mentioned this pamphlet as a source of information, indicating that perhaps it is not as useful as the State of Michigan surmises or perhaps they are not distributed as required.

One woman who had a MRM chose God as her first source of information and her “own feelings” as the second most important source. Another woman stated only the physician was used as a source of information and then said that “My decision was made upon the advice of three physicians.”

Research question three. The third and final question asked what factors were important in making surgical treatment decisions. The BC group chose that surgery because they believed that there was no difference between the two surgeries and felt that the inconvenience of daily radiation treatments was not an important factor. Conversely, the MRM group considered daily radiation treatments to be very inconvenient and the fact that there was no difference between the surgeries to be unimportant.

There were several other factors identified by the subjects as important to their decision. Those selecting BC surgery ranked their feelings about losing a breast and concerns about cost of treatment as important factors in their decision. The women who selected MRM placed a higher importance on knowing of a friend or family member who had experienced a mastectomy, knowing of the preference of someone else and fear of radiation therapy. These findings are congruent with those of Ward, Heidrich, and Wolberg (1989).

Relationship of the findings to the theoretical framework. The theoretical framework for this study was Imogene King’s theory of goal attainment which describes the nature of the nurse-patient relationship. The findings of this study, as they relate to King’s theory are unfortunately difficult to describe because only one nurse influenced a patient’s decision. Regardless, the results of this study do support King’s theory in several

areas. The reader will recall that the concepts in King's theory pertinent to this study were perception, communication, interaction, transaction, role, stress, and time. Each concept is now discussed as it relates to the findings of this study.

The results of this study did not measure the subjects' perception on how the diagnosis of breast cancer influenced her decision for surgical treatment. Therefore, no inferences can be made. Communication was measured using the source of information the subject relied on for decision-making. The most frequently cited sources, physician, family, friends, and another woman, are described by King as direct communication. King also discusses indirect communication such as printed or audio visual materials. Indirect communication sources were not identified by the subjects, in this study, as important. Interaction, which combines the concepts of perception and communication to arrive at a decision for surgical treatment as described by King, can not be supported by the results of this study. An incorrect perception of the diagnosis was not identified by any of the subjects.

Transaction, which is observable behavior of persons interacting with the environment, was supported. The interaction between the woman and any sources of information used to arrive at a decision, describes the transaction concept. Roles of the subject and the nurse as described by King were not supported. It had been postulated that the role of the nurse would be to assist the subject by teaching, counseling, and guiding. The nurses who may have fulfilled this role were not identified as important sources of information in the decision-making process by the subjects.

The concept of stress described by King as an interaction to maintain balance of growth, development and performance, was not measured but inferred. Each subject was placed in a stress state by virtue of their diagnosis, however, the nurse was not instrumental in decreasing the stress for purposes of this study. Finally, the concept of time was an important factor for these subjects. Even though the relationship of time and stress, interaction, and transaction were not measured directly, data analysis revealed that an average of 18 days elapsed between the day of diagnosis and the day of surgery. This time span is relatively short when making surgical treatment decisions because the woman needs to gather information, consider the factors important to her, make her decision, and finally notify the surgeon of the results of her decision.

While several concepts of King were supported by the results of this study, there was inadequate data to draw any theoretical conclusions for much of the theory of goal attainment. Transactions and mutual goal setting between the subjects and the nurse must be studied further as they relate to women with breast cancer making surgical treatment decisions.

Limitations

Several threats to internal and external validity existed because of the retrospective nature of this study. The threat of history as a result of an external event, such as, an article on breast cancer in a woman's journal or a friend having a bad experience with breast cancer, may occur at the same time as the woman with breast cancer is making her decision. Even though this threat existed, subjects were not required to identify if either occurred during their decision making process.

During the data collection period, two incidents occurred which received widespread media attention and may have interfered with internal validity. First, there was some discussion in the medical and lay literature regarding results of outcomes in surgical treatment for early stage breast cancer. A Montreal cancer research team from St. Luc Hospital (one of the centers participating in the study) deliberately falsified data for a breast cancer study that is credited with supporting no difference in survival for early stage breast cancer between MRM and BC surgeries. A statistician for the project reported that removing the falsified data from the study did not change the outcome and a follow-up paper was published to detail the findings minus the falsified data (Fisher, Anderson, Redmond, Wolmark, Wickerham, & Cronin, 1995).

Another incident that occurred during the data collection time happened at the hospital from where subjects were recruited. A local surgeon mistakenly removed the wrong breast of a woman with breast cancer. (This patient was not asked to participate in this study.) This incident was widely publicized both locally and nationally. Following this incident the numbers of women who had breast surgery at the study site decreased from an average 16 per month to 4 in each of the following 2 months. New events such as those cited, were monitored during the data collection period.

There were also several other threats to internal validity. One such threat was the lack of control over the testing environment. It was not possible for the investigator to know the conditions under which the subjects completed the surveys. Some subjects may have had competing demands on their attention as they completed the surveys and some subjects may have misunderstood the directions and/or questions as well.

Another threat to internal validity identified is in concluding the subjects' knowledge of breast cancer influenced their decision. The surgeon may have unfairly persuaded them to choose or failed to offer the surgical treatment alternatives in an unbiased manner. There is not an objective method to determine if this situation occurred with any of the subjects. However, those women who stated that they were not offered a choice were not asked to participate in this study.

The longer women live with and contemplate their diagnosis, the more likely they will be attracted to gaining new knowledge about their disease. The time between decision making and data collection in a retrospective study, such as this, may allow the subjects to gather new knowledge between the time of surgery and the time of completing the surveys used for this study. A woman's knowledge prior to surgery will be either the same or less than after surgery, as a result of progressive accumulation secondary to the hospital environment. This is due to the resources available in the hospital environment that may bar a true test of knowledge at the time the woman made her surgical treatment decision. Every attempt was made to study subjects within as short a time after surgery as possible and prior to discharge teaching in an attempt to obtain realistic breast cancer knowledge scores, that most closely reflect the knowledge level at the time of surgical decision making. The researcher attempted to study subjects between postoperative days 1 and 7 to minimize the risk of gaining more knowledge postoperatively. Ethically, it would be improper to administer the test just prior to surgery and leave a subject with doubts about her decision. Postoperatively, doubts may still occur, but further information and discussion were provided to support the subject, by the researcher or

physician. Physicians were notified of their patient's participation in the study. This notification alerted them that their patients may require further information or discussion postoperatively, as a result of the study. There was no evidence to suggest that any subject had second thoughts about the decision she made for surgical treatment.

The true-false format of the Breast Cancer Information Test - Revised (BCIT-R) may allow subjects to guess correctly on statements they do not know or understand, confounding the true level of knowledge. An option of "don't know" was added to the test to give a more accurate score.

The many limitations to this study, while affecting its usefulness, can still offer implications to nurses and other health care workers who interact with early stage breast cancer patients. These implications are discussed in the following section.

Implications

The findings of this study support the fact that women who are making decisions for surgical treatment of their breast cancer require information on which to base their decision. Because the decisions are made in a very short time (18 days), necessary information must be provided as soon as possible to allow the woman with breast cancer time to understand her situation and reach a knowledgeable decision. The findings of this study suggest that the subjects had limited knowledge in the areas of surgical options and medication management. The subjects in this study, as well as those in the study by Ward, Heidrich and Wolberg (1989), used "people" sources to gather information. Therefore, physicians and nurses have an important role in the education given to these women. The results of this study indicate that physicians were more influential than nurses.

Unfortunately, nurses are not as available in the local community in surgeon's offices to provide the information found insufficient in this study, such as, medication management.

The sources of information used by the majority of women came from the physician, family and friends, or another woman with breast cancer. Nurses are the most logical choice in providing for the educational needs of these women as a result of their emphasis on client education in nursing programs. As the managed care philosophy of decreasing dollars spent on health care gains momentum, expensive services, such as nursing salaries, may be affected. A breast problem clinic where the whole team is available in one location, under the management of the hospital is one way of decreasing health care dollars while increasing the availability of information and education for women with breast cancer. The nurse in such a clinic would be responsible for the education required by the woman with breast cancer and would help her to assimilate the information received from the various team members in a non-threatening, empathetic environment. It is imperative that women make an informed decision because any negative ramifications of this decision will be life long. Those women who select MRM with inadequate knowledge cannot reverse their decision once the surgery is completed. While physicians certainly have the scientific knowledge to counsel women, patients have stated physicians do not spend enough time with them during office visits (Cawley, Kostic, and Cappello, 1990).

The implications of this and similar research have shown that the educational needs of women with breast cancer who are making surgical treatment decisions are not met adequately, as evidenced by the low knowledge scores revealed in this study. Relying on

family, friends, and other women with breast cancer to gather information suggests that those of us on the health care team are not fulfilling the need for professional counseling and education for these women. The following section will discuss recommendations to rectify this situation.

Recommendations

To improve generalizability several recommendations are offered to others replicating this research. First, a larger sample size is needed to determine the scope of the problem both on a local level and nationally. Retrospective report bias was a problem with this study. It is not clear whether the subjects would have identified the same factors considered important in surgical treatment decisions if they had completed the surveys prior to surgery. Conducting this research on pre-operative patients would allow a more accurate analysis of their knowledge regarding breast cancer and therefore provide nurses with concrete data on the areas that require additional knowledge.

There are several other studies that should be conducted to assess women with early stage breast cancer who are making surgical treatment decisions. One study should determine the degree of participation of office nurses in educating breast cancer clients. The results of this study indicate that nurses were not the primary source of information for these women. This could be due to a variety of reasons such as the unavailability of nurses in the surgeon's office or are perhaps they are not trained to teach and counsel this group of clients.

There are several breast problem clinics scattered throughout the United States, that may have an impact on knowledge of breast cancer and surgical treatment decisions

for the women using them. These clinics may provide the client with a more well-rounded picture of her individual situation. They also may be more convenient because the woman does not have to make appointments with several physicians scattered all over the city. Also, the clinics are dedicated to women with breast cancer. Currently, women diagnosed with breast cancer must see her family physician to receive a referral to a surgeon. The surgeon performs the diagnostic test(s) that confirms the diagnosis. The surgeon will then refer the woman to an oncologist, radiation therapist and plastic surgeon for the expertise each can offer on treatment alternatives. Perhaps a study to examine the differences, if any, between the current system used in our location and breast clinics with regard to effectiveness, value to the client, and cost to the health care industry would be useful. It also would be useful to know the nurse's role in such a clinic and if the nurse or physician was more helpful in decision making.

Additionally, it would be interesting to know if the Michigan Department of Public Health pamphlets are available on a consistent basis and are accessible to patients. A study that assessed if the pamphlets were distributed as required and if the woman with early stage breast cancer used them for decision making, would provide additional data on sources of information. Determining if there is a difference in availability and accessibility of the pamphlets between the surgeon's offices and breast care clinics would provide information on consistency of use.

Finally, the same group of subjects should be restudied in the future (5 - 10 years) to see if they would a) make a different selection for type of surgery, b) what they have learned in the intervening years that would have prompted a selection change, and c) what

type of information they received over the years since their surgery that they wished they would have had at the time of their original decision making.

Summary

The purpose of this study was to examine the amount of knowledge, factors considered important, and sources of information used in the decision-making process of women selecting surgical treatment for their breast cancer. The sample size was too small to determine statistical significance, if present, however, several trends were identified. The demographic characteristics were essentially equal between the two groups when comparing age, income, and marital status. The BC group was slightly younger. There was approximately 18 days between the day the diagnosis was made and the day surgery was performed. It was found that women with early stage breast cancer have a lack of knowledge regarding the relationship between characteristics of tumors and surgical treatment options, the appropriateness of chemotherapy, and the use of Tamoxifen for the treatment of breast cancer.

Another finding in this study was that the physician was the most important source of information for the subjects who were selecting surgical treatment options. The subjects indicated that after the physician, family, friends, and another woman with breast cancer helped them with their decision. Unfortunately, the nurse was only mentioned as a source of information by one subject.

The women selecting BC surgery were not concerned with the inconvenience of daily radiation therapy and were aware that there was no difference between the two surgeries in terms of survival. Those women who chose MRM considered daily radiation

treatments to be very inconvenient and the equal survival rates between the two surgeries as not important factors in their decision for surgery.

The results of this study are of limited value because of the very small sample size and nonsignificance of the findings. Further study of how women make their decision for surgical treatment of their early stage breast cancer is needed in order that appropriate resources are made available.

APPENDIX A

DEMOGRAPHIC DATA SHEET

Please complete this form which will help to determine your background and compare it with other participants of this study. You may refuse to respond to any part of this form.

What is your age? _____ years

(3-4)

What is your level of education?

1. _____ 8th grade or less
2. _____ completed high school
3. _____ some college
4. _____ Bachelors degree
5. _____ some post graduate
6. _____ Masters degree
7. _____ Other (please specify)

(5)

What is your household income, yearly?

1. _____ less than \$10,000/year
2. _____ \$10,001 - \$20,000/year
3. _____ \$20,001 - \$30,000/year
4. _____ \$30,001 - \$40,000/year
5. _____ \$40,001 - \$50,000/year
6. _____ more than \$50,001/year

(6)

What is your marital status?

1. _____ Married
2. _____ Separated
3. _____ Divorced
4. _____ Never married
5. _____ Widowed

(7)

What type of surgery did you have?

1. _____ Breast Conserving (lumpectomy)
2. _____ Mastectomy without Breast Reconstruction
3. _____ Mastectomy with Breast Reconstruction

(8)

What date was your diagnosis told to you? _____

(9 - 14)

What date was your surgery? _____

(15 - 20)

What is today's date? _____

(21 - 26)

APPENDIX B

BREAST CANCER INFORMATION SURVEY

For each of the following statements, check "T" if the statement is true and "F" if the statement is false. If you do not know the answer to a statement, check "Don't know" in the appropriate space.

	T	F	Don't know	Do not write in this space
1. Mastectomy is the removal of only the cancerous part of the breast.	___	___	___	_____ (27)
2. Radiation therapy is usually necessary after lumpectomy.	___	___	___	_____ (28)
3. After lumpectomy, there is a 50% chance that cancer will recur in the treated breast.	___	___	___	_____ (29)
4. Breast reconstruction is highly recommended after lumpectomy.	___	___	___	_____ (30)
5. Fatigue is an infrequent side effect of radiation therapy.	___	___	___	_____ (31)
6. Frequently during radiation therapy, the treated area will look and feel as if it has been sunburned (such as redness, itching, peeling).	___	___	___	_____ (32)
7. Sometimes cancer cells break off a tumor, spread to other parts of the body and begin to grow in another area. This new growth is called metastasis.	___	___	___	_____ (33)
8. The usual schedule for radiation therapy is radiation once a day, 5 days a week, for 5 - 6 weeks as an outpatient.	___	___	___	_____ (34)
9. Nausea is the most common side effect of chemotherapy; it is not a frequent side effect of radiation therapy.	___	___	___	_____ (35)

	T	F	Don't know	
10. Regardless of which type of surgery a woman chooses (mastectomy or lumpectomy), at least some of the lymph nodes in the armpit are removed.	—	—	—	(36)
11. For women with Stage I or II breast cancer, overall life expectancy is no different for those who have a lumpectomy than for those who have a mastectomy.	—	—	—	(37)
12. Every woman with breast cancer, regardless of the size or location of the tumor, has an option between having a mastectomy or lumpectomy.	—	—	—	(38)
13. Hormone treatment (Tamoxifen) is used only for pre-menopausal women and only as an alternative to chemotherapy and radiation therapy.	—	—	—	(39)
14. Hair loss is not a common side effect of radiation therapy.	—	—	—	(40)
15. Most mastectomies performed today leave the muscles underneath the breast intact.	—	—	—	(41)
16. Chemotherapy treatment may be recommended regardless of the type of surgery (lumpectomy or mastectomy) a woman has.	—	—	—	(42)
17. Light exercise of one's arm and shoulder after surgery can cause unnecessary tension and strain and should be avoided for the first few months of recovery.	—	—	—	(43)

	T	F	Don't know	
18. Radiation therapy is given to patients in the form of a pill that, once taken, gives off radiation to the cancerous tumor.	—	—	—	(44)
19. Hormone treatment (Tamoxifen) is believed to prevent the recurrence of breast cancer in women who have tumors with high estrogen content.	—	—	—	(45)

APPENDIX C

FACTOR LIST

There are many factors women with breast cancer might consider as they make decisions for the type of surgical treatment.

Please read each of the following statements and then place a check mark next to the one response that best reflects that statement's importance in your decision.

1. Knowing of a friend or family member's experience with breast cancer and/or mastectomy (any type of mastectomy).

<input type="checkbox"/>	not applicable to my situation	<input type="checkbox"/>	important	_____ (46)
<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	

2. Knowing of a friend or family member's experience with lumpectomy.

<input type="checkbox"/>	not applicable to my situation	<input type="checkbox"/>	important	_____ (47)
<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	

3. Knowing my physician's preference for the type of surgery I should have.

<input type="checkbox"/>	not applicable to my situation	<input type="checkbox"/>	important	_____ (48)
<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	

4. Knowing the preference of someone important to me for the type of surgery I should have.

<input type="checkbox"/>	not applicable to my situation	<input type="checkbox"/>	important	_____ (49)
<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	

5. Fear of the cancer returning.

<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	_____ (50)
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	
<input type="checkbox"/>	important			

6. The inconvenience of return visits for radiation therapy.

<input type="checkbox"/>	not at all important	<input type="checkbox"/>	very important	_____ (51)
<input type="checkbox"/>	not very important	<input type="checkbox"/>	extremely important	
<input type="checkbox"/>	important			

7. Fear of radiation therapy.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (52)
8. Wanting to avoid the possible side effects of radiation therapy.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (53)
9. How I would feel about losing a breast.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (54)
10. How I think my partner would feel about my losing a breast.
- | | | | | |
|--------------------------|--------------------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not applicable to my situation | <input type="checkbox"/> | important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
- (55)
11. The fact that there is no difference between the two surgeries in long - term survival.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (56)
12. The possibility of breast reconstruction in the future.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (57)
13. Wanting to avoid the possibility of another surgery in the future.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (58)
14. Fear of dying from cancer.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (59)
15. Concerns about loss of mobility or strength in arm.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (60)
16. Concerns about the amount of pain involved.
- | | | | | |
|--------------------------|----------------------|--------------------------|---------------------|--|
| <input type="checkbox"/> | not at all important | <input type="checkbox"/> | very important | <hr style="width: 50px; margin-left: auto; margin-right: 0;"/> |
| <input type="checkbox"/> | not very important | <input type="checkbox"/> | extremely important | |
| <input type="checkbox"/> | important | | | |
- (61)

17. Concerns about the cost of treatment.

_____ not applicable to my situation
_____ not at all important
_____ not very important

_____ important
_____ very important
_____ extremely important

(62)

18. Were there any other factors that influenced your decision for type of surgery that were not part of this list? If so, what were those factors?

(63)

APPENDIX D

SOURCE OF INFORMATION

There are many resources available to women with breast cancer as they make decisions for the type of surgical treatment. Which of the following resources were most helpful to you as you made your decision? If there were other resources you used that are not on the list, please place them in the space provided at the end of the list. Those you write in should be ranked according to the directions that follow.

Here are sources that we know have information about breast cancer. List by priority the top 3 sources by which you made a decision. Please place the number 1 by the one resource you felt was most helpful to you as decisions were being made regarding your breast cancer. Place a number 2 by the second most helpful resource and a 3 by the third most helpful resource.

- | | | |
|-----------|--|------|
| 1. _____ | Handouts (pamphlets, brochures, etc.) | (64) |
| 2. _____ | Videotape (received by physician's office) | (65) |
| 3. _____ | Physician(s) - such as, surgeon, oncologist, family (primary) doctor | (66) |
| 4. _____ | Nurse | (67) |
| 5. _____ | Friends | (68) |
| 6. _____ | Family | (69) |
| 7. _____ | Media (radio or television) | (70) |
| 8. _____ | Medical journals or books | (71) |
| 9. _____ | Books - not written by a professional | (72) |
| 10. _____ | Another woman with breast cancer | (73) |
| 11. _____ | Magazine or newspaper article (not scientific) | (74) |
| 12. _____ | Other (please specify) _____ | (75) |

APPENDIX E

INFORMED CONSENT

Surgical Treatment Decisions of Women with Breast Cancer: Knowledge, Sources and Factors

The study in which you are being asked to participate is investigating the choices 40 women make regarding surgical treatment for breast cancer. As a participant you are giving permission for the researcher to analyze your knowledge of breast cancer, where you received your knowledge and the factors that influenced your decision. The knowledge will be tested using a Breast Cancer Information Survey in which you are asked to answer "true," "false," or "don't know" to several statements. The study also requires you to complete a "factor list" and "source of information" forms. A questionnaire regarding personal information, such as, age and level of education are also included. The test and 3 forms will take approximately 45 minutes for you to complete.

Information identifying your participation in this study will be kept absolutely confidential. If results of this study are published, you will not be identified in any way.

There is no physical risk to you in participating in this study. However, some statements on the surveys may cause questions in your mind to which you desire more information. In these situations the researcher will be available to discuss these questions and provide you with further information or may refer you to another professional, if you wish. You are free to withdraw from participation in this study at any time. Refusal to participate will not affect your care while in the hospital or in subsequent treatment.

There is a small benefit to you personally in that the researcher is a nurse experienced in the care of women with breast cancer and will be able to provide you with additional information about your diagnosis, at the completion of the surveys. The main benefit will be to women who develop breast cancer in the future, assuring they receive adequate information before making surgical decisions.

This study is being conducted by Deb Bisel. She is a nurse educator in at Butterworth Hospital and currently a student at Grand Valley State University, enrolled in the Masters of Nursing program. This study is being done as part of the course work required to complete the degree. If you have any questions or concerns Deb may be contacted at Butterworth Hospital, (616) 732-2652. Should I have any questions regarding my rights as a patient, I may call the Human Right's Committee representative, Linda Pool, at (616) 774-1291/1299.

I have read and understand the above information and agree to participate in this study. I have received a copy of this consent for my own records.

Participant

Date

Witness

Date

Researcher

Date

APPENDIX F



School of Nursing
University of Wisconsin-Madison

Center for Health Sciences
Clinical Science Center
600 Highland Avenue
Madison, Wisconsin 53792-2455
FAX: 608/263-5332

September 30, 1992


Deb Bisel, RN, BSN
Staff Educator, Gynecology
Butterworth Hospital
100 Michigan Street, N.E.
Grand Rapids, MI 49503

Dear Ms. Bisel:

You have my authorization to use the BCIT-R in your research. I am always pleased to know that the instrument might be useful to another investigator. I have no data regarding reliability and validity that goes beyond that which has been published in the Cancer Nursing articles. I have given permission to other investigators to use the BCIT-R, but so far no one has published results of their work.

I would be more than happy to talk to you as you work toward completing your study. Please feel free to call for statistical, methodological, or other advice.

Best wishes in your work!


Sandra Ward, PhD, RN
Assistant Professor

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