

### RELATIONSHIP AMONG UNCERTAINTY, STIMULI FRAME AND STRUCTURE PROVIDERS IN WOMEN WITH BREAST CANCER CHOOSING BREAST SURGERY

Ву

Julie Kay Walker

## A THESIS

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#### ABSTRACT

#### RELATIONSHIP AMONG UNCERTAINTY, STIMULI FRAME AND STRUCTURE PROVIDERS IN WOMEN WITH BREAST CANCER CHOOSING BREAST SURGERY

By

#### Julie K. Walker

Uncertainty appears as a common theme within the literature addressing stress and coping with breast cancer, but it is not clear at what point in the illness trajectory it becomes operative as an influence on treatment choice. Furthermore, factors that predispose women toward uncertainty or toward the selection of certain treatment options for breast cancer are not well understood. Eighty women with early stage breast cancer were studied after they received a breast cancer diagnosis but before they chose surgery to determine if illness uncertainty predisposed women toward one surgery over another. Of the 80 women recruited into the study, 64 viable cases were included for data analysis. Relationships between uncertainty, sociodemographic characteristics of age, income and years of education were also explored. Surgical choice was not related to uncertainty as measured using the Mishel Uncertainty in Illness Scale (MUIS). Level of education was found to be inversely related to uncertainty, but no relationship with age and income was found.

To my mom, for her courage and sage advice. To Bud, for his tenderness and bountiful love. To Dan, for giving my life true purpose.

#### ACKNOWLEDGMENTS

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#### INTRODUCTION

Cancer of the breast is the most common cancer in women in the United States. It is estimated that over 181,000 new invasive cases will be diagnosed during 1997 (American Cancer Society, 1997). The incidence has steadily increased over the past several decades, placing an increased emphasis on early detection and screening so that cancers can be diagnosed at an earlier stage. Stage of the disease has major implications for the treatment options available to women, particularly when it comes to the breast conserving surgical intervention. Women now have choices about the extent of breast tissue removed during the surgical procedure. Yet little is known about the factors that influence women's choices in this regard. This study will examine the relationship between choice of surgical intervention among women with early stage breast cancer and one factor which may influence women's choices, the level of illness uncertainty.

According to the American Cancer Society (1997), one out of every eight women will be diagnosed with breast cancer during their lifetime. Women whose cancer is diagnosed in the early stages have more options for treatment regarding the extent of breast tissue to be

removed during the surgical procedure. Advanced practice nurses in primary care are certain to encounter women diagnosed with early stage breast cancer. Many women may seek the advice and support of their primary care provider as they go through the process of choosing and undergoing treatment. It is important, therefore, for advanced practice nurses to be informed about survival and recurrence rates as well as other factors associated with the decision making process of choosing surgery options.

#### Statement of the Problem

Numerous studies have explored the biopsychosocial status of women with breast cancer and many have examined the effects of treatment on various psychosocial outcomes. In most cases, data were collected after the diagnosis was made and treatments were either initiated or completed. However, very little is known about the perceptions or understanding women have about their disease and whether or not these influence decision making among women during the time interval between diagnosis of breast cancer and choosing treatment. Specifically, there is a need for more information regarding whether or not women who select one treatment over another do so based on perceptions of uncertainty about their illness.

The results of studies comparing modified radical mastectomy with lumpectomy followed by radiation therapy for treatment of stage I and II breast cancer have shown no statistical differences between these two interventions in

recurrence rates and survival (Fisher et al., 1985; Fisher et al., 1989; Fisher et al., 1995; Early breast Cancer Trialists' Collaborative Group, 1995). Consequently, women now have options for local therapy and can play an active part in choosing the course of their care. Yet little is known about the factors that influence women in making this choice.

Advanced practice nurses are likely to encounter women during the process of selecting treatment options for breast cancer. Educating patients about different treatment options and supporting patients in their decisions is an integral part of the advanced practice nurse's role. Therefore, it is essential that nurses understand the factors that influence women as they select different treatments. The problem that this study addressed was the paucity of information in the literature as to whether or not illness uncertainty is related to choice of surgical treatment for breast cancer. A secondary analysis of original research conducted by Laurel Northouse, PhD, RN from Wayne State University in Detroit, Michigan can shed important new light in this area.

## **REVIEW OF THE LITERATURE**

### Conceptual Definition of the Variables

The concepts under consideration in this study include stage of breast cancer, choice of surgery (lumpectomy and mastectomy), uncertainty, and sociodemographic variables specific to the women who participated.

Staging of breast cancer serves as a guide for treatment, indicates prognosis, and permits a comparison of different treatment methods. While many staging methods have been described, the Tumor-Node-Metastases (TNM) system of staging is recognized worldwide in the staging of breast cancer (Scanlon, 1991). The primary tumor (T) is staged by the size of the mass and degree of infiltration into surrounding tissue, by the degree and location of nodal involvement (N), and by the presence or absence of distal metastases (M). Early stage breast cancer includes breast cancers classified at stage I or stage II with the following TNM classification:  $T_1$ ,  $T_2$ ,  $N_0$ ,  $N_1$ ,  $M_0$ .

 $T_1$  describes primary tumors which are two centimeters or less at the greatest diameter, while  $T_2$  tumors are those greater than two centimeters but less than five centimeters in diameter.  $N_0$  and  $N_1$  describe no regional lymph node metastases and metastases to moveable ipsilateral axillary lymph nodes, respectively.  $M_0$  staging indicates that no distant metastasis is identified. Stage I breast cancers refer to tumors with  $T_1N_0M_0$  classifications. Stage II breast cancers refer to tumor characteristics with  $T_2N_1M_0$ classifications.

Choice of surgery is defined as the selection a woman makes between two surgical interventions, mastectomy or lumpectomy. Mastectomy is a surgical technique in which the breast tissue is removed, axillary nodes are dissected, but the underlying muscle groups are left intact. Lumpectomy

involves the removal of the breast tumor itself plus a margin of healthy tissue surrounding the tumor on all edges, and typically includes lymph node dissection (Balch, Singletary, & Bland, 1993).

Uncertainty is defined as the cognitive state that occurs when the individual is unable to assign definite values to objects or events and/or is unable to accurately predict outcomes (Mishel, 1988). Uncertainty results when patients are unable to form a cognitive schema of illnessrelated stimuli. In situations of illness, uncertainty occurs in four ways: a) ambiguity related to the state of the illness; b) complexity surrounding treatment or the health care system; c) inadequate information about the diagnosis or illness severity; and d) unpredictability about the prognosis or how the disease may progress. This study looked at the concept of uncertainty.

Sociodemographic variables are defined as those characteristics that describe the participant's social or demographic status. In this study, sociodemographic variables include age, education and family income. Conceptual Model

The concept of uncertainty first appeared in the nursing literature approximately 17 years ago when Mishel (1981) published a seminal article reporting results of development and testing of an instrument to quantify uncertainty in illness situations. Since that time, Mishel and others have explored the concept of uncertainty and its

relationship to stress and coping. While other researchers have developed definitions and conceptualizations of uncertainty (Brown & Powell-Cope, 1991; Christman, 1990; Cohen, 1993; Hilton, 1988), by far the most common definition of the concept used in empirical research is the conceptualization by Mishel (1981, 1984, 1988, 1990). An adaptation of Mishel's (1988) model of uncertainty was used as the model for this study.

Mishel's (1988) theory of uncertainty in illness attempts to explain how patients cognitively process illness-related events and develop meaning from those events. According to the theory, uncertainty results when patients are unable to form a cognitive schema of illnessrelated stimuli. The theory can be apportioned into three major parts: antecedent variables, appraisal and adaptation.

### Antecedents to Uncertainty

According to Mishel (1988) the primary antecedent variable is the stimuli frame which refers to the composition, structure and form of the patient's perceptions. The stimuli frame is comprised of three factors: symptom pattern, event familiarity and event congruence. Symptom pattern refers to the extent to which symptoms are consistent over time. When symptoms occur with regularity, patients eventually perceive a pattern and form meaning from the pattern. Event familiarity occurs when situations occur with sufficient frequency. Meaning can be

determined as events become familiar and are associated with similar events in the patient's memory. Event congruence describes the similarity between one's expectations and what is actually experienced. According to uncertainty theory (Mishel, 1988), these components of the stimuli frame work to reduce uncertainty. Conversely, a lack of these components increases uncertainty (Mishel & Braden, 1988).

The components that make up the stimuli frame are influenced by two variables, the cognitive capacity of the client and the resources available to the client (Mishel, 1988). Mishel refers to client resources as structure providers and theorizes that they assist clients in the interpretation of the stimuli frame. Structure providers include social support, credible authority and the educational level of the patient. Structure providers are hypothesized to reduce uncertainty. This is the portion of the model relevant to the present study.

#### Appraisal of Uncertainty

In situations of illness, uncertainty occurs in four ways: a) ambiguity related to the state of the illness; b) complexity surrounding treatment or the health care system; c) inadequate information about the diagnosis or illness severity; and d) unpredictability about the prognosis or how the disease may progress (Mishel, 1988). The experience of uncertainty is neutral until it is appraised. According to Mishel, appraisal is made by two major processes, inference

or illusion, which result in the final appraisal of uncertainty as a danger or an opportunity.

Inference refers to the evaluation of uncertainty using relevant experiential memories. Inference results from basic personality dispositions or attitudes of the patient and includes concepts such as self efficacy, locus of control and learned resourcefulness. When inferential processes are involved, uncertainty is typically appraised as a danger.

Illusions are defined as "beliefs constructed out of uncertainty... and viewed in a particular light with emphasis on their favorable aspects" (Mishel, 1988, p.229). When illusions are formed from uncertainty, the uncertainty is interpreted as an opportunity. In Mishel's model, uncertainty is appraised as an opportunity in an attempt to maintain hope in situations where the outcome has a negative, downward trajectory.

According to Mishel (1988, 1990), strategies for coping with uncertainty are based on the nature of the appraisal. Appraisal of uncertainty as a danger results in mobilizing and emotion-focused coping strategies such as informationgathering and steps to take action. Appraisal of uncertainty as an opportunity leads to buffering coping strategies to support the uncertainty.

#### Adaptation

Adaptation occurs if the coping strategies are appropriate for an event appraised as either a danger or an

opportunity. In other words, adaptation has occurred if coping strategies reduce uncertainty in situations where it is appraised as a danger or maintains uncertainty in situations where it is appraised as an opportunity (Figure 1).

ANTECEDENT

APPRAISAL

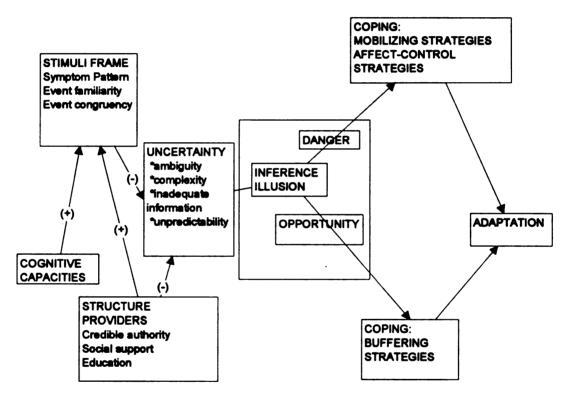


Figure 1. Model of Perceived Uncertainty in Illness (Mishel, 1988).

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#### Current Study Adaptation of Mishel's Model

The variables of interest in this study fit into the antecedent portion of Mishel's (1988) model of uncertainty, specifically under the stimuli frame and structure providers portion of the model (Figure 2). Figure 2 has been adapted for application to the current study (Figure 3). Factors that comprise the stimuli frame include symptom pattern, event familiarity and event congruence. Although Mishel addresses all three factors of the stimuli frame in the written literature (Mishel, 1988; 1990), event congruence was not included in the model representation (Mishel & Braden, 1988) and likewise, does not appear in Figure 2.

In the current study, symptom pattern and event familiarity were examined. The stage of disease served as the symptom pattern. All of the women in this study were diagnosed with early stage breast cancer. In addition, this was a population undergoing a cancer diagnosis for the first time. By definition, women with stage I or II breast cancer have small tumors that have not metastasized to other body systems. These women had not had an opportunity to establish a symptom pattern because of the early stage of cancer progression and because of the fact that they had not had prior breast cancer diagnoses. According to Mishel, an absence of symptom patterns can increase uncertainty (Mishel & Braden, 1988). Therefore, the absence of symptom pattern among the women in this study could lead to higher levels of uncertainty.

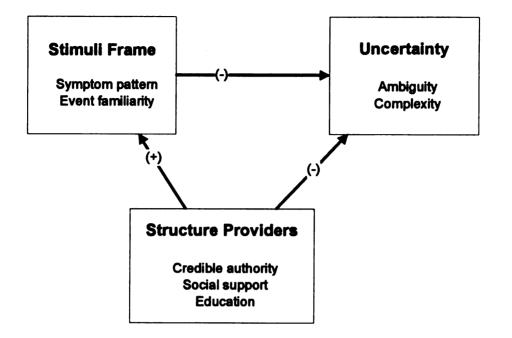


Figure 2. Model of Antecedents of Uncertainty (Mishel & Braden, 1988).

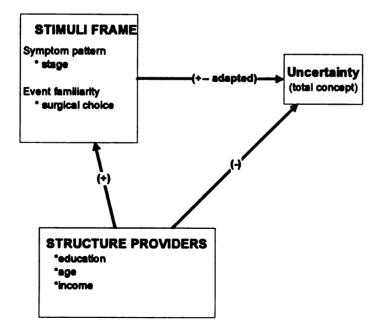


Figure 3. Adaptation of Model of Antecedents of Uncertainty (Mishel & Braden, 1988).

Choice of surgical option served as the event familiarity variable. Women in this study choosing between lumpectomy and mastectomy were likely to be unfamiliar with unfolding events. Because these women had not experienced prior breast cancers, they may have been unable to anticipate future events and prepare for them psychologically and emotionally. Because these women had no prior events to associate with the upcoming treatment, they may have been less able to determine meaning from treatment situations as they were explained by their physician or nurse. An inability to construct meaning from past events can increase uncertainty, according to Mishel (Mishel & Braden, 1988). The lack of event familiarity for upcoming treatment regimens among the women in this study could have resulted in uncertainty about their condition.

Structure providers refer to resources patients might use to assist in interpreting information. In this study the variables of education, age and income were included as structure provider elements. Mishel includes education as a structure provider. Age and income were adapted as structure providers since it could be argued that both of these variables enhance one's ability to interpret information. Additionally, both age and income have been shown to influence both patterns of care (Beisecker, Helmig, Graham, & Moore, 1994; Greenfield, Blanco, Elashoff, & Ganz, 1987) and choice of treatment (Hughes, 1993a; Ward, Heidrich, & Wolberg, 1989; Wolberg, Tanner, Romsaas, Trump,

& Malec, 1987), so more information about these variables was warranted. They therefore were added to the adaptation of Mishel's model used for this study.

# Review of the Literature Regarding Stage of Breast Cancer and Choosing Surgery

Until approximately 1985, women with stage I or stage II breast cancer were given only one surgical option for their disease, the modified radical mastectomy (MRM). This surgery entailed the removal of the breast tissue and axillary nodes, but left the underlying muscles intact. While it offered an improvement in appearance over the radical mastectomy in which all structures down to the chest wall were removed, it still was a devastating surgery for many women.

Lumpectomy involves the removal of the breast tumor itself plus a margin of healthy tissue surrounding the tumor on all edges and axillary node dissection. Physicians became comfortable offering women with early stages of breast cancer a choice between breast-conserving (BC) therapy and MRM over a decade ago, after the results of randomized, prospective clinical trials comparing MRM with lumpectomy and radiation therapy were published (Fisher et al., 1985; Fisher et al., 1989). Follow-up on women in this same study 12 years later continues to indicate that lumpectomy followed by breast irradiation is appropriate therapy for early stage breast cancer (Fisher et al., 1995). More recent publication of a meta-analysis of multiple randomized trials comparing radiotherapy and conservation surgery with mastectomy in treating early stage breast cancer confirmed no definite differences in overall survival at ten years (Early Breast Cancer Trialists' Collaborative Group, 1995). Thus, five, eight and 12-year results indicate lumpectomy followed by breast irradiation in all patients, plus adjuvant chemotherapy in women with positive nodes, is appropriate therapy for Stages I and II breast cancer, provided that the margins of rejected specimens are free of tumor (Fischer et al., 1995). Women now have options for local therapy and can play an active part in choosing the course of their care.

While studies evaluating the recurrence and survival rates between these two surgical interventions have not shown statistical differences, studies comparing the psychosocial outcomes of women undergoing these two surgical interventions have rendered inconsistent findings. While some investigators have found that women selecting lumpectomy report significantly less difficulty with self image and sexuality issues (Steinberg, Juliano, & Wise, 1985), others have found higher levels of distress among lumpectomy patients (Levy, Herberman, Lee, Lippman, & d'Angelo, 1989). Still other investigators found no significant differences between the two groups of women (Fallowfield, Baum, & Maguire, 1986; Fallowfield, Hall, Maguire, & Baum, 1990; Fallowfield, Hall, Maguire, Baum, & A'Hern, 1994; Holmberg, Omne-Ponten, Burns, Adami, &

Bergstrom, 1989). It is these inconsistent findings that make it relevant to examine the concept of uncertainty in the decision making process, since uncertainty has also been linked to negative psychosocial outcomes.

The literature does offer some insight into the selection process of women choosing treatment for early stage breast cancer. Studies have shown that some women prefer an active role in choosing among treatment options for breast cancer (Hack, Degner, & Dyck, 1994), and that women offered a choice adjust to their treatment better than women for whom choice of treatment was not an option (Fallowfield, et al., 1990; Fallowfield, et al., 1994). Study designs using choice of treatment as the dependent variable generally have focused on the factors that influence choice of treatment (Hughes, 1993a; Margolis, Goodman, Rubin, & Pajac, 1989; Ward et al., 1989; Wolberg et al., 1987) or the decision-making process itself (Pierce, 1993).

Hughes (1993a) used a sample of 71 women with stage I and II breast cancer in the process of deciding between lumpectomy and mastectomy to examine how the amount of information and the nature of how the information was presented influenced women's treatment choices. Included among these variables were the number and distinguishing characteristics between options, risks and side effects presented, whether prognoses were presented using descriptive expressions or percentages, whether prognoses

were expressed in terms of survival or recurrence rates, and whether or not a specific treatment was recommended explicitly to the patients. Treatment decisions were found to be unrelated to the manner in which information was presented and to the amount of information presented by the physician. However, choice of mastectomy was significantly related to the amount of information about breast cancer management women received from informal sources such as family, friends and the media.

Margolis et al. (1989) explored factors women considered in choosing breast cancer treatment. Their study included 70 women, 52 of whom chose lumpectomy or mastectomy and 18 who did not have breast cancer but had an increased risk for breast cancer due to family history. This was a retrospective study in which the women with breast cancer were interviewed at least one year following treatment. Women who chose lumpectomy had significantly greater concerns about the effect of treatment on body image, while women who chose mastectomy had significantly greater concerns about dying from breast cancer or believed that mastectomy was more likely to result in a cure. Interestingly, the investigators found that all of the lumpectomy patients would make the same choice if they were asked to make a choice today. However, a statistically significant number of women who chose mastectomy would choose lumpectomy if they were choosing today.

Ward et al. (1989) examined the factors women consider when deciding between mastectomy and lumpectomy. Their sample included 22 women with stage I and II breast cancer who were interviewed one to two weeks following surgery. Women who selected mastectomy were significantly more concerned about radiation therapy side effects and efficacy, whereas women who selected lumpectomy were more concerned about body integrity. Concern over losing a breast, availability of breast reconstruction and the fact that both treatments offered similar survival rates were rated as important factors influencing the decision-making process significantly more among women selecting lumpectomy than women selecting mastectomy.

Wolberg et al. (1987) described the degree to which women who were eligible for lumpectomy actually selected it over MRM as their treatment option. In addition, a battery of scales to determine the psychological profile of the women were administered prior to choice of surgical intervention. In a sample of 206 women, mastectomy was dictated by tumor-related factors in 47% of the women. Fifty-three percent could choose between mastectomy and lumpectomy. Of those eligible for either intervention, 49% selected lumpectomy. Compared with those who selected lumpectomy, women who chose mastectomy were more tense and anxious, more introverted, felt more depressed and dejected, and reported more sexual problems. Women who chose

lumpectomy valued their physical appearance more highly and were generally more self-interested.

Pierce (1993) examined the process of decision making of women choosing between mastectomy and lumpectomy in an attempt to provide empirical grounding for developing a conceptual framework for stressful health care decision making. Qualitative research methods were used on 48 women diagnosed with early stage breast cancer. Five indicators of decision behavior were identified in descending order of importance including perceived salience of alternatives, conflict, information seeking, risk awareness and deliberation. Based on these empirical indicators, Pierce classified women into three decision styles called deferrer, delayer, and deliberator. Deferrers had an immediate attraction toward one option and experienced no decision conflict, made little attempt to obtain more information and did not utilize risk statistics in the decision making process. Delayers considered both options, had minimal decisional conflict, preferred information from nontechnical sources, and tended to vacillate between treatment options. Deliberators considered both options and tended to decompose information to manageable sizes. They experienced moderate degrees of decision conflict, preferred technical information sources such as published articles and were influenced by the relative risk of the intervention.

# Review of the Literature Regarding Surgical Choice and Sociodemographic Variables

The majority of studies comparing choice of mastectomy to lumpectomy were designed to evaluate specific psychosocial factors and not sociodemographics specifically. Sociodemographic findings are discussed in some, but not all of these studies. In studies where sociodemographics were described, findings have yielded inconsistent results. Hughes (1993a) found women who selected mastectomy had significantly lower household incomes, while choice of lumpectomy occurred in women who were older compared to those choosing mastectomy. In contrast to Hughes' results, other investigators have found women who chose lumpectomy to be younger than those selecting mastectomy (Ward et al., 1989; Wolberg et al., 1987).

There is some evidence that patterns of care may be different depending on the age of the women being treated. Such differences may influence the decisions regarding choice of surgery made by elderly women. Greenfield et al., (1987) found that older women with stage I or II breast cancer were less likely to receive appropriate surgical intervention compared to a comparable group of younger women. However, these findings must be interpreted cautiously, since data were gathered retrospectively using tumor registry data. It is unclear whether these differences reflect choices made by the women themselves, or whether physicians undertreated elderly women due to age

biases held by the physician. Beisecker et al., (1994) examined attitudes of oncologists, oncology nurses and patients regarding medical decision making for older and younger breast cancer patients. In general, physicians were significantly less inclined to support patient involvement in medical decisions than were patients or nurses. In addition, older patients were significantly more likely to defer to physicians when a decision was needed. <u>Review of the Literature Regarding Uncertainty and Surgical</u> Choice in Stage I and II Breast Cancer

Themes of uncertainty about treatment choice are not uncommon in the breast cancer literature, but very little is known about uncertainty among women early in the diagnostic phase and specifically at the point of choosing to undergo treatment. Following an exhaustive search of the literature, only one study was found in which uncertainty at the time of decision making was explored. Hughes (1993b) studied 52 women with stage I or II breast cancer. Uncertainty was measured at the time of diagnosis and eight weeks later. Uncertainty was found to be highest at the time of diagnosis and to decrease over time. However, uncertainty was unrelated to treatment type.

The concept of uncertainty as it relates to choice of surgical treatment has been demonstrated retrospectively in the literature. While such studies do not apply directly to the present study, they offer support for conducting the present study since they establish a theoretical

relationship between treatment choice and uncertainty. Two studies examined the concept of uncertainty in women once choice of treatment had been selected. Cawley, Kostec, and Cappello (1990) conducted a retrospective descriptive study of 68 women who had chosen lumpectomy. Themes of uncertainty regarding whether or not they had made the right decision were common among participants. Specifically, concerns that the cancer had spread and that it would recur troubled women the most. Wong and Bramwell, (1992) examined uncertainty in 25 women who received mastectomy for breast cancer to see if uncertainty decreased over time and to examine the relationship between uncertainty and anxiety. Uncertainty was measured one to two days before hospital discharge and one to two weeks after discharge. While they expected that uncertainty would decrease, results were not significantly different. Results from this study are difficult to interpret since the time span between the two data collection times is short and because no baseline scores for uncertainty were collected.

Qualitative studies of women who have survived breast cancer also reveal themes of uncertainty, some of which relate to the treatment decisions women made. Carter (1993) explored the experiences of women who had survived five years or longer after treatment for breast cancer. Even five years later, themes of uncertainty about treatment choice were found among some women who worried whether or not their treatment successfully removed all cancer cells.

Hilton (1988) explored the concept of uncertainty in a phenomenological study of 16 women with breast cancer. Findings from this study revealed that situations that led to uncertainty included inability to foretell the future, feelings of doubt or indecision about treatment and the system of care, and not knowing whether or not the cancer would recur. These studies suggest that uncertainty about cancer and treatment exist long after women have been treated. What remains unclear is the point at which uncertainty becomes operative and whether it predisposes women toward treatment.

# Review of the Literature Regarding Uncertainty and Sociodemographic Variables

The relationship between demographic variables and uncertainty is not well documented in the literature for women with breast cancer. Mishel (1988) hypothesized that education would be negatively correlated to uncertainty. While research in this area has been minimal, two studies have confirmed this in other populations such as renal failure (Brock, 1990) and myocardial infarction (Christman et al., 1988). Among the studies that specifically measured uncertainty in the breast cancer population, demographics were not discussed (Christman, 1990; Hilton, 1989; Hughes, 1993b; Wong & Bramwell, 1992). In a critical review of the research on uncertainty, Mast (1995) reported conflicting results on the relationship between demographics and uncertainty. Therefore at present, it remains unclear

whether or not certain demographic characteristics predispose a person to illness uncertainty.

## Shortcomings in the Literature

Studies have shown that uncertainty is a common theme among women with breast cancer and that often the uncertainty can be tied to concerns about treatment. However, many of the studies were done retrospectively (Carter, 1993; Hilton, 1988; Margolis et al., 1989), relying on women's memories of their presurgery uncertainty. Others focused specifically on women who had chosen either mastectomy (Wong & Bramwell, 1992) or lumpectomy (Cawley et al., 1990) making it difficult to compare across treatment groups. Hughes (1993b) did explore the relationship between surgical choice and uncertainty and found choice of treatment to be unrelated to uncertainty. However, such results need to be replicated if they are to be applied to patients in the clinical setting by clinicians.

The relationship between uncertainty, treatment choice and sociodemographics in women with breast cancer is rarely discussed in the literature. When and if sociodemographics are mentioned, they are considered secondarily rather than as a primary focus of investigation. In such studies, findings have yielded inconsistent results making it difficult to make application to clinical practice. Mishel (1988) theorized that education would be negatively correlated to uncertainty, however the literature in the breast cancer population is insufficient to make this claim.

Sociodemographic variables of family income and age have not been well described in the breast cancer population. Only one study reported on household income (Hughes, 1993a) and relationships between age and treatment choice are conflicting. Therefore, at present, it remains unclear whether or not certain demographic characteristics predispose a person to illness uncertainty.

#### Rationale for Proposed Study

The time from discovery to treatment is the most stressful time for many women with breast cancer (Northouse, 1989). Yet very little is known about the perceptions of women or the factors they consider at the time of diagnosis before the decision to undergo treatment. Investigators have been reluctant to study women newly diagnosed with breast cancer out of a belief that their anxiety renders them unable or unwilling to participate in research. Given that differences in functional and psychological status are reported in the literature among women choosing mastectomy versus lumpectomy, it is reasonable to examine potential factors that might influence women in the decision making process. If advanced practice nurses are going to be assistive to women with breast cancer, they must understand phenomena associated with all phases of the illness trajectory.

The concept of uncertainty is relevant to advanced practice nurses because of the relationship to stress and coping. Uncertainty has been examined and shown to predict

distress (Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995), adjustment difficulties (Christman, 1990), fear of recurrence and the use of specific types of coping strategies (Hilton, 1989), and anxiety (Wong & Bramwell, 1992) in patients with breast cancer. Yet very little is known about the concept of uncertainty at the time of choosing between treatment options. Furthermore, while many women with breast cancer describe uncertainty as a common theme, differences in uncertainty at the time of decision making have not been thoroughly explored. Thus, it is unclear at what point in the illness trajectory uncertainty becomes operative and whether or not uncertainty predisposes women to select one treatment over another.

More can be learned about the relationship between sociodemographics and uncertainty. The proposed study provides an excellent opportunity to explore these concepts when women are learning about their diagnosis and choosing treatment, presumably one of the most stressful periods for many women.

## Research Questions

Women newly diagnosed with breast cancer are asked to make treatment decisions during the most stressful time of the illness trajectory (Northouse, 1989). They must consider the possibility of undesirable outcomes such as physical disfigurement, the chance of recurrence, unfamiliar treatment regimens and long-term survival when choosing breast cancer treatment. Yet women with early stage breast

cancer have very little personal experience to assist them in the decision making process. Women with early stage breast cancer generally do not experience symptoms from their illness and therefore do not receive any physiological cues to assist them in choosing between more- or lessextensive surgical treatments. Furthermore, they do not have the advantage of a prior cancer diagnosis to familiarize themselves with the events and routines associated with either lumpectomy or mastectomy. Therefore, they cannot accurately predict which treatment will result in the best outcome. Thus, while survival and recurrence rates may be comparable between the two surgical choices, uncertainty regarding the right choice may exist due to the myriad of other factors to consider and the lack of personal experiences and symptom cues from which to draw. Additionally, it is unclear if uncertainty is associated with demographics, specifically education, income and age. The purpose of this study is to examine the relationship between uncertainty and treatment choice between mastectomy and lumpectomy (event familiarity) in women with stage I and II (symptom pattern) breast cancer (stimuli frame), and the relationship between uncertainty and sociodemographics (social support and education) (structure providers). The specific questions to be answered are:

 During the time interval between diagnosis of stage I or II breast cancer (symptom pattern) and deciding upon treatment, what proportion of women who choose

mastectomy experience higher levels of uncertainty compared to women who choose lumpectomy (event familiarity) (stimuli frame)?

2. Which (structure provider) variables (age, education, and income) are associated with total uncertainty among women diagnosed with stage I or II breast cancer during the time interval between diagnosis and treatment?

#### METHODS

#### Original Study

The original research, entitled Psychosocial Adjustment to Cancer: Couples at Risk was conducted by Laurel Northouse, PhD, RN from Wayne State University in Detroit, Michigan. This study (Grant Number 5 R29 NR02019) was funded by the National Institute of Nursing Research, National Institutes of Health. The purpose of Dr. Northouse's study was: 1) to explore the psychosocial adjustment of breast cancer patients and their husbands; 2) compare the adjustment of these couples to that of couples in which the women had benign breast disease; and 3) to determine the relationship between certain predictor variables and psychosocial adjustment in women with breast cancer and their partners.

### Sample for the Present Study

The participants from the original study were accepted into this study if they were female, diagnosed with stage I or II breast cancer for which they were treated with either lumpectomy or mastectomy and signed a written consent to participate in research. The sample for this study consisted of a nonprobability sample of newly diagnosed breast cancer patients with no prior evidence of cancer. The sample was obtained from two comprehensive breast centers in Michigan, Harper-Grace Breast Service in Detroit and the Comprehensive Breast Cancer Center in Ann Arbor. Both centers are affiliated with major universities. Eighty women with stage I or II breast cancer were included. Field Procedures and Data Collection

The data analyzed in this study were collected at time point number two, which occurred after breast biopsy but before treatment was initiated. Thus, the women were aware of the cancer diagnosis, but had not yet undergone treatment. Data were derived from two instruments, the Mishel Uncertainty in Illness Scale (MUIS), and the Demographic Information Sheet. All of the questionnaires were self-administered and completed either at the cancer centers or the participants' homes:

A trained research nurse was available to answer questions or assist with questionnaire completion for women unable to read. The questionnaires used for analysis in this study were completed as part of a larger battery of instruments. The entire process took between one and two hours for most participants to complete.

At the request of Dr. Northouse, variables of interest for this study were identified using the original code book.

Analysis was performed using SPSS software at the Center for Health Research at Wayne State University.

#### Protection of Human Subjects

The original study design was reviewed and approved by the Clinical Research Committee at St. Joseph Mercy Hospital in Ann Arbor, MI. In addition, subjects were approached by the investigator and voluntary consent was obtained and signed prior to study enrollment. Permission to conduct the secondary analysis proposed in the present study was reviewed and approved by the Michigan State University Committee on Research Involving Human Subjects. Operational Definitions, Instrumentation, and Scoring of Uncertainty

Uncertainty is defined as the cognitive state that occurs when the individual is unable to assign definite values to objects or events and/or is unable to accurately predict outcomes (Mishel, 1988). Data for this variable were obtained using the MUIS (total uncertainty score) obtained at time point number two.

The MUIS is a 34-item Likert scale that measures subjects' perceptions of uncertainty and contains four underlying dimensions of uncertainty: ambiguity, complexity, lack of information and unpredictability. A 14item condensed version of the original tool was used in the present study because the original tool contains a number of items that are inappropriate for ambulatory patients. A total uncertainty score was used for determining

measurements. In previous studies, the internal consistency reliability (Cronbach's alpha) for the condensed scale ranged from .75 to .90 (Bennett, 1993; Braden, 1990; Hilton, 1989; Wineman, O'Brien, Nealon, & Kaskel, 1993). In the present study, the alpha reliability coefficient was .80. The MUIS has been used in a variety of patient populations including women with breast cancer (Christman, 1990; Hilton, 1989; Wong & Bramwell, 1992).

The MUIS uses a five choice Likert response scale in which 5=strongly agree; 3=undecided; 1=strongly disagree. All items are direct scored except 4, 9, 11, 13, and 14, which are reverse scored. The range of possible scores on the MUIS condensed version is between 14 and 70 points. There is no reported criterion for "high" versus "low" uncertainty scores in the literature. Therefore, a cut-off score based on the median split of the sample was used. Operational Definitions, Instrumentation, and Scoring of Structure Provider Variables

Structure provider variables were defined as those characteristics that describe the participant's social or demographic status. In this study, structure provider variables included age, education, and family income. Age is expressed in years. Education is expressed in number of years of formal education. Family income refers to annual income and is divided into six groupings in ten thousand dollar increments between ten thousand and sixty thousand dollars per year, plus less than ten thousand dollars and

\$61,000 or above. Data for these variables were obtained from the Demographic Information sheet.

# Operational Definitions, Instrumentation and Scoring of Treatment Choice

Choice of surgery was defined as the selection a woman makes between two surgical interventions, mastectomy or lumpectomy. Data for these variables were obtained from the Demographic Information sheet. On this form, participants were asked to select between several options: lumpectomy, partial mastectomy, simple mastectomy or modified radical mastectomy. Only those women choosing either lumpectomy or modified mastectomy were included for data analysis. Women selecting lumpectomy were scored as "0"; women selecting modified radical mastectomy were scored as "1". Operational Definitions of Cancer Stage

Cancer stage was defined as the size of the tumor and extent of infiltration to surrounding tissue, nodes or distal sites. According to the principle investigator, all of the women with breast disease in the original study were diagnosed with breast cancer at either stage I or stage II of progression. Therefore, it was an assumption for this study that all of the participants met the requirements for breast cancer staging.

### Research Design and Data Analysis Plan

This study used a descriptive correlational design to explore relationships between the following study variables: uncertainty, structure provider variables of age, education and income, and choice of surgical intervention among women with stage I or II breast cancer. The research was conducted as a secondary analysis. Approximately 80 women met the criteria for stage I or II breast cancer. Analysis occurred on a subset of  $\underline{n}=64$ , women who had chosen either lumpectomy or modified radical mastectomy.

As a preliminary analysis, descriptive statistics for sociodemographic characteristics including race, employment status and marital status were calculated to describe the sample according to treatment choice. To determine the answer to study question one, a single 2x2 chi-square analysis was done, comparing the proportion of women in each treatment condition who had high versus low uncertainty scores. The original intent was to place women whose total uncertainty scores fell between 14 and 42 into the "low" category and women with total uncertainty scores between 43 and 70 into the "high" uncertainty category. However, this segmented the groups in such a way as to skew the results and provide insufficient power to conduct the statistics. Instead, the sample was placed into "low" and "high" categories of uncertainty using a score of 31 which represented the median split of the sample. "Low" uncertainty included women whose total uncertainty scores fell between 14 and 31 points. "High" uncertainty included women whose scores ranged between 32 and 70 points. A chisquare test of proportions was conducted to determine if there were significant differences in proportions of women

who had higher versus lower uncertainty scores, as a function of treatment group.

Question two was answered by correlating age, education and income (structure providers) with total uncertainty scores. A correlation matrix was analyzed to determine the strength and direction of relationships among these variables.

#### Limitations

The sample size used to answer the research questions was small (n=64) making generalization to the breast cancer population difficult. Additionally, the overwhelming majority of women who participated in the study were Caucasian, and thus generalization to a more diverse population cannot be made. Finally, uncertainty scores among this group of participants was lower than expected making it necessary to use the median split for total uncertainty scores to provide sufficient power to conduct the analysis. These scores may not be representative of all women choosing breast cancer surgery.

#### RESULTS

Statistical analysis for this study was conducted at Wayne State University by the statistician in the Center for Health Research. Study variables for analysis in this study were taken from the original data set on February 21, 1997. Eighty participants from the original data set met the staging requirements for the study. All of the women who met the inclusion criteria for this study were recruited

into the original study within a time period between June 1989 and June 1991.

### Demographic Characteristics

Demographic characteristics represent the entire group of women (N=80) who were diagnosed with stage I or II breast cancer. Women who participated in this study were predominantly Caucasian (97.4%). The majority of women had no family history of breast cancer (70%) and had no other medical problems at the time of diagnosis (56%). Fifty percent of the women were employed at the time of diagnosis, 10% were retired and 39% were homemakers. All the women who participated in the study were married (Table 1).

Eighty women met the criteria for malignant breast cancer. Among the women with malignant breast cancer completing the questionnaires at time point two, 40 women selected lumpectomy, 30 women chose some form of mastectomy, nine women were undecided about what surgical intervention they wanted, and data were missing for one participant. The mean age of the women in this study was 52 years. The women had completed 14 years of formal education on average, and had an average family income of \$36,100 annually.

When the participants were examined according to treatment choice (n=64), no significant differences by demographic characteristic were found (Table 2). Women who selected lumpectomy tended to be slightly more educated, be married more years on average and have marginally higher incomes. The majority of women for both surgical

Table 1.

Demograph	ic Characteri	istics o	f the Sample

Characteristic ( <u>n</u> =80)	מ	<u>\$</u>		
Race	•			
Caucasian	76	97		
Black	1	1		
Other	1	1		
Missing	2	· 1		
Family History of Br	east			
Cancer	24	30		
Yes	55	69		
No	1	1		
Missing				
Comorbids	34	43		
Yes	44	55		· · · · · · · · · · · · · · · · · · ·
No	2	2		
Missing				
Employment	40	50		
Employed	8	10		
Retired	30	38		
Homemaker	2	2		
Missing				
Marital Status	80	10		
Married		0		
Surgical Choice	40	50		
Lumpectomy	30	38		
Mastectomy	9	11		
Undecided	1			
Missing		1		
	Rang	e	М	SD
Age	30-7	5	52.13	10.9
Education	5-22	-	13.83	3.51
		\$60,000	\$36,100	\$14,400

.

### Table 2.

Characteristic	Lumpectomy ( <u>n</u> =40)		Mastectomy ( <u>n</u> =24)		
	м	SD	<b>M</b> .	SD	
Education	14.4	2.9	13.1	3.9	
Years Married	25.6	12.9	22.7	13.1	
Income	\$37,600	\$13,000	\$35,000	\$14,700	
Employment	n	8	n	\$	
Employed	20	50	14	58	
Retired	4	10	3	13	
Homemaker	16	40	7	29	

Surgical Treatment by Demographic Comparison

women selected lumpectomy (40%) over mastectomy (29%). However, there were no statistically significant differences between the two treatment groups.

Among the 31 women who selected more extensive surgery beyond lumpectomy, 24 chose the modified radical mastectomy (MRM) and it was this group of surgical patients included in the analysis when compared with lumpectomy patients. The seven women choosing other types of mastectomies were excluded due to an inability to verify staging of disease. Thus, analysis was conducted on 40 women who chose lumpectomy and 24 women who selected MRM. Table 3 shows the

### Table 3.

Surgical Choice	n Xe	an Uncertainty	8D	Range
Lumpectomy	40	30.47	6.97	18-54
Modified Radical Mast.	24	31.00	6.92	19-45
Undecided	9	39.11	7.06	30-53

Surgical Choice and Mean Uncertainty Scores

#### Presentation of Answers to Research Ouestions

1. During the time interval between diagnosis of stage I or II breast cancer (symptom pattern) and deciding upon treatment, what proportion of women who choose mastectomy experience higher levels of uncertainty compared to women who choose lumpectomy (event familiarity)?

The chi-square analysis showed no statistical significance in higher versus lower uncertainty scores based on surgical treatment  $(\underline{X}^2$  (1, n=64)=.34, p=.56). Higher levels of uncertainty were not associated with the type of surgical intervention selected among the women in this sample (Table 4).

2. Which structure provider variables (age, education, and income) are associated with total uncertainty among women diagnosed with stage I or II breast cancer during the time interval between diagnosis and treatment?

Although all of the variables were negatively correlated with uncertainty, age and income were not

#### Table 4.

		Surgical	Choice	
	Lumpectomy		Mastectomy	
	n	- *	n	- *
Level of Uncertainty				
Level of Uncertainty Low	23	36	12	19

Chi-square Table of Uncertainty and Treatment Choice

 $x^2(1, n=64)=0.34, p=NS$ 

statistically significant. However, uncertainty did show a small negative relationship with years of education ( $\underline{r}$ =-.31;  $\underline{p}$ <.01). The correlation matrix is shown in Table 5. Thus, women with less education experienced greater levels of uncertainty than women who were more educated.

Table 5.

Correlations of Structure Providers and Uncertainty

	Age	Sociodemographics Education	cs Income
Uncertainty	12	31*	12
*p<.01			

### Additional Results

Although not part of the original research questions, one interesting result did surface by examining the group of women who were undecided about which surgical intervention to select. These women showed significantly higher uncertainty scores than either women selecting lumpectomy and those who chose mastectomy ( $\underline{F}=2.43$ ;  $\underline{p}<.05$ ).

#### DISCUSSION

### Sample

Findings in this study were based upon a predominantly Caucasian, middle-income sample of women with at least a high school education. Half of the women (n=40) selected lumpectomy, approximately 40% (n=30) chose mastectomy and 10% (n=9) were undecided about which treatment to select. These demographic characteristics are consistent with samples found in other studies exploring surgical choice of women with early stage breast cancer in that the sample was predominantly Caucasian. Information about indecision, family history of breast cancer or coexisting illnesses has not been reported elsewhere in the literature.

### Uncertainty and Surgical Choice

Treatment choice was found to be unrelated to level of uncertainty in this sample of women of newly diagnosed breast cancer patients. In other words, illness uncertainty did not appear to influence women toward one surgical treatment over another. In this sample, more women selected lumpectomy over mastectomy. Within the mastectomy group, women were evenly split between lower and higher levels of uncertainty. Among the lumpectomy group, more women fell into the low uncertainty category, indicating that these women tended not to perceive much uncertainty about their illness. However, these differences did not result in statistically significant outcomes.

This is consistent with Hughes (1993b) findings in which treatment choice was unrelated to uncertainty at the time of choosing treatment. Hughes used a sample of women that was similar, but not identical to the present study in that Hughes had a higher percentage of Black respondents. However, the present study seems to reaffirm what has been reported elsewhere in the literature among women diagnosed with breast cancer choosing between surgical treatments. Uncertainty and Structure Provider Variables

Illness uncertainty was inversely correlated with education such that lower uncertainty scores were associated with more years of education. While similar results have been reported in populations such as multiple sclerosis (Wineman, O'Brien, Nealon, & Kaskel, 1993) and heart disease (Christman et al., 1988), comparable findings have not been reported within the breast cancer literature on uncertainty.

Household income and the age of a woman were not associated with illness uncertainty. Thus, a woman's capacity to understand information about one's illness is not related to socioeconomic status or age among women with early stage breast cancer. Relationships between uncertainty and sociodemographics have not been reported elsewhere in the breast cancer literature.

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### Relationship of Results to Conceptual Framework

Mishel (1988) theorized that education and uncertainty were inversely related. Education, as a structure provider variable, is postulated to enhance one's ability to understand and process information that is provided about illness or illness situations. Findings in the present study seem to support Mishel's theoretical conceptualization of illness uncertainty.

The two other structure provider variables in this study, age and income were not associated with uncertainty. These variables were adapted as social support variables for this study, under the premise that one's social network is related at least partially to one's age and economic status. Social support is theorized to influence uncertainty through affirmation (Mishel, 1988). Results from this study suggest that age and income are not factors that influence the exchange of opinions and views in such a way as to affect levels of uncertainty.

Illness uncertainty does not appear to predispose women toward one treatment over another, and thus did not support the model conceptualized for this study. This is not surprising in that this study was not designed to test the model specifically. Stage of breast cancer and choice of treatment may not be sufficiently linked conceptually with Mishel's (1988) concepts of symptom pattern and event familiarity respectively. Of interest is the subgroup of women in this sample who were unable to reach a decision at the point in time in which the tool was completed. These women demonstrated significantly more uncertainty than women who had made a decision toward one surgical intervention or another. Thus, it would appear that illness uncertainty does not predispose women toward a specific treatment but rather impairs or interferes with a woman's ability to reach a decision. It may be that these are the women for whom stimuli frame variables were operative, resulting in higher levels of uncertainty. Other studies (Hughes, 1993a, 1993b; Ward et al., 1989; Wolbert et al., 1987) did not report on a population of undecided participants, thus comparisons to other studies cannot be made.

Pierce (1993) classified women into three decision styles based on certain decision making indicators and the degree of decisional conflict they experienced. It may be that women who immediately migrated toward a decision, regardless of whether it was for lumpectomy or mastectomy, fit Pierce's conceptualization of deferrers. These were women who had an immediate attraction toward one option and experienced no decision conflict. On the other hand, the small subset of women who had not yet made a decision fit closer with either deliberators or delayers in which vacillation between treatment options or greater levels of decisional conflict were more pervasive.

### Recommendations for Research

Very little is known about the factors women consider when choosing breast cancer treatment. Studies need to be

developed that identify factors that influence decision making. Such studies should occur at the point in time that women receive the diagnosis, presumably the most stressful time during the illness trajectory. However, studies that examine the entire experience from the point of diagnosis through treatment and into recovery and their relationship to illness uncertainty would be helpful.

Studies that have examined choice of treatment have included predominantly white populations. There is a paucity of information about decision making among minority women. Thus studies need to be developed that identify factors in the decision making process for minority women. It then needs to be determined whether women of different races consider similar or different factors when making decisions.

The concept of uncertainty is relevant to advanced practice nurses because of its relationship to stress and coping. While uncertainty has been a common theme in breast cancer decision making, it is not clear at what point and under what circumstances illness uncertainty becomes operative. Thus, additional research is need to determine how breast cancer patients perceive uncertainty over time and how these perceptions influence their overall well being.

The relationship between indecision and uncertainty needs to be better understood. Findings in this study suggest that women who experience the highest amount of

uncertainty had difficulty coming to a decision about surgical treatment. More light needs to be shed on the relationship between indecision and uncertainty. Methods to assist clients in moving toward decisions must also be explored, defined and described.

Finally, more needs to be learned about conditions in which uncertainty is useful or adaptive and when uncertainty is detrimental to patient outcomes. Mishel (1988) hypothesized that in certain circumstances, maintaining uncertainty is beneficial for patients such as in situations in which eliminating uncertainty would result in a patient giving up hope for recovery. Such might be the case among women with breast cancer recurrence or more extensive stages of illness within the breast cancer population. Research is needed to verify whether or not uncertainty is in fact a more desired state for some patients.

#### Implications for Education

Uncertainty has ramifications for how patients cope with illness. Thus, nurses would benefit from nursing programs that include information about uncertainty as part of the curriculum. Additionally, more information in the nursing literature is needed such that nurses can become better informed about illness uncertainty and its consequences. Included in this should be information about conditions that predispose patients toward uncertainty, when during the illness trajectory uncertainty is at its highest levels, and effective strategies for managing uncertainty.

Nurses need to educate patients about all aspects of the breast cancer experience: diagnosis and staging, treatment options and their associated survival and recurrence rates and how different treatment choices typically affect the daily activities of breast cancer patients. A thorough understanding of the entire illness trajectory is critical to appropriately managing illness uncertainty. In situations where death is inevitable, as in some forms of cancer, minimizing uncertainty may not be the nursing goal. Instead, assisting patients to tolerate rather than diminish uncertainty may be appropriate in these situations (Oberst, 1993).

Nurses also need to be educated about the factors that women consider when choosing breast cancer treatment. Nursing programs frequently offer information about treatment options and survival rates. Most programs include very little information about women's perceptions about breast cancer or the factors that influence decision making. Including such theoretical information as part of the nursing curriculum about breast cancer is especially appropriate in advanced practice nurse programs and would enhance the educational process.

### Implications for Advanced Practice

Understanding the concept of illness uncertainty has direct application to the advanced practice role in primary care. Advanced practice nurses are likely to encounter women diagnosed with breast cancer in the primary care

setting. As coordinators of care, it is the responsibility of the advanced practice nurse in primary care to assure that patients understand their illness and the treatment options available. Information about breast cancer and its treatment should be clearly presented using unambiguous and non-medical language. The amount of information needs to be tailored to the individual patient, taking care not to overwhelm the patient with unnecessary or conflicting information.

Given that education and uncertainty are inversely related, care must be taken with the less educated client to assure that they fully understand the disease process and the differences in treatment options. Additionally, information about how treatments may affect their lives may be particularly beneficial in this population.

Women who appear to be struggling with the decision making process may require particular attention by the advanced practice nurse, as it appears to be this subgroup of patients who experience the greatest amount of illness uncertainty. Thus, advanced practice nurses must assess clients ability to select treatment and be prepared to intervene on their behalf as appropriate. This might include assisting clients to obtain all the information they need about their illness or the ramifications of different treatment options. Similarly, advanced practice nurses should encourage patients to reach a decision they are comfortable with rather than proceeding based on the

perceived wishes of their oncologist or other persons of influence to the patient.

Because of the relationship between uncertainty and stress and coping, advanced practice nurses should assess women's stress levels and coping styles. Advanced practice nurses should be attuned to behaviors associated with increased levels of distress or anxiety.

Finally, advanced practice nurses need to advocate on behalf of women with early stage breast cancer. This includes supporting women in their treatment choices and promoting the importance of education and decision making for all clients within the primary care system.

#### SUMMARY

Receiving a diagnosis of breast cancer is a devastating blow for most women. The time immediately following diagnosis is the most stressful for women, yet they are asked to make treatment decisions that will have major ramifications throughout the remainder of their lives. Thus, understanding all we can about the perceptions of women during this time and the factors women consider when making decisions is vitally important. Assisting women to understand about breast cancer, treatment options and all aspects of the illness trajectory is an important part of caring for women with breast cancer.

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### APPENDIX A

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# UCRIHS Approval

	N I V E R S I T Y	
Dece	mber 16, 1996	
<b>TO</b> :	Gwen Wyatt A230 Life Sciences College Of Nursing	
RE:	IRB#: TITLE:	96-776 Relationship among uncertainty, stimuli frame and structure providers in women with breast cancer choosing breast surgery
	REVISION REQUESTED: CATEGORY: APPROVAL DATE:	N/A 1-E 12/14/96

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The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.



OFFICE OF RESEARCH AND GRADUATE PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

STUDIES University Committee on

Research Involving Human Subjecte (UCRIHS)

Michigan State University 232 Administration Building East Lansing, Michigan 48824-1046

> 517/355-2180 FAX: 517/432-1171

cc; Julie K. Walker

David E. Wright Ph.D UCRIHS Chair

Sincerely,

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The Michigan State University IDEA is Institutional Diversity Excettence in Action

MSU is an allumative action equal-opportunity institution

MOULO AND CTATE

### 13. ANONYMITY/CONFIDENTIALITY

The confidentiality of the participants from the original data set will be maintained for the subset of women used in the data analysis for this study. Only research identification numbers assigned by the original investigator will be used. No information that would identify participants will be divulged during data analysis for this study.

#### 14. RISK/BENEFIT RATIO

This study only entails secondary data analysis of data already collected. There are no additional risks to participants as a result of this study. It is not expected that participants will benefit directly from this study. However, information learned in this project may assist other women with breast cancer in the future.

#### 15. CONSENT PROCEDURES

No additional informed consent procedures are required for this study since this study is designed only to perform additional data anlaysis on data that have already been collected. Participants in the original study signed consent forms which are on file with the principle investigator. The original consent form and research proposal were reviewed and approved by the Clinical Research Committee at St. Joseph Mercy Hospital in Ann Arbor, Michigan. UCRIHS APPROVAL FOR

THIS project EXPIRES:

DEC 1 4 1997

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SUBMIT RENEWAL APPLICATION ONE MONTH PRIOR TO ABOVE DATE TO CONTINUE Is your application COMPLETE? Please SEE the CHECKLIST on page four of the UCRIHS Instructions. APPENDIX B

Patient Consent for Research

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### Appendix B

### Psychosocial Adjustment to Breast Disease

### PATIENT CONSENT FOR RESEARCH

### Introduction

You are being asked to participate in a research project to study the ways in which the process of diagnosis and treatment of breast disease impacts a woman and her husband, and their relationship to each other, family members and friends. The purpose of this study is to obtain information that will allow nurses and other health professionals to provide more effective and personalized care to women with breast disease and their spouses.

This study is sponsored by Wayne State University with funding from the National Center for Nursing Research of the National Institute of Health. The study will be conducted at Harper-Grace Breast Service in Detroit and the Breast Center at Catherine McAuley Health Center. Approximately 160 couples will participate in this study.

### **Description of Procedures**

Should you decide to participate, you and your spouse will be asked to meet alone with the nurse researcher four times: 1) before the breast biopsy is done, 2) several days after biopsy, 3) 60 days later, and 4) one year later. At each of these meetings, you and your spouse will be asked to independently complete several questionnaires. Each of these meetings would take about 60-90 minutes, and will be held in your home. In addition, your medical records will also be reviewed. In the event that a larger than average number of women are diagnosed with benign breast disease, only a randomly selected group of those women and their husbands will be asked to complete follow up interviews.

How often you see your doctor before and after your breast biopsy, and the type(s) of tests, medicine(s), and treatment(s) you receive will be determined by your physician based on your physical condition, and will be the same as you would receive if you did not participate in this study.

### **Risks and Discomforts**

There are no physical risks associated with this study. There is, however, the possibility that you or your spouse may experience some uneasiness responding to the personal nature of the questions asked about your emotional feelings and relationships with others.

### **Benefits**

It is not possible to predict whether any personal benefit will result from you or your spouse's participation in this study. One benefit is that you will have the chance to discuss your feelings about your breast biopsy and any follow up care you may have with an experienced nurse. In addition, you will have the chance to discuss problems you may be having with your relationships with others, and may receive comfort or information which is helpful to your or your spouse.

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Another possible benefit of your participation is that useful information may be obtained which will help nurses and other health care professionals provide more effective and personalized care to women with breast disease and their spouses in the future.

There is not financial compensation for participation in this study.

### Alternatives

Your alternative to participating in this study is not to participate. If you choose not to participate you will not meet with the nurse researcher or complete any of the questionnaires.

### **Rights and Responsibilities**

Your participation is completely voluntary and you may withdraw at any time without penalty to you by calling Laurel Northouse at (313) 577-0272 or Linda Lampman at (313) 665-8285.

All information obtained for this study is confidential and the identity of you or your spouse will not be revealed. A code number will be used to identify the questionnaires which you and your spouse complete, and only the nurse researcher will have access to the number which identifies you by name. Neither you nor your spouse will have access to each other's responses. After the entire study is completed, you may request a summary of the findings from this study from the nurse researcher.

In the unlikely event of any injury resulting from participation in this study, no financial compensation or free medical treatment is available from Wayne State University or the Catherine McAuley Health Center.

Should you have any questions about your rights as a subject, you may contact the Director, Clinical Research Office at (313) 572-5470.

I have had an opportunity to ask questions about the study and was given sufficient time to consider my participation. I have received a copy of this consent form and agree to participate.

Participant's Signature

Date

Spouse's Signature

Date

Investigator's Signature

Date

R-90-254 CRO90-59 Rev 6/90 APPENDIX C

Demographic Information

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### Appendix C

### Demographic Information

- 1. What type of surgery did you have?
  - \_\_\_\_\_ Lumpectomy with radiation
  - \_\_\_\_\_ Partial mastectomy
  - \_\_\_\_\_ Simple mastectomy
  - \_\_\_\_\_ Modified radical mastectomy
  - \_\_\_\_ Other
- 2. How old are you?
- 3. Are you married? yes\_\_\_\_\_ no\_\_\_\_\_
- 4. Employment Status:
  - Employed Retired
  - \_\_\_\_\_ Homemaker

5. Education: Number of years of formal education\_\_\_\_\_

## 6. Annual Family Income:

Less than \$10,000	\$41,000-\$50,000
\$10,000-\$20,000	\$51,000-\$60,000
\$21,000-\$30,000	\$61,000 or above
\$31,000-\$40,000	

7. Race:

Caucasian	Hispanic
Oriental	Other
Black	

APPENDIX D

Uncertainty in Illness Scale - Patient Form

## Appendix D

No.\_\_\_\_\_

### UNCERTAINTY IN ILLNESS SCALE--PATIENT FORM

Then place an "X you agree with a s you disagree with	" under the co statement, the a statement, now you feel,	blumn that most cl n you would mark then mark either "	osely measures h under either "Str Strongly Disagre	out what each statement ow you are feeling TOD rongly Agree" or "Agree e" or "Disagree". If you hat statement. Please re
I don't know what	-		<b>D</b> .	
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
I have a lot of que	stions withou	it answers.		
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
I do not know whe				
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
I understand every	thing explain	ned to me.		
Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree . (5)
The doctors say th	-		• •	
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
There are so many				
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
I have been given	many differir		what is wrong wi	
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
It is not clear what	t is going to h	happen to me.		
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disa (5)
The results of my		nsistent.		
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disa (1)
I'm certain they w	ill not find an			<u> </u>
Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disa (5)
They have not giv	en me a speci	fic diagnosis.		
Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disa (1)
•	e nurses to b	e there when I nee		
Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disag (5)
The doctors and n	urses use even	ryday language so	I can understand	what they are saying
Strongly Agree	Agree	Undecided	Disagree	Strongly Disag

