

**A DESCRIPTIVE STUDY OF INFORMATION NEEDS  
OF WOMEN WHO HAVE HAD A BREAST BIOPSY  
WITH BENIGN OUTCOME AND THE  
RELATED UNCERTAINTY AND ANXIETY**

**by**

**KAREN DEANE**

**A Thesis**

**Submitted to the Faculty of Graduate Studies  
in Partial Fulfillment of the Requirements  
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**BY**

**KAREN DEANE**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial  
fulfillment of the requirements for the degree of**

**MASTER OF NURSING**

**Karen Deane**

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Name and Title of  
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Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

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## ABSTRACT

The purpose of this study was to describe the information needs and levels of uncertainty and anxiety experienced by women who had a breast biopsy with benign outcome. Seventy women from two community sites were interviewed after receiving the breast biopsy diagnosis. A survey instrument composed of four parts: Information Needs Questionnaire, Mishel Uncertainty in Illness Scale - Community Form, State-Trait Anxiety Inventory, and a Demographic Questionnaire were completed by the subjects. A focus group was conducted before the study to determine nine of the most important information needs of women after a benign breast biopsy. Thurstone's Law of Comparative Judgement - Case V was used to develop profiles of the nine information needs arranged in 36 pairs in the Information Needs Questionnaire.

The most important information determined by the total sample related to when patients would know the biopsy diagnosis. The next four information needs on the profile addressed concerns related to the risks of developing breast cancer. Information about the tests for follow-up breast health care and diagnosis of a breast lump were less important than the information related to the threat of breast cancer. Women experienced heightened uncertainty and anxiety levels related to the breast biopsy experience. Profiles of information needs were also developed for women with high and low levels of uncertainty and anxiety, and for different demographic backgrounds. Profiles of information needs for women with high uncertainty, high state anxiety, and high trait anxiety resembled the groupings of information needs for the total sample.

Nursing care during the diagnostic process for a breast lump should provide appropriate information and emotional support for women facing a pending breast biopsy for definitive diagnosis. Research to determine the factors of uncertainty and anxiety that may be influenced by information is required.

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## CHAPTER ONE: INTRODUCTION

### Background of the Study

A considerable (50%) proportion of the female population will be affected with benign breast disease in their lifetime (Baron & Walsh, 1995; Link, 1993; Sinclair, 1988). A woman presenting with a lump in her breast embarks on a progressively more invasive course of examinations and diagnostic tests to assess the pathology of a breast lump and her future health. Nursing performs an important role in supporting the patient as she experiences uncertainty and anxiety related to breast disease and fears of a dreaded cancer diagnosis. It is imperative to provide accurate information in a timely manner throughout the experience of diagnosis for a breast lump.

Clarification and confirmation of accurate information by nurses will aid in dispelling myths and misconceptions related to breast disease and promoting appropriate breast care for women. Information and emotional support related to the breast biopsy procedure, threat of a malignant diagnosis, and appropriate follow-up care must be provided in a compressed time frame and within a highly emotional state. Information needs and levels of uncertainty and anxiety may vary with women from different sociodemographic backgrounds.

### Purpose of the Study

The purpose of this study was to describe the information needs of women having a breast biopsy with benign outcome and



the levels of uncertainty and anxiety they experienced. Quality, holistic nursing care during the diagnostic process of a breast lump will ensure an opportunity for nurses to support and educate women about breast health. Nursing care for this large and vulnerable population of women is an important consideration for women's healthcare.

### Significance of the Study

The uncertainty and anxiety elicited by the discovery of a breast lump are associated with the threat of breast cancer and ongoing medical surveillance related to breast cancer risks. Canadian Cancer Society statistics state that 1 in 9 women will develop breast cancer in their lifetime, with 17,700 cases estimated to be diagnosed in Canada during 1995 (Canadian Cancer Statistics, 1995). Breast cancer is the leading cause of death in women between 35 to 54 years of age. Annual mortality rates of approximately 5,400 are estimated for women of all ages.

The National Institute of Canada (1994) estimates that 730 new cases of breast cancer will be diagnosed in Manitoba during 1995. Approximately 80% of breast biopsy procedures ( $730 \times 80\% = 58400/20 = 2920$ ) result in a negative outcome. The total number of breast biopsy procedures performed in Manitoba annually equals 3650 ( $730 + 2920$ ) with 2920 of these resulting in a benign outcome.

Most breast lumps are self-discovered; this can result in a great deal of anxiety related to the threat of breast cancer

(Baron & Walsh, 1995; Redman, Hendikas, Clover, & Sanson-Fisher, 1993; Schifeling & Hamblin, 1991). Nursing plays an important role in providing accurate information and resources to facilitate appropriate health care decisions during the uncertain and anxious diagnostic time. The woman's uncertainty and anxiety are related to the threat of breast cancer and can affect her presentation of symptoms, decision-making abilities, treatment options, and general health (Lauver, 1992; Owens, Duffy, & Ashcroft, 1985).

Fortunately, approximately 80% of all breast biopsy procedures result in a negative outcome (Shaw, Wilson, & O'Brien, 1994). However, the provision of accurate, meaningful information about benign breast disease is complicated by the difficulty in interpreting the various classifications of benign breast disease and assessing the impact of other risk factors such as family history, age, reproductive history, and lifestyle behaviours. Women scheduled for a breast biopsy can experience uncertainty and anxiety because of inconsistent or unreliable test results that cannot definitively eliminate the threat of breast cancer (Hughson, Cooper, McCardle, & Smith, 1988, Mishel, 1990; Scott, 1983).

A diagnostic triplet consists of a physician breast examination, mammography, and fine needle aspiration. Three negative results from this diagnostic triplet provide a 98% to 99% accuracy rate for diagnosis of a benign breast lump;

however, one positive result warrants a breast biopsy (Palmer & Tsangeris, 1993). The surgical breast biopsy is the only means of providing a definitive diagnosis for a breast lump. Although most breast biopsies result in a negative outcome, the diagnostic experience is not a benign one for the patient.

A surgical breast biopsy is a final diagnostic procedure that follows a physician breast examination, mammography, fine needle aspiration, and/or sonogram used to evaluate the pathology of the breast lump. A surgical breast biopsy provides a definitive diagnosis of a breast lump that is deemed suspicious by other diagnostic tests. The patient's feelings of uncertainty and anxiety heighten as progressively more invasive tests can provide inconclusive and sometimes inconsistent results.

Ambulatory care and outpatient surgery affect the care experience provided to this vulnerable population. There is limited time, within a same day surgical experience, available for nurses to provide accurate breast health information and emotional support during the stressful peri-operative experience (Barrere, 1992; Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995). Nursing care consisting of timely, appropriate information about breast health may have implications for decreasing uncertainty and anxiety during the diagnostic phase of a breast lump.

#### Statement of the Problem

The fact that women of all ages are prone to develop a

breast lump, often self-discovered (90%), raises nursing care considerations for women's breast health (Baron & Walsh, 1995; Norwood, 1990). Discovery of a breast lump elicits feelings of uncertainty and anxiety related to confusing and complicated information about benign breast disease and the threat of breast cancer. The need for a surgical breast biopsy to provide a definitive diagnosis of a breast lump can increase the uncertainty and anxiety associated with the risk of developing breast cancer.

Fibrocystic breast disease (FBD) is a term commonly used to describe benign breast changes occurring in over 50% of all women of reproductive age. Norwood (1990) defined fibrocystic breast disease as a "benign condition characterized by cyclically fluctuating palpable irregularity of breast tissue accompanied by pain and tenderness that becomes progressively worse until menopause" (p.116). Symptoms of FBD include breast discomfort which ranges from an aching, full sensation to bilateral pain that begins in the upper outer quadrants of the breasts. Pain often occurs during the week prior to menses and subsides with menstruation. The inconsistency of the symptoms and the discomfort experienced can disrupt a woman's daily activities as well as fuel feelings of uncertainty and anxiety related to the significance of the symptoms.

A surgical breast biopsy provides the only means of determining a definitive diagnosis of a breast lump. Benign

breast conditions can include a variety of conditions managed conservatively (healthy lifestyle behaviours), simply in the physician's office (fine needle aspiration), or surgically (open biopsy). The significance of a specific diagnosis is influenced by both the histological classifications of benign breast changes and other personal risk factors. A clinical interpretation of all the risk factors and test results provides the medical rationale for determination of the breast care regimen.

Benign breast condition is histologically categorized as 1) non-proliferative, 2) proliferative disease without atypia, and 3) atypical hyperplasia. Non-proliferative benign breast diagnoses include normal, fibroadenoma, cysts, duct ectasia, apocrine metaplasia, and mild hyperplasia. Proliferative disease without atypia encompasses intraductal papilloma, radial scar, sclerosing adenoma, and moderate or florid ductal hyperplasia of the usual type. Atypical ductal hyperplasia and atypical lobular hyperplasia make up the third category of benign breast condition diagnoses and represent pre-cancerous lesions (London, Connolly, Schnitt, & Colditz, 1992, p.942).

Mastitis and trauma that may result in hematoma or fat necrosis are other forms of benign breast conditions (Black & Matassarini-Jacobs, 1993). Various theories attempt to explain benign breast changes through an understanding of hormonal, aging, environmental, lifestyle, and hereditary factors. These theories remain unresolved in determining the etiology

of benign breast changes. However, an assessment of the implications of different types of benign breast conditions within varying age groups may provide important information in spite of the unknown etiology.

A list of possible causes of breast masses related to a woman's age, compiled by Robbins et al. (1984), is depicted in Table 1 (Black & Matassarini-Jacobs, 1993, p. 2174).

Table 1

**CAUSES OF BREAST MASSES**

<b>UNDER 35 YEARS</b>	<b>35-50 YEARS</b>	<b>OVER 50 YEARS</b>
Fibrocystic Disease	Fibrocystic Disease	Carcinoma
Fibroadenoma	Carcinoma	Fibrocystic Disease
Mastitis	Fibroadenoma	Traumatic fat necrosis
Traumatic fat necrosis	Traumatic fat necrosis	Paget's Disease
Carcinoma	Mastitis	Acute mastitis
	Papilloma	Papilloma

Fibrocystic breast condition is the most common cause of a breast mass in women under the age of 50 years. However, cancer climbs from the least likely cause in women under 35 years of age to the second possible cause of a breast lump in women between 35 and 50 years old. In women over the age of 50 years cancer is the primary cause, while fibrocystic breast condition is the second possible reason for a breast lump in this age cohort.

The dramatic rise in risk of a breast cancer diagnosis

for a mass in women over the age of 35 years influences the number of breast biopsy procedures being performed. Even though the breast mass in women under the age of 35 years is less likely to be cancerous, younger women diagnosed with breast cancer have higher mortality rates than older women. The stage of disease at diagnosis, found to be an important predictor of survival rate, affects the clinical decision to schedule the woman for a breast biopsy (Lauver, 1992; Neale, Tilley, & Vernon, 1986). The benefits of early detection and conservative treatment options on morbidity and mortality rates are inversely affected by symptom presentation delays that may be due to uncertainty and anxiety related to a breast cancer symptom (Hackett, Cassem, & Rakker, 1973; Magery, Todd, & Blizard, 1977; Neale et al., 1986).

Other factors such as the increasing incidence of breast cancer and patient anxiety can determine the need for a breast biopsy. A woman's feelings of uncertainty and anxiety heighten with inconclusive or inconsistent diagnostic test results. The surgical breast biopsy is the last of a number of tests that may include physician breast examination, mammography, fine needle aspiration, sonogram, and needle localization used to evaluate the pathology of the breast lump. Indications for a breast biopsy have been described by Leis, Cammarata, LaRaja, & Higgins (1985) to include:

- 1) true three dimensional, dominant lumps even with negative screening results, except for cysts that can be

- aspirated;
- 2) suspicious mammographic lesions even with no clinical abnormalities;
  - 3) breasts with yellow, pink, bloody, or watery nipple discharge in spite of no palpable mass and negative findings on mammogram or aspiration;
  - 4) those with other signs of cancer that cannot be explained on a benign basis such as skin or nipple changes, suspicious axillary nodes, and induration without infection. (pg. 115).

A number of factors contribute to the increase in breast biopsy procedures being performed. These factors include a constant overall mortality rate for breast cancer since the 1950's, increasing incidence of breast cancer for every age group, mortality rates being indirectly related to age at diagnosis, and improved survival rates with early detection (Colditz, 1993; Magery et al., 1977; Winchester, 1990).

A breast biopsy is a surgical procedure considered to be relatively safe and usually uneventful with respect to complications. Physiological complications that do occur including hematoma, wound sepsis, pain, and residual deformity demand quality nursing care. Nurses must also respond to the psychological concerns related to the underlying reason for having a breast biopsy that elicits uncertainty and anxiety about the threat of a malignant outcome. A paucity of empirical information is presently available on the role of



the nurse providing pre-operative psychosocial and informational support for patients having a breast biopsy with a benign outcome (Barrere, 1992).

Emotional stress related to the fear of mutilation and death persist in spite of statistics demonstrating that approximately 80% of breast biopsy procedures result in a benign diagnosis (Benedict, Williams, & Baron, 1994b). Accurate knowledge related to benign breast conditions and a woman's personal risk factors is essential for the nurse who provides emotional support and facilitates appropriate health-seeking behaviours and follow-up care after a benign breast biopsy. The breast biopsy, considered by the medical profession to be a minor surgical procedure, becomes a major life event for the patient.

Uncertainty can be associated with anxiety (Hilton, 1992; Hirst & Whitehead, 1984; Wong & Bramwell, 1992). The breast biopsy experience is profoundly influenced by the woman's level of uncertainty and anxiety during the diagnostic phase. Mishel (1981) found that patients undergoing rule-out diagnostic procedures perceive more uncertainty than medical and surgical patients with determined diagnoses (pg.262). The uncertainty may be related to the surgical procedure, threat of breast cancer, or risk of benign breast disease developing into cancer. Since the breast biopsy procedure is generally performed on an out-patient basis the nurse must provide emotional support, breast health education, perioperative

care, and follow-up information during the patient's brief but emotionally intense surgical encounter.

Northouse et al. (1995) found that 42% of the variance in distress levels of women having a breast biopsy was accounted for by concurrent stress, lower education, hopelessness, and uncertainty. As well, anxiety levels were found to be three times higher for women awaiting a breast biopsy than for the normal population. Much of the uncertainty and anxiety experienced by a woman having a breast biopsy is related to the risk associated with developing breast cancer.

Benign breast conditions are illustrative of the ambiguities of risk. There is an inherent degree of uncertainty in assessing risk related to breast cancer risk factors. Controversy between epidemiologists and clinical medical practitioners surrounds the determination of risk and influences the interpretation of a benign breast condition symptom and the breast care regimen. The prevalence of breast tissue changes is not necessarily indicative of a disease process but does raise concerns about the significance of risk factors for developing breast cancer related to a benign breast disease diagnosis. A benign-malignant continuum provides a framework for interpreting the risk of benign breast condition developing into breast cancer (McDivitt, Stevens, Lee, Wingo, Rubin, Gersell, & the Cancer Steroid Hormone Study Group, 1992; Sinclair, 1988).

A woman's subjective interpretation of the risk may also

differ from the medical practitioner's perspective (Cohen, 1993; Janes, Stall, & Gifford, 1986). A benign breast condition diagnosis alters a woman's perception of health and illness because risk is now experienced as a symptom of hidden future illness which transforms her into a new physical state of "ill-health" (Janes et al., 1986). Nursing education and support during the diagnostic phase and follow-up care is imperative for women contending with continual cancer surveillance of benign breast changes coupled with inconclusive determination of individual risk factors.

The psychosocial impact on a woman who discovers a breast lump is intense regardless of the expected pathological outcome of the biopsy. A focus on women's breast health is popular as advances in diagnostic technology, alternative treatment regimes, feminist movement, and public anxiety about breast cancer gain media attention and momentum. Nursing concerns for breast health relate to issues of early detection, emotional support related to fear of breast cancer and diagnostic tests, and appropriate follow-up care for women with a benign breast condition. Provision of accurate knowledge and skills to discover and determine the appropriate health care behaviours for self-discovered breast changes must be facilitated and shared with women in meaningful ways.

Breast cancer symptoms can produce a prolonged stress response that may weaken normal physiological functioning. This response is contrary to the stress response's intended

protective purpose of restoring and maintaining homeostasis. Anxiety is a behavioral expression of the stress response. Unconscious mental processes including anxiety have been found to contribute to symptom presentation delay (Magery, Todd, & Blizzard, 1977).

Delay in presentation of a breast cancer symptom can have a negative impact on women who are diagnosed with a benign breast condition as well as a malignant disease. Anxiety about the threat of a breast cancer diagnosis can result in a stress response that may inhibit a woman's ability to present the symptom to a health care professional. Prolonged stress has been implicated in increased risk for developing illnesses that include immune diseases, cardiac illnesses, psychosocial problems, endocrine disorders, infectious diseases, and gastrointestinal diseases, and cancer (Fagin, 1986). Nursing interventions that provide accurate information and promote prompt presentation will aid in managing the uncertainty and anxiety associated with a breast biopsy for definitive diagnosis.

#### Conceptual Framework

Mishel's Uncertainty in Illness Theory is an appropriate conceptual model to use when studying women after a benign breast biopsy procedure. Mishel's Uncertainty in Illness Model has been used to study various classifications of patient illnesses including rheumatoid arthritis (Bailey & Nielsen, 1993), benign (Warrington & Gottlieb, 1987) and

malignant (Mishel & Sorenson, 1991) gynaecological disease, children with chronic illnesses (Cohen, 1993; Wiener & Todd, 1993), coronary bypass surgery (Redeker, 1992), and breast cancer (Hilton, 1989; Wong & Bramwell, 1992). Cognitive appraisal of uncertainty has not previously been studied with women experiencing a benign breast biopsy. The management of uncertainty associated with the diagnosis of a breast lump constitutes an integral component in the successful adaptation of an illness and its treatment.

Mishel (1988) described the components of this middle range theory of uncertainty. Uncertainty is defined as "the inability to determine the meaning of illness-related events" (Mishel, 1988, p.225). The purpose of the uncertainty theory is to explain how patients cognitively process illness-related stimuli and construct meaning for these events. Uncertainty can take many forms, some of which are related to the ambiguity concerning the state of the illness, complexity regarding treatment and the system of care, lack of information about the diagnosis and its seriousness, as well as unpredictability about the disease course and prognosis (Mishel, 1988; Mishel Padilla, Grant, & Sorenson, 1991).

Three major antecedents of uncertainty in the Uncertainty of Illness Model (Appendix A) include stimuli frame, structure providers, and cognitive capacities. Components of the stimuli frame encompass (a) symptom pattern, (b) event familiarity, and (c) event congruence. Symptom pattern, event

familiarity, and event congruence are inversely related to uncertainty and provide different types of information about the illness (Mishel, 1988, p. 225). The symptom pattern information relates to physical sensations experienced, event familiarity is concerned with the actual health care environment, and event congruence is affected by the predictability and stability of the stimuli.

Knowledge of symptom pattern is important for a patient to assess the consistency, saliency, and distinguishability of a breast cancer symptom. Evaluation of the symptom pattern regarding the number, intensity, frequency, duration, and location of symptoms serves to reshape the interpretation and reduce the ambiguity. Symptom pattern in benign breast conditions can be inconsistent as lumps appear and disappear with a woman's menstrual cycle and are sometimes accompanied by tenderness, pain, and warmth. It is difficult to discern a specific pattern that represents a risk of breast cancer with such ambiguous symptoms.

Event familiarity is developed over time through experiences within the structure of the health care environment. Components of event familiarity include the health care environment, complexity of cues, and novelty of events. Interpretation of the uncertainty is affected by information related to a previous illness experience, familiarity with a health care practitioner, as well as cultural and social factors. Complexity of cues resulting

from multiple tests in a diagnostic work-up for a breast lump can increase uncertainty.

The concepts of novelty and complexity interact with event familiarity, with novelty being surmised to generate uncertainty (Mishel, 1988; Scott, 1983). A woman's first experience with a breast cancer symptom and the diagnostic regimen to assess a breast lump can increase feelings of uncertainty. Event familiarity in breast disease can render the discovery of a breast lump a signal for medical attention, the threat of a devastating disease, or both. Appraisal of the appropriate health care behaviour for a self-discovered breast lump can depend upon the woman's personal or previous experience with a loved one's breast disease.

Event congruence refers to the consistency between the expected and the experienced in illness-related events and is indirectly related to the uncertainty (Mishel, 1988, p.225). Event congruence affects the perceptions of predictability and stability of events (Mishel, 1988, p. 227). A previously successful experience with a doctor being able to accurately assess and advise a loved one about a breast cancer symptom will provide a woman with knowledge and trust in the health care system during the diagnostic assessment of her breast lump. The uncertainty is subsequently reduced when the patient recognizes a pattern of symptoms and diagnostic tests that can be accurately and meaningfully interpreted.

Familiarity with a diagnostic process that facilitates

the expected outcomes being congruent with the information obtained by the health care professional throughout the process also diminishes uncertainty. A number of uncontrolled factors can influence event congruence including unmet expectations of cure, unforeseen reoccurrence, limited treatment effects (as with radiation therapy), and unexpected rapid changes. Symptoms of a disease or treatment side effects that affect memory and skills can influence one's cognitive capabilities and compromise the decision making process. Scott (1983) found that patients (n=85) experienced higher anxiety and lower critical thinking capability during a breast biopsy than after the procedure. The high anxiety associated with the threat of breast cancer can affect a woman's cognitive skills and ability to comprehend and subsequently act on breast health information.

Stimuli frame components are positively affected by structure providers, antecedents to uncertainty which includes credible authority, social support, and education. Health professionals, family and friends who have experience with breast cancer, and educators serve as information sources that can directly and indirectly affect knowledge about the stimuli frame components. Credible authority is an essential component of uncertainty for women having a breast biopsy for definitive diagnosis. Patients rely on health care providers for clarification of diagnostic test results and interpretation of the meaning of symptoms and risk factors



associated with a breast cancer symptom. Suominen, Leino-Kilpi, & Laippala (1994) found that breast cancer patients (n=109) and nurses (n=125) held different perceptions of the nurse's role in providing information. Patients preferred that the physician provide information about breast cancer rather than nurses. This choice may impede the potential supportive and educative role of the nurse.

Structure providers (credible authority, social support, education) buffer uncertainty by providing a knowledge base, lay feedback mechanisms for appropriate interpretation of the symptoms, and trust/confidence in professional validation or judgements regarding symptoms and resulting care decisions (Mishel, 1988). Lauver (1992) suggests that trust and empathy, characteristics associated with quality health care, may explain some care-seeking behaviours of African-American patients. Support from both emotional and physical health resources provides a stable core serving to minimize the unpredictability of an outcome.

Social support can directly and indirectly influence ambiguity, complexity, and unpredictability factors related to uncertainty in illness (Mishel, 1988). Previous experience with a friend or relative's breast lump diagnosis can provide a frame of reference as the woman embarks on her diagnostic journey. However myths and inaccurate information, also provided by the support network, may be accepted and negatively affect health care decisions of women who self-

discover a breast lump.

Cognitive capacities, the third antecedent to uncertainty, can positively affect evaluation of the symptom pattern, event familiarity, and event congruence. Anxiety related to a pending biopsy for definitive diagnosis can interfere with a woman's information processing abilities. Information that is provided by health professionals may not be understood or retained at the time the woman experiences heightened anxiety related to the threat of breast cancer.

Uncertainty has been related to anxiety and depression in studies of pediatric intensive care, coronary care, and cancer patients (Mishel, 1988). A loss of credible authority, event unfamiliarity, and lack of symptom pattern can influence the anxiety associated with the appraised uncertainty. The relationship between the health care provider and the patient is deemed the major means for the prevention of uncertainty (Mishel & Braden, 1987).

The components of the uncertainty theory are supported by numerous studies and thus provide an impressive framework to evaluate uncertainty in women experiencing a benign breast biopsy. Patients' experiences of heightened uncertainty and anxiety provides support for ongoing exploration of these concepts and the development of nursing care strategies to promote successful adaptation. Evaluation of the uncertainty is important since uncertainty may be also perceived positively in certain situations if interpreted as hope

(Hilton, 1989, Mishel, 1987). Some women may prefer to live in the unknown rather than receive confirmation of a malignant diagnosis. Understanding uncertainty in benign breast disease biopsy experience will provide valuable information to support women undergoing a breast biopsy for a definitive diagnosis.

### Research Questions

1. What are the patterns of information needs of women who have experienced a breast biopsy with a benign breast disease outcome?
2. What is the level of uncertainty experienced by women who have had a breast biopsy with a benign breast disease outcome?
3. What is the level of anxiety experienced by women who have had a breast biopsy with a benign breast disease outcome?
4. Do women experiencing high levels of uncertainty related to a benign breast biopsy have a different pattern of information needs than women with low uncertainty levels?
5. Do women experiencing high levels of anxiety related to a benign breast biopsy have different patterns of information needs than women experiencing low anxiety?
6. Do women experiencing high levels of uncertainty related to a benign breast biopsy also experience heightened anxiety?

### Assumptions

The main assumption in this study is that women

experience heightened feelings of uncertainty and anxiety during a benign breast biopsy procedure. The elusive nature of breast cancer symptoms and inconsistent diagnostic test results can serve to escalate existing patient uncertainty and anxiety. Even if some women do not experience increased uncertainty and heightened anxiety, they will be presumed to be interested in accurate information related to benign breast condition and risks associated with developing breast cancer.

A bias may exist for some patients if they assume that medical practitioners are capable of accurately determining risks and providing control and stability of breast cancer symptoms. The Mishel Uncertainty in Illness Theory does not presently address chronic illnesses or the temporal variability of uncertainty (Mishel, 1990). Uncertainty associated with the diagnosis of a breast lump may be an evolving process that can be appraised as a positive, desirable state, a negative consequence, or fluctuate between the two appraisals.

#### Operational Definition of Terms

##### Uncertainty in Illness:

- "the inability to determine the meaning of illness-related events" as measured by the Mishel Uncertainty In Illness Scale - Community Form (Mishel, 1988). Scores for the MUIS-C Form range from 23 to 115. High and low uncertainty scores were determined by a split of the median scores (54) for the study sample.

**Anxiety:**

-a transitional emotional state aroused in a situation that presents a perceived threat to future health as measured by the State Trait Anxiety Inventory. High and low anxiety scores were determined by a split of the median sample scores for the state (51) and trait (36) anxiety scales.

**Information Needs:**

-the kinds of information required by the peri-operative female patient who has experienced a breast biopsy with a benign outcome.

**Breast Biopsy:**

-the surgical excision of a suspicious lump in a breast which provides the only means of definitive diagnosis.

**Chapter Summary**

Although the outcome of a breast biopsy is usually negative, the diagnostic journey of a breast lump remains an emotional event for a woman. Numerous definitions and histological variations of breast tissue changes illustrate the challenges of determining the risks associated with developing breast cancer. The increasing incidence of breast cancer and higher mortality rates associated with a younger woman being diagnosed fuel the uncertainty and anxiety associated with the evaluation of a breast cancer symptom.

The diagnostic process for determining the pathology of a breast lump is fraught with delays, inconsistent test results,

and an inability to accurately assess individual risk factors for breast cancer. Although a breast biopsy, performed at the end of an anxious diagnostic journey, provides a definitive diagnosis it is also accompanied by the added stress of having to endure a surgical procedure. Peri-operative nursing care must encompass quality education and emotional support for patients within the constrained ambulatory timeframe of same day surgery.

## CHAPTER TWO: LITERATURE REVIEW

### Introduction

A review of research related to the definition, prevalence, types, and possible causes of benign breast condition was conducted. This chapter synthesized literature related to the nature of benign breast disease, breast cancer risk factors, diagnostic tests, surgical breast biopsy, information needs, uncertainty in illness, and anxiety.

### Benign Breast Disease

Benign breast disease (BBD) is the diagnosis given to a lump that presents as a palpable thickening, localized swelling, or change in the breast. Wide variations in normal breast tissue are commonly diagnosed as fibrocystic breast condition for over 50% of women during their reproductive years (Baron & Walsh, 1995; McDivitt et al., 1992; Sinclair, 1988). Histological confirmation of benign breast disease is evident in 90% of all surgical breast biopsy cases clinically diagnosed as fibrocystic breast disease (Janes et al., 1986; Norwood, 1990; Palmer & Tsangeris, 1993). Other types of benign breast conditions include simple cysts, fibroadenoma, papilloma, mastitis, and trauma that may result in hematoma or fat necrosis (Black & Matassarini-Jacobs, 1993).

Benign breast disease is a term that encompasses various histological changes in breast tissue. Controversy exists over the labelling of benign breast changes as disease because of the prevalence (50%) of these changes in the adult female

population (Baron & Walsh, 1995; Link, 1993; McDivitt et al., 1992; Sinclair, 1988). Medical opinions also vary regarding the evaluation of the significance of breast changes in relation to increasing risk for developing breast cancer. A review of breast anatomy and the various types of benign breast conditions will illustrate the complexity associated with diagnosis and treatment of benign breast disease.

### Breast Anatomy

The breast; an endocrine target organ whose primary function is to produce milk; is composed of adipose tissue, fibrous tissue, connective tissue, and mammary glands (Ellerhorst-Ryan, Turba, & Stahl, 1988). Fifteen to 25 lobes containing lobules and acini make up the glandular portion of the breast (Ellerhorst-Ryan et al., 1988; Reifsnider, 1990). Mammary glands are clusters of glands that produce milk during pregnancy and breast feeding. Mammary glands empty into a system of alveolar ducts that extend to the nipple. The breast's lymphatic drainage system consists of lymph nodes that are small kidney shaped glands linked in chains throughout the body. Two chains of lymph nodes drain the breast; the first is a larger chain that extends up under the axilla and the second is a smaller chain that reaches deep into the breastbone.

The pectoralis muscle lies directly under the breast, extending from the sternum up to the clavical and axilla, from just above the first rib down to the sixth rib. The



superficial fascia lies between the pectoralis major muscle and the adipose tissue which serves to encase and support the breast. The amount of adipose tissue present is related to the woman's age and weight with breasts tending to become softer and more droopy with age due to the large fat content.

Breast tissues changes are related to hormonal fluctuations throughout a woman's life. Estrogen and progesterone play a role in the growth of ductal tissue and glandular tissue respectively (Reifsnider, 1990). Seven of the common types of benign breast diseases will be outlined next (Black & Matassarini-Jacobs, 1993; CCS, 1995; Link, 1993; Miers, 1991; Reifsnider, 1995).

#### Fibrocystic Breast Disease

Norwood (1990) defined fibrocystic breast disease (FBD) as "a benign condition characterized by cyclically fluctuating palpable irregularity of the breast tissue accompanied by pain and tenderness that becomes progressively worse until menopause" (p.116). FBD is a term commonly used to describe benign breast changes that occur in 50% of all women of reproductive age (Link, 1993). Alternate, although less familiar, names such as mammary dysplasia, fibrocystic mastopathy, and chronic cystic mastopathy are given to a condition producing symptoms that include pain, tenderness, lumps, and/or nipple discharge.

Fibrocystic breast condition is the most common cause of breast lumps in women 35 to 50 years of age but can affect

women in their middle 20's through menopause. Although unknown, the cause of fibrocystic breast condition is thought to be related to normally elevated hormone levels before menstruation that produce fluid which is not properly drained by the lymph system. A fibrocystic breast disease diagnosis accounts for 80% of all surgical breast procedures performed.

A breast biopsy is indicated when additional breast cancer risks require definitive determination of a benign or malignant condition. A breast biopsy provides histological evaluation of the lump to better understand the patient's risk for developing breast cancer. Ductal and lobular hyperplasia are indicative of a pre-cancerous condition. Ductal hyperplasia is found in 20% of all breast biopsy specimens. Atypical lobular hyperplasia is found in 1% of all breast biopsy specimens.

#### Simple Cysts

Cysts are single or multiple fluid-filled sacs, lined by epithelial cells, that occur occasionally during the 20's and repeatedly during the 30 and 40 year age group. No significant increase in fibrous tissue occurs with cyst development, however they can be quite painful. The fluid aspirated from cysts can provide information about the length of time the cysts have been present, relieve the tenderness, and be used for cytological evaluation. The colour of the fluid changes from straw, to dark green in new and older cysts respectively. Dark red fluid may indicate either a recent

trauma or possible malignancy (Ellerhorst-Ryan et al., 1988; State, 1991). A sonogram is done to distinguish between fluid-filled cysts and solid masses. Solid masses and recurring cysts are routinely biopsied.

### Fibroadenoma

Fibroadenoma is the breast lump of younger women, usually occurring between 18 to 35 years of age, although menopausal women can be diagnosed with a fibroadenoma. Characteristics of a fibroadenoma include factors such as solid, painless, slow-growing, moveable, rubbery texture, and usually range from 1 to 5 cm in size. They are surgically removed in younger women if they cause tenderness or increase in size in order to prevent the need for a larger scar in the future. Fibroadenomas are generally removed in women over 35 years of age or if there is a familial history of breast cancer. Although fibroadenomas can decrease in size with age they can calcify over time and appear as coarse calcifications on mammogram; thus mimicking malignancies (Link, 1993).

### Papilloma

Papillomas usually occur in a woman's fourth decade of life. Intraductal papillomas are lesions (2 to 3 mm) growing in the terminal portion of the duct or throughout the duct system of a sector of the breast. Papillomas can be solitary, multiple, or intraductal. Nipple discharge; the presenting symptom of a papilloma; can be clear, white, green, or bloody coloured, and is not significant if it does not occur

spontaneously (Link, 1993). A galactogram or ductogram is a diagnostic means of locating the papilloma or confirming the diagnosis.

Solitary intraductal papillomas are usually benign. Multiple papillomas are occasionally cancerous. Intraductal papillomas present with a serous, serosanguinous, or bloody nipple discharge. The mass is often not palpable, however sometimes a small, soft tumor can be felt in the central or periareolar portion of the breast. A biopsy is always performed on a papilloma in order to rule-out a carcinoma.

#### Mastodynia and Mastalgia

Breast pain is the most common breast complaint. Fortunately, pain is not usually associated with cancer. Pain and tenderness of the breast are usually associated with high caffeine intake, high salt and high fat diet, lack of exercise, and/or poor bra support.

#### Mammary Duct Ectasia

Duct ectasia is a disease of the ducts in the subareolar zone that usually occurs around menopause. Symptoms include a thick, sticky nipple discharge, burning, itching, and inflammation. Cellular debris accumulates in the duct where the epithelial lining breaks down. Although duct ectasia is not associated with breast cancer, a breast biopsy is performed since cancer can present in a similar manner.

#### Breast Feeding Problems

Breast feeding problems include lactation mastitis,

nipple fissure, and breast abscess. Bacteria enter the mammary ducts through a cracked nipple causing an induration and an infection (mastitis). Antibiotics, analgesics, warm, moist compresses, and lanolin-based, bland creams applied to the nipples are means of treating breast feeding problems. Continued frequent breastfeeding or manual expression of the milk is recommended to prevent engorgement.

The numerous types of benign breast conditions make it difficult to determine the reason for changes in the breast tissue. A number of etiological theories have attempted to explain the cause of fibrocystic breast condition by linking it to estrogen and progesterone levels, luteal-phase deficiency of progesterone, prolactin levels, and/or methylxanthines such as caffeine (Norwood, 1990). However, inconsistent results, that have impeded an accurate understanding of the causes of fibrocystic disease, do not provide clear direction for dependable treatment regimens.

Although the etiology of benign breast changes remains an unresolved issue, the various types of breast lumps can be attributed to higher risk for women at different ages. Robbins et al. (1984) grouped causes of breast masses according to age in order of prevalence (Black & Matassarini-Jacobs, 1993). Women under 35 years of age experience breast lumps due to fibrocystic condition, fibroadenoma, mastitis, traumatic fat necrosis, and carcinoma of the breast. Between 35 and 50 years of age breast masses are caused by fibrocystic

condition, carcinoma, fibroadenoma, traumatic fat necrosis, mastitis, and papilloma. Women over 50 years old are most likely to have lumps diagnosed as a carcinoma first, then fibrocystic condition, fat necrosis, Paget's disease of the breast (1% to 4% of breast cancers), mastitis, and lastly papilloma (Black & Matassarini-Jacobs, 1993).

Alleviating symptoms associated with fibrocystic breast condition is an important aim of treatment and follow-up care. However, a prime concern of health professionals is the determination of the patient's relevant risk for breast cancer. A non-specific pathologic diagnosis of fibrocystic breast condition has limited meaning because it does not recognize the benign-malignant continuum of breast tissue changes. Sinclair (1988) advocated a more comprehensive approach delineating the multi-stage development of cancer from normal cells, through hyperplasia, dysplasia, and carcinoma-in-situ. Breast cancer risk factors are associated with a woman's age and as such age can be one determination of the need for a breast biopsy.

Some researchers have interpreted benign breast conditions according to Dupont and Page's classifications depicted on a continuum with breast cancer (McDivitt et al., 1992; Sinclair, 1988). Tissue changes and cancer risk were proposed to involve a multi-stage process from normal cells through hyperplasia, dysplasia, carcinoma-in-situ to the development of invasive carcinoma (Sinclair, 1988). Varying

histological changes found in benign breast conditions may represent different degrees of risk for developing breast cancer. Histological benign breast changes, personal risk factors, clinical judgement, inconclusive diagnostic tests, and patient anxiety combine to influence the clinical decision to perform a breast biopsy.

The histological results of the breast biopsy have been useful in assessing a woman's risk for developing breast cancer. Hyperplasia refers to the number of cells in the epithelial lining with two cells being considered normal, between two and four cells representing mild hyperplasia, and moderate and florid hyperplasia are diagnosed with extensive epithelial proliferation (Miers, 1991). A diagnosis of atypical hyperplasia indicates evidence of lesions resembling carcinoma-in-situ without sufficient changes in the lesions to diagnose a cancer (Miers, 1991). Lobular carcinoma-in-situ (LCIS) is a pre-malignant lesion or marker indicating a 1% per year risk for developing breast cancer (Link, 1993). Ductal carcinoma-in-situ (DCIS) is a rapidly growing lesion that presents as a malignant calcification on mammogram and often requires mastectomy due to its diffuse and extensive involvement of the breast (Link, 1993).

Table 2 describes Dupont, Parl, Hartmann, Brinton, Winfield, Worrell, Schuyler, & Plummer's (1993) classifications of benign breast changes according to their relative risk of developing breast cancer.

Table 2

**CLASSIFICATION OF BENIGN BREAST DISEASES**

<b>HISTOLOGICAL CHANGE</b>	<b>INCREASE IN RISK</b>
NON-PROLIFERATIVE FIBROCYSTIC CHANGES	NO RISK
PROLIFERATIVE WITHOUT ATYPICAL CHANGES	TWO-FOLD INCREASE IN RISK
ATYPICAL HYPERPLASIA	FIVE-FOLD INCREASE IN RISK
CARCINOMA-IN-SITU	TEN-FOLD INCREASE IN RISK
FIBROADENOMA WITH ATYPICAL HYPERPLASIA	INDEPENDENT RISK FACTOR

The classification of 1) non-proliferative fibrocystic changes affords no risk, 2) proliferative without atypical changes assumes a two-fold increase in risk, 3) atypical hyperplasia carries a five-fold risk, and 4) carcinoma-in-situ is associated with a ten-fold increased risk of developing breast cancer. Understanding the prevalence of benign breast changes in relation to determining the significance of the histological variations is a difficult challenge for physicians who endeavour to evaluate individual risks in order to determine appropriate health care strategies. The nursing role must provide ongoing emotional and informational support of benign breast biopsy patients to ensure appropriate follow-up care is heeded. The nature of the nurse-patient relationship affords many opportunities for emotional support and education throughout the health care process of diagnosing



and treating benign breast conditions.

### Epidemiology

From an epidemiological perspective every adult female has a one in nine chance of developing breast cancer in her lifetime. However, the relationship between benign breast condition and the development of breast cancer has not been conclusively determined. Benign breast condition, evident in over 50% of women of reproductive age, produces variations in normal breast tissue which may be influenced by age, hormones, heredity, dietary, and environmental factors (Colditz, 1992; McDivitt et al., 1992; Sinclair, 1988).

The prevalence of breast tissue changes suggests that benign breast condition may be a normal change and not necessarily represent a disease process. Although some researchers speculated a general association between benign breast disease and breast cancer, the significance of benign breast condition as a risk factor for developing breast cancer has not been determined (Janes et al., 1986). Certain benign breast changes combined with other risk factors such as age, family history, diet, alcohol consumption, cigarette smoking, reproductive history, and hormone replacement contribute to the need for a breast biopsy to rule out a breast cancer diagnosis.

Age is the only breast cancer risk factor that universally affects all women. Breast cancer can develop in the absence of risk factors in up to 25% of diagnosed cases

(Schifeling & Hamblin, 1991). However, research on additional risk factors to the baseline breast cancer risk of age remains inconclusive (Baron & Walsh, 1995; Spratt, Greenberg, Kuhns, & Amin, 1989). Translating an epidemiological risk ratio for breast cancer (1:9) into a meaningful clinical evaluation for an individual woman's risk remains a difficult challenge for physicians. The uncertainty inherent in accurately assessing numerous risk factors can result in anxiety and fear about a woman's current and future state of breast health (Miers, 1991). This resulting uncertainty and anxiety persist as a woman continues her journey through the diagnostic breast biopsy experience.

#### Histological Determinants

A specific pathologic diagnosis of fibrocystic breast condition is required to accurately and meaningfully assess breast tissue changes (Sinclair, 1988; McDivitt et al., 1992). A benign-malignant continuum is considered a more appropriate means of evaluating the various classifications of benign breast condition. Sinclair (1988) advocated a change from the rigid dichotomous classification of breast lesions as either being benign or malignant to a comprehensive approach that delineates the multistage development of cancer from normal cells, through hyperplasia, dysplasia, and carcinoma-in-situ.

Various researchers have studied the risks associated with different classifications of benign breast condition by retrospectively reviewing histologic slides (Dupont et al.,

1993; London et al., 1992; McDivitt et al., 1992; Sinclair, 1988; Spratt et al., 1989). Classification criteria previously developed by Dupont and Page to facilitate the determination of risk for developing breast cancer in women with benign lumps were used as guidelines by these researchers. Four stages of benign breast condition were determined according to their relative risk of developing cancer. Non-proliferative fibrocystic changes afforded no risk, proliferative without atypical changes assumed a two-fold increase risk, atypical hyperplasia carried a five-fold increase risk, and carcinoma-in-situ was associated with a ten-fold increased risk of developing breast cancer (Lay, Crump, Frykberg, Goedde, & Copeland, 1990; Sinclair, 1988).

Other researchers have employed case-control designs to evaluate risk for breast cancer in relation to benign breast disease (Dupont et al., 1993; London et al., 1992; McDivitt et al., 1992). Findings from breast biopsy slide reviews showed that the majority of benign breast disease patients were at no risk, whereas a family history associated with atypical hyperplasia contributed to a significant increase in risk for developing breast cancer. London et al. (1992) found that premenopausal women with atypical hyperplasia were at a higher risk of developing breast cancer. Differences in the age of subjects and limited availability of slide acquisition may have contributed to slight variations in results compared to previous research findings. McDivitt et al. (1992) determined

that fibroadenoma presented as an independent risk factor and, when coupled with atypical hyperplasia, placed the patient at the greatest risk for developing breast cancer. Limited retrieval of breast biopsy slides in this study may also have biased the findings.

#### Personal Risk Factors

Controversy exists about the importance of specific and multiple risk factors associated with the development of breast cancer. Although the majority of breast cancers develop in the peri-menopausal stage, women between the age of 20 to 40 years are believed to also be at risk. Swanson (1993) studied survival patterns of younger women (<40 years) with breast cancer and found that both lay and clinical misconceptions about the incidence of breast cancer in this age cohort resulted in presentation and treatment delays. Black women from 15 to 19 years of age were found to have an increasing prevalence of breast cancer until the age of 85 years. There was a continuous rise in breast cancer for white women from 20 to 24 years of age through 75 to 79 years. An analysis of young women between the ages of 20 to 49 years (23%), from a sample of 77,368 subjects who died from breast cancer, revealed an indirect relationship between age at diagnosis and survival rate.

Colditz (1993) retrospectively reviewed data from the Nurse's Health Study on Breast Cancer to evaluate risk factors for breast cancer. Current use of oral contraceptive and

post-menopausal hormones increased the risk for breast cancer by 53% and 36% respectively. Conversely, Rohan, L'Abbe, & Cook, (1992) conducted a case-control study that did not support an association between the use of oral contraceptives and an increased risk of proliferative forms of benign breast disease. Findings from Colditz (1993) also suggested that cancer risks varied with the histopathological differentiations and were further increased among premenstrual women as well as those with a family history of breast cancer.

Obesity, although inversely related to risk in pre-menopausal women, provided an increased risk in post-menopausal women. Adolescent nutrition was shown to possibly have a long-term impact on growth and cancer risk. Use of permanent hair dyes, cigarette smoke, breast feeding, consumption of dietary fat, and selenium intake showed no significant increase in risk for developing breast cancer in this study. Assumptions based on the influence of estrogens, lactation, and environmental factors for increasing risk factors were not supported by the findings (Colditz, 1993).

Spratt, Greenberg, Kuhns, & Amin (1989) reviewed risk factors such as age at first birth, nulliparity, breast size, family history, and previous malignancy to determine a woman's risk for developing breast cancer and appropriate follow-up care. Family history risk did not differ for pre- or post-menopausal women unless the relative diagnosed with breast cancer was a sister or had bilateral disease. Multiple

factors including family history, age at first birth and nulliparity, and large breasts combined to produce an increased risk when associated with breast biopsy showing proliferative changes with atypia. Evans, Fentinman, McPherson, Ashbury, Ponder, & Howell (1994) also noted that, although 4% to 5% of breast cancer cases were due to a familial gene, the heredity risk was more likely associated with early age at symptom presentation, multiple relatives with breast cancer, bilaterality, and a history of related cancers.

Schnitt, Jimi, & Kojiro (1993) studied histologic findings in two groups of 266 Japanese patients who had a breast biopsy for benign lump one decade apart (1974-75 & 1984-85). Results showed that the increase in breast cancer in Japan was coupled with an increase in benign proliferative breast disease. Young Japanese women (<40 years) had higher frequencies of benign proliferative breast lesions than the older population. Influence of the Western lifestyle such as changing dietary habits was presumed to affect this difference. Although the incidence of lesions with proliferative changes in Japanese women was less frequent than in American women, both countries experienced increases in benign and malignant tumors. Nursing must be concerned with proliferative changes that may be attributed to higher risk of developing breast cancer occurring in the younger (<40 years) female population.

Some physicians and patients advocate an extreme strategy to manage patients who have many factors contributing to a higher risk of developing breast cancer. Subcutaneous mastectomy for women with atypical hyperplasia, hereditary factors, and multiple breast biopsies is sometimes perceived to be an acceptable means of removing the risk and preventing the development of breast cancer. However, the use of surgical treatment as a preventive treatment is alarming to many physicians. Concerns focus on a faulty assumption that all the breast tissue containing risk can be definitely removed with a subcutaneous mastectomy (Janes et al., 1986; Spratt et al., 1989). If most of the tissue at risk remains on the chest wall the perception of prevention and cure could be misleading and may result in relaxed follow-up care with subsequent development of later stage cancer. Women need to be well-informed of the capability and consequences of such treatment choices so that perceived certainty of the removed risk is not overshadowed by realistic assessment of the limits and side effects of such a dramatic procedure. Nurses must be adequately informed and prepared to thoroughly review explanations of surgical procedures and address issues related to benefits and risks of preventive treatment choices.

#### Diagnostic Tests

Patients undergoing breast biopsy for a benign lump have previously been subjected to one or more diagnostic screening tests. Advances in various technologies have improved early

detection rates which have a positive effect on long-term survival rates. An increase in the number of breast biopsies has resulted from the use of mammogram, fine needle aspirations, needle localizations for non-palpable lesions, and sonography. Each diagnostic test has an appropriate place in the evaluation process but none can stand alone for a definitive diagnosis that is both accurate and reliable.

Whenever there is any concern about the diagnosis based on preliminary screening tests an open breast biopsy is warranted (Palmer & Tsangeris, 1993). The patient's uncertainty and anxiety can escalate throughout the diagnostic process of enduring numerous procedures performed by a variety of unfamiliar health care professionals who are unable to assess the absolute likelihood of the threat of cancer. Perioperative nurses must appreciate the emotional toll of the diagnostic process as the patient embarks on her final segment of the diagnostic journey in the operating room.

Empirical research does not support the use of a single technique for diagnosis since each technique is associated with inaccurate results in a high proportion of cases (Nyirjesy & Billingsley, 1992). A diagnostic triplet consisting of physical examination, mammography, and fine needle aspiration provides the most reliable test combination. The diagnostic triplet has an accuracy rate of 98% to 99% with three negative results (Palmer & Tsangeris, 1993). The fine needle aspiration represents the weak link in the diagnostic



triplet (Winchester, 1990). However, a suspicious result on any single test is sufficient reason to schedule an open breast biopsy.

Benefits of early detection and advances in treatments, producing improved survival rates, have been countered by the rising incidence of breast cancer. Early detection by mammogram screening that is capable of distinguishing tumors under 2 cm. in diameter may contribute to the rising incidence of breast biopsy procedures. Mammograms are a valuable diagnostic aid in detecting small and non-palpable lesions that are favourably responsive to more conservative treatments. However, this technique is not as valuable in the assessment and evaluation of breast lumps in younger women who have denser breasts which are more difficult to assess radiologically.

Winchester (1990) evaluated management approaches of breast lumps based on implications of screening and clinical findings. Table 3 displays a summary of the strengths and weaknesses of the diagnostic screening techniques used for evaluation of benign breast disease. The false positive and false negative rates for each test are also identified in the table.

Table 3

**DIAGNOSTIC SCREENING TECHNIQUES  
FOR BREAST DISEASE**

TEST/PURPOSE	FACTORS AFFECTING ACCURACY	FALSE NEG RATE	FALSE POS RATE
Physical Examination  Key assessment for palpable mass	Clinical expertise Small lesions hard to feel especially in large breasts Overestimates true proportion of masses assessed as cysts	5%	0%
Mammography  Evaluation of subclinical pathology	No standard guidelines for younger women Younger women have denser breasts that limit evaluation Fibrocystic breast disease can mimic malignant appearance Unable to definitively assess if clinical lesion is benign (10% of breast cancers can mimic well-circumscribed benign lesions) Not to preclude breast biopsy with palpable mass Confusing results if x-ray is not delayed 2 weeks after aspiration	5-10%	
Fine Needle Aspiration  Aspiration of cysts Evaluation role of breast mass not clearly defined	Technical expertise Attainment of good cytological specimen Availability of an experienced cytopathologist May be a definitive diagnosis for benign cysts Medullary cancers can mimic cysts	10%	0-4%

TEST/PURPOSE	FACTORS AFFECTING ACCURACY	FALSE NEG RATE	FALSE POS RATE
Sonography Detection of cysts Localization of deeply situated cysts for aspiration	Differentiation of non- palpable mammographically detected mass Must have follow-up mammogram 2 weeks after aspiration of cyst Not used for evaluation of solid cysts	10%	
Diagnostic Triplet  To identify patients not needing an open biopsy To evaluate women refusing open biopsy	1) Physical examination 2) Mammography 3) Fine Needle Aspiration  Fine needle aspiration is the weak link Suspicious result of any of the three tests dictates an open breast biopsy Three negative results gives a 98-99% accuracy rate	1-2% with 3 neg	
Open Breast Biopsy  Definitive diagnosis Different- iation of benign biopsy to identify prolifera- tive pathology	Relatively low mortality rate Representative sample with appropriate tissue margins Accuracy of pathological assessment	0%	0%

A physician breast examination (PBE) is a generally perceived to be a valuable assessment for a palpable mass. However, the PBE has a 5% false negative rate that is attributed to factors such as clinical expertise, the difficulty in identifying small lesions in large breasts, and a tendency to overestimate the true proportion of masses as cysts.

Standard guidelines for mammography are only available for women over 40 years of age (Owen & Long, 1989). Younger women (<40 years) have denser breasts that make interpretation difficult and limit the use of mammogram for this age cohort. Mammography can produce false negative results in 5% to 10% of cases since fibrocystic breast condition can mimic a malignancy on x-ray and 10% of breast cancers can present as well-circumscribed benign lesions. A mammogram should be delayed for two weeks after a fine needle aspiration to prevent confusing results.

A fine needle aspiration requires technical expertise to attain a good cytologic specimen and the availability of an experienced cytopathologist for interpretation. Although a fine needle aspiration may be a definitive diagnosis for benign cysts, caution must be exercised since medullary cysts can mimic cancers. False negative rates can be as high as 10% for fine needle aspiration while a false positive rate can range from 0% to 4%. A sonogram which yields a 10% false negative rate, is used to detect cysts that are deeply situated and to identify a non-palpable mammographically detected mass. A follow-up mammogram is required two weeks after aspiration of a cyst. A sonogram is not used for the evaluation of solid lesions.

#### Ambulatory Care

Many studies have examined the questions of who performs which tests in what location to provide accurate, reliable

diagnostic results in combination with continuous, quality care. Mitchell & Homer (1982), Nyirjesy & Billingsley (1992), and Lee (1986) purported that the Gynaecologist's office is an appropriate place for diagnostic evaluation of breast abnormalities. A Gynaecologist, as the primary physician for many women, made this setting conducive to timely and continuous emotional and physical care within an established trusting relationship.

Mitchell and Homer (1982) cited objections to managing breast biopsy care in the Gynaecology office. Concerns related to the possibility of implanting tumor cells at the time of biopsy, the technical inability of the physician, and the possibility of denigrating the importance of the breast biopsy (pg. 128). Lee (1986) described the Gynaecologist as having a clear role and skill expertise to manage the diagnostic aspects of breast assessments ranging from physical exam through biopsy procedure. However, the General Surgeon was considered to have the training, skill expertise, and accepted domain for performing further surgical treatments.

Mitchell and Homer (1982) studied 144 of 146 breast lumps that were correctly diagnosed by mammography resulting in 46 malignant lesions and 97 benign lumps. Needle localization was performed on non-palpable lesions. Nyirjesy & Billingsley's (1992) larger sample of 500 patients showed that fine needle aspirations and sonography were good extensions for a clinical assessment accompanied by a mammogram.

Sonograms were shown to be useful for accurate detection of cysts (175/189 cysts) that can then be treated by fine needle aspiration.

Homer, Smith, & Marchant (1984) and Nyirjesy & Billingsley (1992) determined mammography to be the standard cancer screening tool because it can identify minimal cancers that produce microcalcifications. Minimal cancers have a favourable long-term survival rate. Cysts may also coexist with carcinomas which warrants use of a mammogram. However, the mammogram should be postponed for 2 to 3 weeks after an aspiration to prevent confusing imaging findings.

Homer et al. (1984) and Smith & Ghani (1986) examined biopsies of non-palpable lesions using percutaneous needle localizations. Both samples were small (n=97 & n=109 respectively) which limits the generalizability of findings. The authors reported that most non-palpable lesions are benign, making this approach cosmetically appealing. The study demonstrated the importance of good communication between the radiologist and surgeon in determining the success of the localization. Factors affecting needle aspiration results included the aspirator's level of experience and individual technique employed, availability of skilled cytopathologists, and the quality of the aspirate obtained.

Zuk, Maudsley, & Zakhour (1989) and Griffith, Kern, & Mikkelsen (1986) evaluated fine needle aspirations done on an outpatient basis. Zuk et al.'s, (1989) smaller sample (n=180)

showed that the clinical examination tended to overestimate the true proportion of masses assessed as cystic. Thirty-two of 137 solid lesions were accurately predicted on clinical examination to be malignant. There was one false positive result while the false negative rates ranged from 12.5% to 29.4%. The average false negative rates ranged from 4% to 48% and were dependent on clinical assessments, aspirator skill level, and size of the tumor. Small (<2cm) and very large tumors have lower rates of positive cytological detection.

Griffith et al.'s (1986) larger sample of suspicious lesions (n=335) were grouped into positive, suspicious, and benign categories. A number of factors limit the reliability and validity of this study. These include a low (63%) accuracy rate, no false positive results, a 10% rate of biopsy or follow-up refusal, and diagnostic conservatism which produced lower proportions of definite abnormal diagnosis.

Many researchers supported the use of mammogram, sonograms, and fine needle aspirations in outpatient settings for diagnosis of breast lesions (Bell, Hadju, Urban, & Gaston, 1983; Griffith et al., 1986; Homer et al., 1984; Smith & Ghani, 1986; Zuk et al., 1989). The outpatient setting permitted diagnosis in a safe, efficient, cost effective manner. It also provides a high rate of accuracy and reliability when a diagnostic combination modality was used, provides patient and family counselling services, fosters patient participation in the decision-making process, allows

for evaluation of metastases at a lower cost, encourages team coordination, and receives good patient acceptance (Nyirjesy & Billingsley, 1992, Mitchell & Homer, 1982; Lee, 1986; Homer et al., 1984; Smith & Ghani, 1986).

### Breast Biopsy

A breast biopsy is considered to be a minor surgical procedure, usually performed on an outpatient basis, resulting in a negative outcome in most (80%) cases. However, the subjective surgical experience can be laden with anxiety and fear for a woman who must also contend with the threat of breast cancer. The importance of the role of the breast care nurse has recently received attention as the patient's feelings of uncertainty and anxiety during the diagnostic phase of a breast lump are recognized as significant health issues (Barrere, 1992; Hirst & Whitehead, 1984; Kelly, 1993; Lay et al., 1990).

Barrere (1992) studied the role of the Oncology Clinical Nurses Specialist (OCNS) and the use of goal-directed communication techniques for assessing and supporting a breast biopsy patient's pre-operative anxiety. Techniques employed by the OCNS such as rephrasing, personalizing, and confrontation were found to lessen pre-operative anxiety and provide direction for appropriate resource suggestions before diagnosis. The OCNS also provided support through the use of refocusing and facilitation techniques prior to the biopsy.

Specific nursing interventions were used after a



diagnosis of benign, pending, or malignant was learned. The OCNS employed focused counselling and teaching techniques to facilitate emotional coping and to encourage adherence to appropriate follow through breast health behaviours. A peri-operative nurse/patient interaction; lasting approximately 10 minutes; employed open ended questions to elicit expression of individual feelings, fears, assess family support, correct information, and determine the need for referral to the OCNS.

Breast cancer is the second leading cause of cancer death among women in the United States. Open biopsy for breast abnormality is the only definitive means of assessing malignancy. Leis et al. (1985) describe four reasons for performing a biopsy:

- 1) true three dimensional, dominant lumps even with negative screening results, except for cysts that can be aspirated;
- 2) suspicious mammographic lesions even with no clinical abnormalities;
- 3) breasts with yellow, pink, bloody, or watery nipple discharge in spite of no palpable mass and negative findings on mammogram or aspiration;
- 4) those with other signs of cancer that cannot be explained on a benign basis such as skin or nipple changes, suspicious axillary nodes, and induration without infection. (pg. 115).

Palmer & Tsangaris (1993) reviewed 40 charts of women

under 30 years of age, where the probability of breast cancer may be low, but is not zero. Patient anxiety, difficulty in accurate physical assessment for younger women, and cosmetic results were important factors for consideration in this age cohort. Even though results confirmed a low breast cancer incidence of 2.5% in this sample, the importance of appropriate follow-up was advocated to avoid a misdiagnosis. Controversy exists about appropriate screening methods and management strategies for this younger age group of women.

Lay et al. (1990) examined the changing patterns of breast biopsy (n=1,342) over a five year period (1983 to 1987). Results showed that both mammography and surgical breast biopsy procedures were effective in identifying and treating an increasing number of nonpalpable lesions. Although 85% of the biopsies were benign, early detection of malignancies in 22 nonpalpable lesions were identified. Most (91%) of the nonpalpable lesions were diagnosed as carcinoma-in-situ and stage 1 breast cancer compared to 29.2% of the palpable carcinomas.

Fifty-eight patients diagnosed with breast cancer had previously undergone a total of 78 benign breast biopsies. In 30 cases one prior biopsy had demonstrated nonproliferative disease (n=16), proliferative disease without atypia (n=7), and atypical hyperplasia (n=7). Two prior benign biopsies on 22 of the 58 women showed nonproliferative disease (n=9), proliferative disease without atypia (n=6), and atypical

hyperplasia (n=7). Six of the women had three previous benign breast biopsies showing nonproliferative disease (n=3) and atypical hyperplasia (n=3) (Lay et al., 1990; p.81). An increase in the number of younger patients (<50 years) diagnosed with proliferative disease illustrated the need to individually assess a woman's risk for developing breast cancer and provide emotional and informational support throughout the breast biopsy experience.

Benedict et al. (1994a) retrospectively examined the effect of a benign breast biopsy on subsequent breast cancer detection practices such as breast self examination (BSE), mammography, and physician breast examination (PBE). A sample of women with benign breast biopsy (n=238) was compared with 243 women with no history of breast disease. Women with benign breast disease significantly increased the frequency of breast cancer detection practices compared to the control group after the breast biopsy. Yearly mammography increased from 34.1% to 47.0%, BSE increased from 28.2% to 40.6% ( $Z=-4.69, p<0.0001$ ), and PBE increased every six months from 10.0% to 30.6%.

Open biopsy for a breast lump is considered to be a definitive means of diagnosing a breast lump. However, human error can put the patient at risk of a misdiagnosis. Zitarelli, Burkhart, & Weiss, (1993) assessed reasons for a possible false negative biopsy result of a palpable breast mass. This 12-year study of biopsies performed at eight

institutions suggested that sampling error by the surgeon, inaccurate microscopic evaluation by the pathologist, and development of cancer after excision of a benign lump may have accounted for false negative results. A desire for acceptable cosmetic results, especially in younger women, must not prevent surgeons from obtaining a representative sample that includes all the tumor cells within appropriate margins.

Ersek and Denton (1986) acknowledged the rising incidence of breast cancer due to increased use of screening methods and the importance of breast biopsy. Four out of five breast biopsy procedures performed result in a benign diagnosis which translates into a quarter of a million to one half million procedures being done each year (Ersek & Denton, 1986). The researchers performed 52 breast biopsies over two years using a periareolar incision in all but two cases. Periareolar approach provided accessibility for most breast masses and minimized scarring, thus reducing psychological anxiety associated with both symptom presentation delay and fear of mutilation.

#### Meaning of Risk

The term "risk factor" may be interpreted in various ways. Spratt et al. (1989) described three different meanings associated with risk related to: the probability of a specified outcome such as a disease occurring (risk marker), the probability of the occurrence of disease (risk determinant), and as a determinant that can be modified by

intervention in order to reduce the risk (modifiable risk factor) (p.42). The terms "risk" and "uncertainty" are sometimes used interchangeably to describe issues related to evaluation of disease factors. Janes et al. (1986) described two kinds of risk: "measurable uncertainty" which is represented by the laws of probability and "unmeasured uncertainty" which is not captured by numerical probabilities (p. 220). An individual's interpretation of the meaning attributed to risk influences one's ability to properly assess the risk and choose the appropriate healthcare behaviour.

The concept of risk plays an important role in the understanding of etiology and prevention of chronic diseases. Janes et al. (1986) explored the varying perspectives of risk as interpreted by the epidemiologist, medical doctor, and lay patient. Epidemiologists viewed risk as a statistical measure of the degree of association between a characteristic and a disease within a well-defined population. Risk from this perspective measured the properties of a group in an objective, depersonalized, unambiguous, and scientifically quantitative manner.

Clinical practice and lay perspectives differed dramatically from the epidemiological view since their interpretation of risk took on various intended and unconscious meanings (Janes et al., 1986). The physician and the patient sought to understand risk in a more qualitative, subjective, and highly ambiguous fashion through the

integration of practical knowledge about personal and social aspects of a woman's life. Nursing interactions throughout the diagnostic and treatment phases provide opportunities to clarify individual factors affecting care. Ongoing assessment and clarification of risks pertaining to each patient is a valuable nursing skill.

Benign breast condition is illustrative of the ambiguities of risk (Janes et al., 1986; p.218). There is an inherent degree of uncertainty in understanding specific risk factors and in making decisions about the amount of chance or danger associated with a given set of symptoms and factors. Judgements about the importance of an event are complicated by ambiguity of a situation. Hilton (1992) examined the concept of uncertainty, the assessment of emotional factors related to uncertainty, and possible interventions for modifying its impact.

Hilton (1992) defined uncertainty as "a cognitive state created when an event cannot be adequately defined or categorized due to lack of information" (p. 70). Stimuli are assessed by the individual to make sense of the uncertainty and to comprehend its implications. For a situation to be certain; stimuli must be specific, familiar, consistent, complete, limited in number, and clear in boundaries (Hilton, 1992). These criteria which provide an important, familiar frame of reference are missing in benign breast condition since symptoms tend to fluctuate with a woman's age, menstrual

cycle, and behavioural lifestyle choices. Perceptions of possible future outcomes with uncertain illness trajectories remain unclear, resulting in an increase in a patient's anxiety level.

Worry, anxiety, and fear related to the threat of breast cancer can affect a woman's ability to make appropriate decisions about care. The emotional reactions to uncertainty interfere with the accurate assessment of a situation and diminish the coping ability of a patient (Hilton, 1992; Stanton & Snider, 1993). Nurses' attention to a patient's attitude as well as verbal and non-verbal communication may prompt conversations that allow feelings to be expressed and information to be clarified.

Most research on uncertainty in illness has addressed the concept as it relates to an acute illness with a downward trajectory. Perceived uncertainty and stress experienced by hospitalized patients have been shown to be linked. Mishel (1988) found that the multi-attributed ambiguity factor of the Mishel Uncertainty in Illness Scale (MUIS) was a significant predictor of stress when the MUIS was compared with the Hospital Stress Events Scale (HSES) for hospitalized patients (n=100). Recent interest in uncertainty experienced by patients contending with chronic illness has provided empirical evidence of uncertainty as an important aspect of the benign disease population's illness experience. Warrington & Gottlieb (1987) explored a possible theoretical

link between uncertainty and anxiety for women (n=20) having a hysterectomy for benign disease. The Mishel Uncertainty in Illness Scale and the State-Trait Anxiety Inventory instruments measured uncertainty and anxiety, respectively, at three different times during hospitalization (day 1 pre-operative, day 3 post-operative, and day 6 post-operative). Results showed that patients experienced higher levels of uncertainty and anxiety before than after surgery and women with high uncertainty expressed more anxiety than those with low uncertainty levels.

Responding to a stress involves skills in problem-solving as well as management of the emotional impact of an event. The level of stress experienced is directly related to an evaluation of the danger levels of a situation and the perception of an event as threatening or challenging (Scott, 1983). Patients remain unable to apply appropriate coping strategies because their energy is taxed trying to anticipate whether feared or improved changes will occur or not. Hilton (1992) described an array of emotion-focused coping strategies that patients choose in order to manage the stress caused by uncertainty. These coping strategies included avoidance, denial, smoking, over-eating, super-normalizing, and expressing anger. These coping strategies can affect the patient's risk of developing cancer either directly, as in the case of smoking, or indirectly through delay in presentation of a symptom to a health professional.



Suls and Mullen (1981) examined the role of uncertainty as it related to life events, perceived control, and illness. Previous research sought to determine if stressful events could evoke faulty pathophysiological adaptive mechanisms resulting in illness. Various aspects of a major life event can contribute to the event's impact on a person's health. Factors such as the amount of readjustment required, the sense of control or helplessness, number and frequency of changes, and coping mechanisms have been found to have more impact than whether the event is negative or positive. Researchers have found that an accumulation of recent life events perceived as both undesirable and uncontrollable was the most likely combination to predispose an individual to subsequent illness.

Physicians endeavour to translate the concepts of epidemiological risk into clinical risk, thereby diminishing the ambiguity in the lived experience of an illness, and determining the clinical uncertainty associated with a breast change. The medical model proposes an assessment of the meaning of risk in the same manner as disease signs and symptoms are clinically evaluated. Risk is seen as something that can be understood and therefore physically treated in spite of its inherent ambiguity.

A breast biopsy is perceived as one means of assessing and removing the risk. However, Janes et al. (1986) described the subsequent problems of multiple biopsies for an individual patient. Multiple biopsies can camouflage small cancers

making it difficult to produce accurate histological assessments. As well, criteria for histological assessment may vary among clinicians and across institutions, scars can hamper the interpretation of future clinical exams, and the resulting medicalization of the patient may have negative psychological implications.

The diagnosis of benign breast condition changes a woman's perception of health and illness because risk is experienced as a symptom of hidden future illness and she is transformed into a new physical state of "ill-health" (Janes et al., 1986, p.236). Continual monitoring of a benign breast condition keeps a woman in a state of uncertainty with the dreaded breast cancer continually looming in the shadows of her life. However, attention to a change in her breast must not be discouraged since it can also result in early detection of a breast cancer with improved treatment and morbidity results.

Anxiety has been linked to uncertainty when the uncertainty is appraised as a danger and when information related to that appraisal changes (Cohen, 1993; Mishel, 1988; Wong & Bramwell, 1992). Wong & Bramwell (1992) used a combined qualitative and quantitative design (n= to study the uncertainty and anxiety experienced by women who recently had a mastectomy. A positive, significant relationship between uncertainty and anxiety was found only in time two interviews. This may have been due to factors such as the close interview

timeframes (1 to 2 days pre-discharge and 1 to 2 weeks post-discharge), limited pathology and treatment information available for patients at time one, and limitations of the self-report instruments (MUIS, STAI).

#### Anxiety and Detection of a Breast Lump

Calcan (1985) conducted a study (n=2524) on women's beliefs and feelings about breast cancer and it's control. Cancer was rated as an alarming disease with major concerns related to loss of a breast or dying by one quarter of the respondents. Although 80% of the women did not feel personally vulnerable to developing breast cancer, almost half of the sample expressed a perceived inability to prevent the occurrence of cancer in their lives.

Hill & Shugg (1989) studied beliefs, attitudes, intentions, perceived barriers, benefits, past experiences of breast self-examination (BSE), and perceived susceptibility to breast cancer. The study sample included three groups of females: (1) breast cancer patients (n=117), (2) benign breast disease patients (n=208), and (3) general practice controls (n=329). Although BSE practice ranked highest in benign breast disease patients, no association was found between BSE practice and perceived risk of developing breast cancer. Barriers to BSE practice, such as forgetting, fear of lump, laziness, not knowing how, lack of time, and confusion are factors that can be addressed through comprehensive nursing care.

MacFarlane & Sony (1992) retrospectively explored anxiety prior to a breast biopsy with telephone surveys of 42 females. An interview guide and modified version of the State-Trait Anxiety Inventory were used to examine the impact of discovering a breast lump, hospitalization experience, and factors contributing to increased or decreased anxiety levels. High anxiety was experienced by women upon discovery of the lump and prior to knowing the biopsy results. Patients between the ages of 29 and 39 years experienced the most anxiety while patients younger than 29 years or older than 62 years expressed the least stress. A significant relationship (.0145,  $p < .05$ ) was found between stress and delay in presenting the self-discovered lump and contacting the physician.

Benedict et al. (1994b) described recalled anxiety related to the discovery of a breast mass using a visual analogue and qualitative interviews to determine coping strategies. The visual analogue results showed that a large proportion of patients experienced severe (58%) or moderate (32%) worry. Five patterns of coping strategies employed ranged from diversionary, spiritual, interpersonal, hopeful, and avoidance tactics. A mean of 34.54 days was found from discovery to diagnosis. A significant difference in mean age was related to mode of discovery; BSE practice (47 years), mammography (57 years), and clinical breast examination (54 years). The qualitative and retrospective nature of this

study limits the findings.

Lierman (1988) retrospectively examined breast cancer patients' (n=20) discovery of the breast cancer symptom. Researchers found that both presentation and treatment delays were experienced by the patients. Four coping strategies used to deal with the self-discovered breast lumps (75%) included early help-seeking, ignoring symptoms, wait and see approach, and preparation for death. Factors such as lack of knowledge about breast cancer and its treatment were related to symptom presentation delay. The small sample size limits generalizability as does the extremes in delay time that ranged from one week to seven years.

#### Anxiety Related to a Breast Biopsy

Psychological stress related to a benign breast biopsy has been supported in empirical literature. The overwhelming emotion associated with the breast biopsy is related to the threat of a possible malignant outcome. Although approximately 20% of breast biopsies result in a malignant diagnosis, researchers have found that the worry causes anxiety levels to exceed the pre-operative anxiety experienced by general surgery patients (Barrere, 1992; Hughson et al., 1988; Scott, 1983).

Scott (1983) examined anxiety, critical thinking, and information processing abilities in women (n=85) during and after a breast biopsy. Higher anxiety and lower critical thinking skills were evident more during the biopsy event than

after. A positive relationship was found between state anxiety, as measured by the State-Trait Anxiety Inventory, and judged duration at six weeks. Although a significant effect of state anxiety was found after the crisis for the high anxiety group, the low anxiety group ( $n=2$ ) was too small to analyze.

Hughson et al. (1988) compared 91 breast biopsy patients (44 with cancer, 47 with BBD) with 30 female cholecystectomy patients to assess the psychosocial morbidity in patients awaiting breast biopsy. Results from observer and self-rated scales showed that the benign group was more depressed, irritable, anxious, and had more loss of libido than the cancer or the cholecystectomy group. The benign breast condition and cholecystectomy groups showed more social dysfunction than the cancer group. Younger cancer patients (under 45 years) were more anxious and had more loss of libido than patients aged 46 years or over. However, older benign patients (over 46 years) experienced more depression and social dysfunction than younger benign patients. The researchers concluded that breast biopsy patients were more distressed and thus more vulnerable than general surgery patients.

Hughes, Royle, Buchanan, & Taylor (1986) also found that women ( $n=140$ ) having a benign breast biopsy experienced higher statistically significant levels of depression. Schonfield's (1975) study of the depression, anxiety, and life experiences

of Israeli women prior to breast biopsy lends support for the high stress levels experienced by women having a benign breast biopsy. Northouse et al. (1995) studied distress factors of women and husbands prior to the woman's breast biopsy and found that 42% of the variance in the couple's distress levels were accounted for by numerous factors including uncertainty related to the breast biopsy.

Ambulatory care surgical procedures limit the time available for the nurse to meet the patient care needs of women having breast biopsies. Nursing intervention is believed to be the key in reducing patient stress (MacDonald-Ross, 1986; Suominen, Leino-Kilpi, & Laippala, 1995). The patient experiencing a biopsy for a benign lump does not know which of three diagnoses; benign, pending and malignant; she will receive before leaving the ambulatory care unit. Nursing care must be tailored to meet any of the three possible scenarios for a patient having a breast biopsy.

#### Anxiety and Delay in Symptom Presentation

Anxiety about breast cancer has been shown to affect the presentation of symptoms to the physician. Owens et al. (1985) found that 15% to 20% of women delayed presenting a discovered lump for three months. These women stated they would have presented earlier if they knew about more conservative treatment modalities such as lumpectomy. This delay and limited knowledge about current practice served to escalate the fearful emotions compounded by the anxiety

related to the surgical procedure.

Redman et al. (1993) studied symptom presentation delay in 745 Australian women with a self-discovered breast lump that may or may not have been associated with their menstrual cycle. Presentation of symptoms to a physician was no different for period-related lumps versus cancer-related breast symptoms. The researchers found that factors associated with delay in presentation included age, education, income, perception of the seriousness of the symptom, and anxiety level. Hackett et al. (1973) found that worry about the meaning of breast cancer symptoms was based on lack of information, affected delay in presentation, and diminished with knowledge (p. 19). Accurate information is required to help patients with a breast lump assess their individual risk factors and cope with the heightened uncertainty and anxiety that may inhibit prompt presentation of symptoms and appropriate follow-up measures.

A number of studies demonstrated the impact of anxiety on presentation of a breast cancer symptom to a health care professional (Hackett et al., 1973; Lauver, 1992; Magery et al., 1977; Neale et al., 1986; Timko, 1987). Magery et al.'s (1977) interviews of women (n=90) one day before the breast biopsy demonstrated significant findings of anxiety, especially non-verbal expressions, influencing symptom presentation. Feelings of denial, suppression, intellectualization, pre-interview anxiety, non-verbal anxiety



signs, and depression accounted for 43.4% of the variance in symptom presentation delay.

Lauver (1992) found that although factors such as education, occupation, and family history explained intention to present a breast cancer symptom (n=96), anxiety was positively but not significantly related to intention. Differences in the education, socioeconomic status (SES) of the subjects, and sample size (68% white, 32% black) may have accounted for the impact of race on the findings. Hackett et al. (1973) and Neale et al. (1986) also found that lower SES affected presentation delays.

#### Nursing Role in Information Giving

Information-giving has been a component of the nursing role for many years. Consideration of the kinds of information appropriate for nurses to tell patients and under what circumstances predominated the initial concerns about providing emotional support (Boylan, 1982). Issues related to not overstepping the medical practitioner's role have been replaced by concerns about the kinds of information that are deemed important by the patient. Acceptance of an autonomous, independent nursing role, distinct from medical practice, has promoted the emotional and informational support roles of the nurse.

#### Breast Cancer Information Needs

Patients' concerns and questions about cancer have become progressively more difficult to answer as increased

media attention on cancer and a consumer driven health care system present challenges to the information-giving role of the nurse (Morra, 1988). Recent nursing studies to determine the information needs of breast disease patients have been directed mainly at breast cancer (Bilodeau & Degner, in press; Cawley, Kostic, & Cappello, 1990; Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller, in press; Kostbade Hughes, 1993b; Luker, Beaver, Leinster, Owens, Degner, & Sloan, 1995; Suominen et al., 1994; Suominen et al., 1995).

Suominen et al. (1995) examined the nurses' and patients' perceptions of information and emotional support provided to Finnish breast cancer patients (n=109 patients, n=125 nurses). Although both nurses and patients agreed that patient support was inadequate, their evaluations differed on the kinds and amount of support provided during the breast cancer diagnosis and treatment phases. Nurses valued the role of psychological support whereas patients wanted accurate information.

Lovelys and Klaich (1991) describe the breast cancer patients' qualitative experiences of illness demands which were represented by illness-related stressors, strains, or problems. Contextual factors within which the illness was experienced affected a patient's interpretation and assessment of meaning of the event. Fourteen illness demand domains were determined to include: treatment issues, changes in life context or perspective, acceptance of the illness, social

interaction or support, physical changes, reconstructing the self, uncertainty, loss, making comparisons, acquiring new knowledge, making choices, mortality issues, financial or occupational concerns, and making a contribution. Personal descriptions of 14 illness demand domains provided valuable insights into the lived experiences of women (n=79) with breast cancer.

Findings in this study differed from previous research in terms of which aspects of information were important to women with breast cancer. The most common areas of concern noted by Lovelys and Klaich (1991) were treatment issues, social interaction or support, changes in life context of perspective, and acceptance of the illness. Less focus was attributed to emotional responses related to constructing a new self; while sexuality and femininity issues were predominantly addressed in previous studies. Information about the lived experience with breast cancer is valuable for health care providers seeking accurate interpretation of a woman's experience on which to base quality care. This information will facilitate the integration of psychosocial and medical factors necessary for the provision of holistic health care.

Suominen et al. (1994) compared Finnish patients' (n=109) and nurses' (n=125) opinions of the nurses' role in informing breast cancer patients. Molleman et al. (1984) operationally defined uncertainty of a cancer patient, not as an emotion,

but as a lack of illness-related knowledge (Suominen et al. 1994, p. 7). Tilley (1987) found that although nurses have the appropriate skills and knowledge to deliver accurate information, many patients still looked to the physician as their source of information (Suominen et al., 1994, p.7).

Separate questionnaires assessed patient's readiness and resources for participation, perception of the information and support provided by the nurse. The amount of information received prior to hospitalization positively affected the patient's knowledge about examinations and treatment by improving their ability to ask questions, comprehend answers, retain information, and increase the nurse's ability to assess and provide knowledge during hospitalization. This study supports the importance of the role of the breast clinic and ambulatory care nurse prior to hospitalization for breast cancer surgery by demonstrating that the patient's knowledge level affected other aspects of the illness. Findings also support previous study results suggesting that information seemed to promote recovery in cancer patients.

The information needs of women with breast cancer have been examined using a control preferences card sort showing preferred and actual decision-making roles, Thurstone scaling method of paired comparison for information needs, and a meaning of illness scale (Bilodeau & Degner, 1994, in press; Degner et al., 1995, in press). Degner et al. (1995) found that younger women (<50 yrs) with more than high school

education desired an active (22%) or collaborative (44%) role in their treatment decision. However, over half (58%) of the women did not feel they had achieved their preferred role in decision-making. A profile of information needs showed that information about chances of cure and spread of disease ranked first, followed by information about treatment options and family risk of getting breast cancer. Younger women (<50 yrs) desired information about sexuality while information about self-care was more important to women over 70 years of age.

Bilodeau & Degner (1994) interviewed 74 women recently diagnosed with breast cancer and also found that older women preferred (43.2%) and assumed (56.8%) a passive role in treatment decision-making. Only half of the women (18.9%) who desired a collaborative role actually achieved it. A rank order of information needs profiled information about stage of disease, likelihood of cure, treatment options, emotional impact on family, side effects, risk to relatives, social activities, self care issues, and sexuality from most to least important. Women preferred and received personal sources of information from health professionals, friends or relatives over written sources. Davison, Degner, & Morgan (1995) examined the information and decision-making preferences of men with prostate cancer and found that although men wanted the doctor to make the final decision, they still desired information about the treatment.

Kostbade Hughes (1993b) explored the role of information

in treatment selection for stage I or II breast cancer patients (n=71). A telephone survey determined information recall and treatment selection six to eight weeks post surgery. Treatment choice was unrelated to the amount of information provided during the clinic visit and presentation style but was affected by the amount of information given prior to the clinic visit. Patients also experienced poor recall for information about treatments and risks.

Cawley et al. (1990) conducted an exploratory, descriptive study using an original questionnaire to examine the informational and psychosocial needs of women who choose conservative surgery/primary radiation for early stage breast cancer. Results showed that 74% of the sample (n=68) felt they received good pre-operative information but required more knowledge about lymph node removal discomfort and post-operative arm exercises. This study's findings that older women (>60 yrs) felt less informed than younger patients (<60 yrs) may suggest a paternalistic approach was used by physicians for this age cohort. Patients requested more pre-operative information to promote a greater understanding of the treatment options and aid in decision-making. Adequate emotional support required increased sensitivity and advocacy from the health care professionals, and availability of treatment-specific support groups.

A British study (Luker et al. 1993) examined the information needs, decision-making style preferences, and

meaning of illness for newly diagnosed breast cancer patients (n=150). Women who had recent breast biopsies with benign results (n=200) were used as the control group. It was felt that this group who had a "near miss" with a possible cancer diagnosis could empathize appropriately with the fears and information needs of the newly diagnosed group. Results showed that newly diagnosed patients preferred a passive role in treatment decision-making as opposed to the more collaborative style preferred in the benign group. Lack of appropriate knowledge was a key factor expressed as inhibiting a more active role for the newly diagnosed group. However, health professional's perception was that this group actually did participate in a more active manner in their actual treatment decisions.

Information need profiles for both groups revealed a similar order with variations only in spacing when nine information needs were compared. Both groups felt that information concerning the physical aspects of the disease related to cure, spread, and treatment options outweighed the emotional and sexual impacts of the disease. Both groups choose "challenge" from among Lipowski's eight categories to describe the meaning of illness for them. Differences in age, education, and social class may have influenced results as the benign group was a younger, more educated group of women from a higher social class than the newly diagnosed women. However, the results do support the notion that the threat of

breast cancer elicits similar fears and specific information needs in women experiencing breast biopsy for benign lump as it does for those women with breast cancer.

#### Information Needs for Breast Biopsy

Empirical literature on information needs of women before the breast biopsy procedure is limited. However, the importance of information and emotional support during the diagnostic process is gaining appreciation among health care professionals. Shaw et al. (1994) qualitatively examined the information needs of women (n=11) and significant others (n=8) prior to the woman's breast biopsy. Women were most concerned with finding out the diagnosis and dealing with the uncertainty while waiting for the biopsy. Women experienced strong emotional reactions ranging from feelings of shock, anxiety, fear, powerlessness, and fatalism while waiting to learn the diagnosis for a breast biopsy, especially if it was an unfamiliar experience for them.

Although the surgeon was the primary resource for information many women were "too shocked" to think of any questions to ask before the biopsy. Management of information was a coping strategy that resulted in desiring simple, concrete, not too detailed procedural information provided in specific time intervals. Some women used suppression, denial, staying busy to normalize the day, and spiritual coping mechanisms prior to the biopsy and learning the diagnosis.

A focus group to determine information needs of women



(n=9) after a breast biopsy was conducted by the author to provide variables for an instrument to be used in this thesis (Deane, submitted). Women were most concerned with learning the diagnosis, information related to the types of benign breast disease, meaning of risk associated with a benign breast condition, and diagnostic tests required to evaluate a breast lump. Information related to ambulatory care surgery and breast cancer treatment was deemed less important during the diagnostic phase for a lump that resulted in a benign outcome. Reifsnider (1990) supports an advocacy role of the nurse in providing education for women with breast disease. Nurses can be role models for breast health behaviours and educators to dispel public myths and misconceptions about screening and treatment concerns.

Although uncertainty and anxiety levels have been noted to be high in women experiencing a breast biopsy the relationship of these emotions to information needs has not been addressed (Barrere, 1992; Hirst & Whitehead, 1984; Hughson et al., 1988; Scott, 1983). The nature of the information that may alleviate the heightened emotions and facilitate coping with a surgical procedure for a definitive diagnosis have not been delineated. Information related to learning the final diagnosis, suggested to be foremost in the minds of the patients by Hirst and Whitehead (1984), was supported in a focus group of women who had experienced a benign breast biopsy (Deane, submitted). Subjects in a focus

group unanimously chose learning when the results of the biopsy would be known as the most important information need.

#### Chapter Summary

This chapter summarizes and critiques literature related to the diagnosis and treatment of benign breast condition. The variables of uncertainty, anxiety, and information needs are explored in literature related to breast health. The elusive nature of benign breast disease, in terms of its etiology, demands that a patient endure numerous diagnostic tests that can remain inconclusive in determining one's risk for developing breast cancer. Heightened anxiety and uncertainty about the pending diagnosis make this large population of women vulnerable to health concerns. Patients undergoing a breast biopsy with a benign outcome require quality nursing care to address the emotional and informational needs of the patient.

Although recent limited research has supported the high levels of anxiety experienced by women undergoing a benign breast biopsy, knowledge about the levels of uncertainty and anxiety and the kinds of information important to this population requires further investigation. Identification of accurate and appropriate information will provide the basis for nursing interventions that could decrease the anxiety and uncertainty and support women through the diagnostic phase of a benign breast lump.

### CHAPTER THREE: METHODOLOGY

#### Design

A cross-sectional, retrospective, descriptive survey design was used to describe the information needs of women having a breast biopsy with a benign outcome and the related uncertainty and anxiety. A survey is a Level II non-experimental design used to collect data in questionnaire or interview format resulting in generalizable findings. Survey designs lack the control afforded in experimental designs but provide an efficient means of accessing data for a variety of purposes including: description, correlation, comparison, and evaluation (Brink & Wood, 1989; Polit & Hungler, 1991).

#### Setting and Population

The settings for this study were an ambulatory care breast clinic and a general surgeon's office in Winnipeg, Manitoba, with one surgeon in each site. The target population, to which this study will be generalizable, includes all women of the two surgeon's practices who have undergone a breast biopsy resulting in a benign breast disease outcome.

#### Sampling and Selection Criteria

A non-probability sampling technique was employed using a quota sample of women who had a breast biopsy with a negative result. There are approximately 730 new diagnoses of breast cancer annually in Manitoba with 80% of breast biopsies resulting in a negative outcome (Canadian Cancer Society,

1995). These statistics suggest that approximately 2920 benign breast biopsy procedures ( $730 \times 80\% = 58400/20 = 2920$ ) are performed annually in Manitoba. A proportional sample was recruited from each general surgeon's practice in an effort to eliminate a potential physician bias.

The ambulatory care breast clinic assesses approximately 200 women monthly with an average of 20 breast biopsies performed each month. There are 240 breast biopsies performed annually with approximately 80% ( $n=192$ ) resulting in a negative outcome. The surgeon performs 6.5% ( $192/2920 \times 100$ ) of the benign breast biopsy procedures in the province.

The surgeon in general practice performs approximately 6 to 10 breast biopsies monthly. This produces an annual breast biopsy population average of 96 ( $8 \times 12$ ) with 80% ( $n=77$ ) resulting a benign outcome. This surgeon performs approximately 2.3% ( $67/2920 \times 100$ ) of the breast biopsy procedures in Manitoba.

The population ( $n=269$ ) for this pilot study included approximately 10% ( $269/2920 \times 100 = 9.2\%$ ) of the benign breast biopsy procedures performed in Manitoba. The sample ( $n=70$ ) for this study included a proportion of the patients from the two sites. Recruitment from the ambulatory care breast clinic included ( $20/28 \times 70$ ) 50 subjects patients and ( $8/28 \times 70$ ) 20 subjects from the general surgery practice. Data were collected over a six month time period, from September 1995 to February 1996.

Selection criteria included women who had undergone a breast biopsy with a negative result within the previous two weeks at either site; patients of either general surgeon; were aware of the negative pathology result; could read, speak, and write English; and had not been diagnosed with a psychiatric illness.

### Recruitment of Subjects

Ethical approval from the University of Manitoba and access approval from the Research Review Committee at the ambulatory care breast clinic hospital and general surgeon's office were obtained prior to recruitment of subjects for the study. Nurses at the breast clinic and the physician's office were provided with the inclusion criteria for the study and the invitation to participate form (Appendix B). Participants meeting the selection criteria were approached by the clinic and office nurse upon return visits. The nurse informed patients that a research nurse was conducting a study about the information needs of women who had a breast biopsy with a benign outcome and the related uncertainty and anxiety experienced.

It is common practice for women to be told of the negative pathology result when they telephone to make an appointment to have their sutures removed 7 to 10 days after surgery. These patients were asked if they would speak with the researcher about the study after their clinic or office visit. This allowed patients time to make arrangements to

stay after their suture removal appointment. Women who did not know their pathology result before seeing the physician were approached by the clinic or office staff after their appointment, but before leaving the clinic or office.

The researcher was present at the clinic and office each day patients were seen to explain the study and survey subjects. The ambulatory care breast clinic operates 11 hours weekly (Monday to Friday) on a regular schedule of Monday and Friday mornings from 9 to 12 AM, Wednesday from 4 to 6 PM, and Thursday alternating weekly between 9 to 12 AM and 1 to 4 PM. The researcher was also be available during the surgeon's office hours on Monday and Wednesday 9 to 3 PM to survey interested patients.

After being introduced to the patient by the clinic or office nurse, the researcher explained the purpose of the study, reviewed the ethical considerations, and obtained informed consent (Appendix C). A signed and witnessed consent form provided the researcher with permission to access the patient's medical record to complete missing information related to the breast biopsy pathology. Consenting participants were provided with a copy of the survey, a quiet, private room, and assistance from the researcher as required to complete the survey. The survey took approximately 20 minutes to complete.

### Ethical Considerations

The researcher obtained and witnessed the informed

consent after carefully explaining the purpose of the study to the participant. Participants were made aware of the voluntary nature of the study and the freedom to withdraw at any time during completion of the questionnaire without affecting their care. Anonymity was ensured by having only code numbers on the survey questionnaires.

The participant's names and code numbers appeared together only on a master list. The master list and completed surveys will be kept in a locked cabinet at the researcher's home for seven to ten years. After the seven to ten year period the surveys will be shredded by the researcher. Aggregate data rather than individual results will be reported to ensure confidentiality. Only the researcher and thesis advisor will have access to the names of the study subjects.

#### Risks and Benefits

There were no expected risks associated with participation in the study. Potential benefits to the participants included an opportunity to express their feelings related to experiencing a breast biopsy for definitive diagnosis and to have their questions answered by the nurse researcher. The researcher provided emotional support as required to women who expressed an emotional response while completing the survey. Results of the study will not directly benefit participants but will be used to provide information in the future for women with benign breast disease experiencing breast biopsy.

### Data Collection Methods

Development of one of the study instruments occurred prior to the thesis using a qualitative design. A focus group composed of women (n=9) who had experienced a benign breast biopsy was conducted within the clinical component of a required major course in the Master of Nursing program.

#### Focus Group

A focus group was conducted prior to the research study to develop the variables for one of the questionnaires (Appendix D). A focus group is a qualitative study defined as a: "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (Kruger, 1988). Focus groups originated in marketing researcher and consist of six to twelve same sex participants with an experience in common, who share their ideas, feelings, and perceptions about a given event. A moderator, the researcher, is generally employed to lead the focus group interview with approximately five questions over four to five sessions until saturation of the topic is achieved.

The focus group in this study followed a more structured format using a questionnaire composed of 31 statements developed by the researcher from the literature and clinical experience. Although focus groups are not generalizable they are cost and time efficient while providing a great deal of valuable data related to feelings, trends, and patterns. One



focus group was conducted on March, 18 1995, with nine women from an ambulatory care breast clinic. Women were asked to think back to a timeframe that encompassed the interval between scheduling the biopsy and learning the diagnosis. The purpose was to determine nine of the most important information needs from a list of 31 statements related to the diagnosis of a breast lump. The nine information needs derived within the focus group provided the basis for an instrument using Thurstone scaling in this thesis.

### Instrumentation

A four part survey questionnaire was used to collect the data. The questionnaires included: 1) Information Needs Questionnaire, 2) Mishel Uncertainty in Illness Scale - Community Form (MUIS-C Form), 3) Spielberger's State-Trait Anxiety Inventory (STAI), and 4) Demographic Questionnaire.

1. Information Needs Questionnaire (Appendix E) was developed from the nine information needs selected as "most" important for women experiencing a breast biopsy with a benign result by the focus group participants. The nine information needs, or stimuli, were chosen from a list of 31 information statements derived from the literature and the researcher's clinical experience. The nine stimuli related to information about the types of breast disease, the meaning of risk associated with benign breast disease, and the tests required to determine a definitive diagnosis of a breast change. Patients were asked to consider which information need was

more important for each pair during the interval between being scheduled for a breast biopsy and learning the diagnostic results.

### Thurstone Scaling

Thurstone (1927) provided a rationale for ordering stimuli on a psychological continuum based on subjective reactions and variance of judgement over time (Dunn-Rankin, 1983). Thurstone's Law of Comparative Judgement encompasses five cases, each with it's own set of assumptions and purposes (Thurstone, 1927). Thurstone's Law of Comparative Judgement - Case V was used to determine profiles of the most important needs for women who have experienced a breast biopsy with a benign result.

Thurstone's Case V is the simplest case which involves assumptions related to a normal distribution, unidimensionality of the psychological continuum, and equality of all the discriminial dispersions. The discriminial dispersion is the standard deviation of the distribution of the discriminial processes on the scale. The discriminial process is a fluctuating judgement of a single observer when comparing a series of stimuli. The discriminial difference is the scale difference between the simultaneous judgement of two stimuli. The assumption of a normal distribution implies that the most frequent reaction, the mode, is equal to the mean. The mean represents the scale value for the stimuli item. The variance of the normally distributed reactions to each item in

the pair is assumed to be the same (Dunn-Rankin, 1983).

Paired comparisons of two stimuli at a time results in a rank order that disallows equal judgements of the items being scaled. Thurstones' Law of Comparative Judgement assumes that each stimulus is compared with every other stimulus repeatedly and serves in turn as the standard (Torgerson, 1958). The number of items available were compared relative to each other and through forced choice an average rank order of importance was established. The difficulty associated with assessing the value of numerous items simultaneously is avoided using the paired comparison method.

The total number of combinations of a specific number of stimuli was derived using the formula:  $nC2 = n(n-1)/2$ . When the number of stimuli ( $n=9$ ) is entered into the formula, the total number of possible paired comparisons is equal to:  $nC2 = 9(9-1)/2 = 36$ . The nine information needs were arranged in 36 pairs according to the Ross matrix of optimal ordering (Ross, 1974) (Appendix F). Ross' optimal ordering of pairs controls for biasing effects by alternating the position of the item for half of the pairs, separating pairs having one item in common, and eliminating any detectable pattern of "correct" responses from being discerned (Torgerson, 1958, p.168). This technique ensures maximum spacing of items which avoids a selection bias.

A fatigue effect can result when higher numbers of stimuli ( $>16$  items) are presented in pairs for comparison.

Subjects were asked to select from nine stimuli (information needs) comprising 36 paired comparisons, thus minimizing the fatigue effect. Researcher support was provided during survey completion for any respondent experiencing a fatigue effect.

Scale scores were computed using the actual percentage that an item is preferred (Sloan, Doig, & Yeung, 1994, p. 7). Preference frequencies represent the percentages of the total number of subjects who chose one item over another. These preferred proportions were translated into standard normal scores (Z-scores). The Z scores were computed by dividing the preference frequencies by the sample size ( $n=70$ ). Averaging the individual item Z scores produced the Thurstone scale value for every item in relation to each other item.

A problem results due to the fact that these scale scores will always sum to zero. Simple linear regression was used by McKenna et al. (1981) to rescale the Thurstone scale value in order to obtain a meaningful estimate of a real zero (Sloan, Doig, & Yeung, 1994). Thurstone scale scores were Z scores plotted on a normal curve with zero representing the mean. Positive scores indicated that 50% or more of the subjects preferred an item while all negative scores demonstrated that less than half of the respondents chose that item as more important than its comparison item (Sloan et al., 1994).

An index of reliability related to the internal consistency of the subject's judgements was assessed by summing the number of circular triads. Circular triads are an

intransitive preference pattern resulting from non-linear ordering (Dunn-Rankin, 1983). Circular triads may occur because of a subject's careless completion of the task; numerous, randomly assigned tasks of comparison; perception of items being very similar; items representing more than a single dimension; or an individual's personality or ability trait (Dunn-Rankin, 1983, Sloan et al., 1994). The maximum number of circular triads for an odd number of stimuli equals:

$$\begin{aligned}
 (K^3-K)/24 &= (9 \times 9 \times 9 - 9)/24 \\
 &= (729 - 9)/24 \\
 &= 720/24 \\
 &= 30
 \end{aligned}$$

In examining the circular triads one can assume that a logical third pair choice based on the two previous pair selections exists. An example of items entered into the computer as I12, I23, I13 using the Ross matrix of optimal ordering provides an understanding of circular triads. When a subject chose item "1" over item "2" and item "2" over item "3", then it is logical to assume that item "1" would also be deemed more important than item "3". A circular triad results when "3" is chosen as more important than "1".

Response data were entered into the computer as "1" for preferring the first choice in the pair and "0" for the selecting the second choice. The total number of circular triads, depicted as (0-1-0) or (1-0-1) combinations, provides an appreciation of the degree of difficulty in choosing

between the pairs of information needs, the amount of confusion experienced by the respondent, and/or an indication of the overall integrity of the data (Sloan et al., 1994, p. 27).

Kendall's Coefficient of Agreement (zeta) determines if the number of triads chosen is due to chance or inconsistent logic (Sloan et al., 1995). The Kendall Zeta coefficient can range from 0-1 and is indirectly related to the number of circular triads. When there are no circular triads zeta equals one, but as the number of circular triads increases the zeta coefficient decreases. The maximum number of circular triads is achieved when zeta equals zero (Sloan et al., 1994).

One qualitative question requested subjects to note any other types of information important to them that were not included in the paired comparison questionnaire.

2. The Mishel Uncertainty in Illness Scale - Community Form. Approval from Dr. Merle Mishel was obtained to use the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C Form) to measure the level of uncertainty experienced by women who had a benign breast biopsy. The MUIS-C Form (Appendix G) is a modified version of the Mishel Uncertainty in Illness Scale adapted for ambulatory care services. The MUIS-C Form is a one factor (multi-attributed ambiguity), 23-item scale in 5-point Likert-type format with categories ranging from strongly agree, agree, undecided, disagree, to strongly disagree. Patients were asked to make their choice for each

question thinking back to the time interval between the scheduling of their biopsy and learning the diagnosis. MUIS-C Form responses are summed (range 23 to 115) and the total score is directly related to the level of uncertainty measured (Mishel, 1990).

The MUIS-C Form has been used to study patients (n=396) with illnesses such as epilepsy, coronary artery bypass, lupus, post myocardial infarction, multiple sclerosis, rheumatoid arthritis, irritable bowel disease, and mixed cancers. Reliability for all the cases (n=396) is .92, while the mixed cancer cases have alpha coefficients of .90 (Mishel, 1990). Confidence intervals for the mixed cancer cases ranged from 87 to 93 with a mean of 90 (Mishel, 1990). Validity of the MUIS-C Form has been previously established (Mishel 1989).

3. Spielberger's State-Trait Anxiety Inventory (Appendix H) is a two-part scale with 20 items per scale arranged in a 4-point Likert format. Likert categories in the state anxiety scale include: not at all, somewhat, moderately so, and very much so. Patient's were instructed to choose responses in the state anxiety scale based on how they felt during the time they were scheduled for the biopsy until they learned the diagnosis. Respondents chose from almost never, sometimes, often, and almost always categories in the trait anxiety form. The state anxiety scale measures how anxious a person feels at a particular moment in time, while the trait anxiety scale focuses on a person's general level of anxiety (Scott, 1983).

Spielberger, Gorsuch, and Lushene (1970) report the reliability of the state anxiety scale, using the alpha coefficients, between .83 to .92 (Scott, 1983). Alpha coefficients for working female adults provide the norms for the state anxiety scale (.93) and the trait anxiety scale (.91). The Spielberger STAI instrument has proven reliability and a high degree of internal consistency (MacFarlane & Sony, 1992).

4. Demographic Questionnaire (Appendix I) was completed at the end of the study. Information on variables related to the participant's age, marital status, educational level, residence, ethnicity, date of breast biopsy, hormone use, presenting symptom, experience with a family or friend experiencing breast cancer, and site of surgery was requested. The researcher obtained data related to the breast biopsy diagnosis from the patient's medical record. The signed consent form provided the researcher with permission to access the patient's medical record which was kept in the breast clinic or the surgeon's office.

#### Reliability

Reliability of the information need pairs was attained through computation of the circular triads which provided an indication of the internal consistency of the subjects' responses. Previously established Cronbach alpha coefficients for both the MUIS-C Form (.92) and the STAI (.83 to .92) surveys indicate good measures of internal consistency for



these multiple response scales. Cronbach's alpha is an appropriate conservative estimate of reliability for both unidimensional scales.

### Content Validity

Content validity of the paired comparison scale was achieved through the focus group conducted with women who have undergone a breast biopsy with a negative outcome. These women represent experts based on their own benign breast biopsy experience. The 31 information statements derived from the literature and the researcher's clinical experience were discussed to depict nine of the "most" important information needs for women after a benign breast biopsy. The nine focus group participants surpass Lynn's (1986) suggested guideline of at least three experts to evaluate the items in a scale (Brink & Wood, 1989). Consensus of the nine "most" important information needs to comprise the paired comparison scale was attained by all participants in the focus group.

### Data Analysis

After completion of the data collection, analysis of the 70 survey questionnaires was conducted using two statistical computer packages. Case V - Thurstone Law of Comparative Judgement provided the methodology for ranking the paired comparisons of the information needs for various demographic groups of subjects. A statistical program developed by Sloan et al. (1994) was used to analyze the paired comparison data. The SAS computer program was used to analyze data obtained

from the MUIS-C Form, STAI, and Demographic Questionnaires. Descriptive and inferential statistics were computed on the data.

The Thurstone scaling program computed preference frequencies, preferred proportions, Z-scores, and Thurstone scale values for the paired comparison data (Sloan et al., 1994). Preference frequencies were determined for each of the items in the paired comparisons. Total preferences for each item over every other item were summed to derive these frequencies. Preferred proportions, calculated by dividing the preference frequencies by the sample size, were translated into z-scores. The Thurstone scale values for each item were derived by averaging the z-scores for every item. An artificial comparison of each item with itself was included and always resulted in a score of zero. The meaningful zero point was added to each of the averaged z-scores and the scores were rescaled to sum to the desired maximum value (Sloan et al., 1994).

#### Analysis of the Research Questions

- 1. What are the profiles of information needs of women who have experienced a breast biopsy with a benign breast disease outcome?**

Profiles of information needs for women experiencing breast biopsy with a benign result were determined for the total sample (n=70). Profiles were examined comparing women across two demographic categories: age (<40, 40+) and "love one", determined by whether or not patients had a relative or

friend with breast cancer. The data were examined for normalcy and parametric tests were applied to the normal distribution. The interval-like data of the Thurstone scales and the robust nature of a t-test provided a rationale for using parametric tests on a normal distribution of non-probability sample data.

The total number of circular triads were summed to indicate the internal consistency of the subject's ranking of the nine information needs. Kendall's Coefficient of Agreement (zeta) was calculated to evaluate if the number of triads resulted from chance or inconsistent logic. The number of circular triads were calculated to show the consistency of the choices made by the participants and represent an index of reliability. Guilliksen and Tukey's coefficient was determined to assess the reliability.

**2&3. What is the level of uncertainty and anxiety experienced by women who experience a breast biopsy with a benign breast disease outcome?**

Descriptive statistics including frequencies, percentages, central tendencies, ranges, and standard deviations were calculated to summarize and describe the MUIS-C Form and STAI data. Total scores for the MUIS-C Form and the STAI were summed to provide a level of uncertainty and anxiety, respectively, for the sample (n=70). Data distributions were examined for normalcy and normal distributions were determined for both total sample scores. If the data distribution was found to be non-normal, a

Wilcoxin rank-sum test or a Mann-Whitney U test would have been computed as determined appropriate through statistical consultation. Reliability coefficients using Cronbach's alpha were determined for the MUIS-C Form and the STAI scales and compared with normative data for the instruments.

Uncertainty and state anxiety levels were computed for the demographic variables of age (<40, 40+) and "love one" (yes, no), which determined if the patient had a relative or friend who had experienced a breast cancer diagnosis. T-tests were computed to determine if any significant differences existed between the younger (<40 years) and older (40+ years) group means of patients experiencing uncertainty and state anxiety. T-tests were computed to determine if any significant differences existed between the group means of patients who knew a loved one with breast cancer and those who did not, in relation to the uncertainty and anxiety experienced.

4&5.        **Do women experiencing higher levels of uncertainty and anxiety related to a benign breast biopsy have different profiles of information needs than women with lower uncertainty and anxiety levels?**

The sample was split at the median on the total scores of the MUIS-C Form (median=54), the State Anxiety Inventory (median=51), and the Trait Anxiety Inventory (median=36) scales. Profiles of information needs were determined for women with low (below the median) and high (median+) levels of uncertainty, state anxiety, and trait anxiety.

**6. Do women experiencing high levels of uncertainty related to a benign breast biopsy also experience heightened anxiety?**

A correlation matrix, using Pearson  $r$ , was computed on the total scores of the three scales: MUIS-C Form, state anxiety, and trait anxiety. A scatter plot was produced to depict correlations between the MUIS-C Form and state anxiety total scores.

Chapter Summary

The survey, composed of four questionnaires, was completed by 70 patients who had a benign breast biopsy. Data collection from two general surgeon's practice at two sites: an ambulatory care breast clinic and a surgeon's office was completed within six months. The four questionnaires consisted of an Information Needs Questionnaire, the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C Form), the State Trait Anxiety Inventory (STAI), and a Demographic Questionnaire. The information needs data were analyzed using a Statistical Analysis System (SAS) program developed by Sloan et al. (1994). The MUIS-C Form, STAI, and demographic data were analyzed using SAS to provide descriptive and inferential statistics. Ethical and access conditions, as described, were followed during the data collection phase of the study.

## CHAPTER FOUR: FINDINGS

### Introduction

The results of the study are reported in this chapter. The demographic characteristics of the sample are described. Findings from the Information Needs Questionnaire, the Mishel Uncertainty in Illness - Community Form, and the State-Trait Anxiety Inventory are presented. A summary of the significant findings in the study analysis completes the chapter.

### Demographic Findings

Participants (n=70) were recruited from September 1995 to February 1996 at a breast clinic and a surgeon's office following the patient's suture removal appointment. Patients were scheduled to have sutures removed from seven to ten days after the breast biopsy and to learn their diagnosis at the same time. Forty-four subjects (62.9%) from the breast clinic and 26 patients (37.1%) from the surgeon's office were interviewed for a total sample size of 70. Four patients did not complete the survey. One patient did not meet the criteria of being able to read English and one participant's benign frozen section diagnosis was subsequently changed to malignant on permanent section examination. Two women refused to be interviewed, citing lack of interest or being too busy as reasons for not wanting to participate.

Approximately ten of the 70 subjects were not interviewed on their appointment day but were provided with the survey, explanation cover letter, and a stamped, self-addressed return

envelope. The researcher called the patients at home, within 3 days of their appointment, after receiving verbal permission to have their telephone number. Any questions regarding the survey were answered over the telephone and the researcher's home telephone number was given to the participant. All of the ten subjects returned the completed survey within one week of receiving it.

The age of participants ranged from 16 to 75 years with a mean of 41 years ( $SD=13.38$ ), a median of 43 years, and a mode of 45 years. This resulted in an almost normal distribution of the age variable. There were 28 (40%) subjects under 40 years of age and 42 (60%) women 40 years of age or over. Fifty-one (72.9%) of the women were married or living in a common-law relationship, while 19 (27.1%) of the subjects were without a partner; being either widowed, divorced, or never married. Forty-nine participants (70%) had completed post-secondary education. The remaining 21 women (30%) had completed either elementary or some high school education.

Most of the participants ( $n=59$ , 84.3%) lived in Winnipeg while 11 women (15.7%) lived outside of the city. Over half ( $n=44$ , 62.9%) of the participants were English Canadian with almost equal distribution across the ethnic categories of Ukrainian ( $n=3$ , 4.3%), French Canadian ( $n=4$ , 5.7%), British ( $n=3$ , 4.3%), German ( $n=4$ , 5.7%), Aboriginal ( $n=2$ , 2.9%). Ten subjects (14.3%) responded to the "other" ethnic category which included Irish, Polish, Metis, and Phillipino ethnic backgrounds.

Occupational categories were evenly distributed among professional categories such as secretary (n=4, 5.8%), teacher (n=4, 5.8%), and nurse (n=3, 4.3%). Twelve (17.4%) of the women were homemakers and eight (11.6%) were retired. Over half of the sample (n=38, 55.1%) chose the "other" category which was composed of unemployed students (n=3) and service oriented jobs (n=35) such as waitress, hairdresser, therapist, team developer, sales representative, real estate agent, school tour coordinator, para-professional, postal office, warehouse, and management. One woman did not respond to this category.

Over half of the subjects (n=41, 58.6%) knew a loved one, either relative or friend, who had been diagnosed with breast cancer. If a patient knew of more than one category of loved one who had breast cancer the response chosen was in the order of closest bloodline and included mother (n=4, 5.7%), sister (n=4, 5.7%), grandmother (n=7, 10.0%), aunt (n=8, 11.4%), and cousin (n=1, 1.4%). Sixteen (22.9%) of the women knew a friend who had been previously diagnosed with breast cancer. One patient, who had been diagnosed with breast cancer on the opposite breast from this biopsy last year, marked "self" in the "other" category. The researcher took the time to answer any questions respondent's posed about breast biopsy or breast cancer. For example, one women wondered if her friend's mother who had a mastectomy last year could have had more conservative treatment if the cancer was diagnosed at an earlier time.

Table 4 and table 5 summarize the demographic and disease



characteristics, respectively, for the total sample.

Table 4

BENIGN BREAST BIOPSY PATIENTS	
DEMOGRAPHIC PROFILE OF SAMPLE (N=70)	
DEMOGRAPHIC VARIABLE	FREQUENCY (%)
AGE	
<40 years	28 (40%)
40+ years	42 (60%)
MARITAL STATUS	
Married/Common-law	51 (72.9%)
Widowed/Divorced/Never married	19 (27.1%)
EDUCATION	
High school or less	21 (30%)
Post secondary	49 (70%)
RESIDENT	
Winnipeg	59 (84.3)
Other	11 (15.7%)
OCCUPATION	
Homemaker	12 (17.4%)
Professional	11 (15.9)
Retired	8 (11.6%)
Other	38 (55.1)
ETHNIC	
English/Canadian	44 (62.9%)
Ukrainian	3 (4.3%)
French Canadian	4 (5.7%)
British	3 (4.3%)
German	4 (5.7%)
Aboriginal	2 (2.9%)
Other	10 (14.3%)
RELATIVE/FRIEND EXPERIENCE	
Yes	41 (58.6%)
No	29 (41.4%)

RELATIVE OR FRIEND	
None	30 (42.9%)
Mother	4 (5.7%)
Sister	4 (5.7%)
Grandmother	7 (10.0%)
Aunt	8 (11.4%)
Cousin	1 (1.4%)
Other	16 (22.9%)

Table 5

BENIGN BREAST BIOPSY SAMPLE (N=70) DISEASE CHARACTERISTICS	
VARIABLE	FREQUENCY
PRESENTING SYMPTOM	
Lump	50 (71.4%)
Nipple discharge	5 (7.1%)
Other	15 (21.4%)
HOSPITAL	
Hospital A	44 (62.9%)
Hospital B	26 (37.1%)
DIAGNOSIS	
Fibrocystic disease (FBD)	32 (45.7%)
Fibroadenoma	19 (27.1%)
Papilloma	2 (2.9%)
Pre-cancerous lesion	2 (2.9%)
FBD & Papilloma	2 (2.9%)
Other	13 (18.6%)
HORMONE THERAPY	
None	26 (37.1%)
Birth control pill (BCP)	33 (47.1%)
Estrogen	8 (11.4%)
BCP & Estrogen	2 (2.9%)
Other	1 (1.4%)
LENGTH OF HORMONE USE	
None	26 (37.1%)
< 1 year	4 (5.7%)
1-5 years	23 (32.9%)
5-10 years	10 (14.3%)
> 10 years	7 (10.0%)

Most (n=44, 62.9%) of the breast biopsies were performed at

Hospital A while the remaining subjects (n=26, 37.1%) had their surgery at Hospital B. Fifty of the women (71.4%) identified a lump as the symptom that initiated the diagnostic investigation. Only five (7.1%) of the sample experienced nipple discharge as the first breast symptom. The "other" category, accounting for 15 (21.4%) of the presenting breast symptoms, included mammogram and physical examination.

The researcher reviewed the patients' charts to obtain the diagnosis which was then categorized as fibrocystic breast disease, fibroadenoma, papilloma, pre-cancerous lesion, or other. Thirty-two (45.7%) women were diagnosed with fibrocystic disease, which is understandable given the young age of the sample. The fibrocystic breast disease diagnosis also included comments related to proliferation, sclerosing adenosis, epitheliosis, fibrosis, microcalcifications, ductal ectasia, and apocrine metaplasia. Consultation with the breast clinic doctor and a pathologist confirmed that all of these descriptions of breast changes belonged to the fibrocystic breast disease category.

Fibroadenoma, often considered to be a "young woman's breast lump", was the second most common diagnosis for 19 (27.1%) participants. Papilloma, more commonly found in "older woman", accounted for only two (2.9%) of the diagnoses. Two women (2.9%) had a combined diagnosis of fibrocystic disease and papilloma. Two pre-cancerous lesions (2.9%), including atypical ductal hyperplasia and atypical lobular hyperplasia, were diagnosed. The "other" category included diagnoses such as unremarkable

breast tissue, skin lesion, epidermal cyst, lymph node, accessory breast tissue, lipomata, adipose tissue, and lactating adenoma. The "other" category accounted for 13 (18.6%) subjects in the sample.

Hormone use was considered over the patient's lifetime. If a respondent had taken both the birth control pill (BCP) and estrogen, the total number of years on hormone replacement was recorded. Twenty-six women (37.1%) had never taken hormone replacement, 33 (47.1%) had taken the BCP, eight (11.4%) were on estrogen therapy, and two (2.9%) had taken the BCP and estrogen in their lifetime. One patient (1.4%) was on progesterone.

Mishel Uncertainty in Illness Scale - Community Form (MUIS-C)

Subjects completing the MUIS-C Form were instructed to substitute the word "symptom" for "pain" if applicable to their situation and to consider the biopsy, that is the removal of the risk, as the "treatment". Total scores on the sample data of the MUIS-C Form ranged from 32 to 85 out of a possible range of 23 to 115 (Mishel, 1989). The mean score was 55.357 ( $SD=11.865$ ), the median was 54, and the mode was 51; resulting in an almost normal distribution for this sample. The MUIS-C Form reliability, calculated by a standard alpha coefficient, for this sample was .85. Normative data from mixed cancer studies and all cases were compared with this study sample. The mixed cancer study mean was 41 ( $SD=10.7$ ), and the alpha was .90. The mean for normative data for all cases was 60 ( $SD=17.1$ ), with an alpha of .92. Table 6 displays the means, standard deviations, and reliabilities for

the sample data and normative comparison data.

Table 6

<b>MISHEL UNCERTAINTY IN ILLNESS SCALE - COMMUNITY FORM</b> 1 Factor 23 Items Means, Standard Deviations, and Reliabilities (Coefficient Alpha)		
MUIS-C FORM SAMPLE SCORES	Mean	55.36
	SD	11.86
	Alpha	.85
NORMATIVE DATA (MIXED CANCER)	Mean	41
	SD	10.7
	Alpha	.90
NORMATIVE DATA (ALL CASES)	Mean	60
	SD	17.1
	Alpha	.92

#### State-Trait Anxiety Inventory (STAI)

A weighted score from one to four was given to each of the variables in the STAI tool (Spielberger, Gorush, Lushene, Vagg, & Jacobs, 1983). Answers were weighted for either anxiety-present (1,2,3,4) or anxiety-absent items with anxiety-absent scores being reversed (4,3,2,1). Ten anxiety-absent items on the state anxiety scale and nine anxiety-absent items on the trait anxiety scale were reversed to score.

Scores for the STAI have a possible range from 20 to 80 for each sub-scale. State anxiety is related to a particular incident, in this case the breast biopsy procedure to determine if the lump was benign or malignant. The sample scores for the state anxiety tool ranged from 23 to 80 with a mean of 51.67 (SD=14.40), a median of 51, and a mode of 36. Adult female normative data for the state anxiety scale include a mean of

35.20 (SD=10.61), and a standard alpha of .93. The reliability coefficient for this study sample was .95.

Trait anxiety measures the subjects' general disposition or level of anxiety in their normal, everyday life. The trait anxiety scores ranged from 21 to 66 from a possible range of 20 to 80. The mean for the trait scale was 36.13 (SD=9.20), median was 36, and mode of 27. The mean for normative data on the trait anxiety scale for adult females is 34.79 (SD=9.19) and an alpha of .91. The alpha coefficient reliability for this study data was .91. Table 7 displays the means, standard deviations, and reliabilities for the state and trait sample data, and the normative data.

Table 7

STATE - TRAIT ANXIETY INVENTORY Means, Standard Deviations, and Reliabilities (Coefficient Alpha)					
	STATE ANXIETY			TRAIT ANXIETY	
STAI SAMPLE SCORES	Mean	51.67		Mean	36.13
	SD	14.40		SD	9.20
	Alpha	.95		Alpha	.91
NORMATIVE DATA	Mean	35.20		Mean	34.79
	SD	10.61		SD	9.19
	Alpha	.93		Alpha	.91

Uncertainty and state anxiety were correlated with two demographic variables: age and experience with either a relative or friend having a previous breast cancer diagnosis. Age was divided into two categories: less than 40 years old (n=28) and forty years of age or over (n=42). "Loveone" was a dichotomous

variable answered by a yes (n=41) or no (n=29) response which identified whether or not the patient knew a relative or friend who had experienced breast cancer. Although neither of the two demographic variables, that were tested using a t-test, showed a significant association with the uncertainty or state anxiety scales, the age variable nearly approached significance (1.8398,  $p>.07$ ) when correlated with the uncertainty scores (MUIS-C Form).

Pearson correlation was calculated for the state anxiety scale, trait anxiety scale, and the MUIS-C Form scale. The alpha coefficients, plotted on a scatter graph, are displayed in Appendix J. Statistically significant positive correlations were found between the uncertainty and state anxiety scores, uncertainty and the trait scores, and the state and trait anxiety scores ( $p<.01$ ) for women experiencing a benign breast biopsy. Table 8 shows the correlation coefficient matrix computed for the three scale total scores.

Table 8

CORRELATION ANALYSIS OF MUIS-C FORM AND STAI TOTAL SCORES			
SCALES	MUIS-C FORM	STATE ANXIETY	TRAIT ANXIETY
MUIS-C FORM	1.0000	.44039*	.35281*
STATE ANXIETY	.44039*	1.0000	.32199*
TRAIT ANXIETY	.35281*	.32199*	1.0000

\* = statistically significant ( $p<.01$ )

### Information Needs

The profile of information needs of women who had a benign breast biopsy was determined using the Thurstone Scaling Methodology: Case V. The preferred proportions (Appendix K),

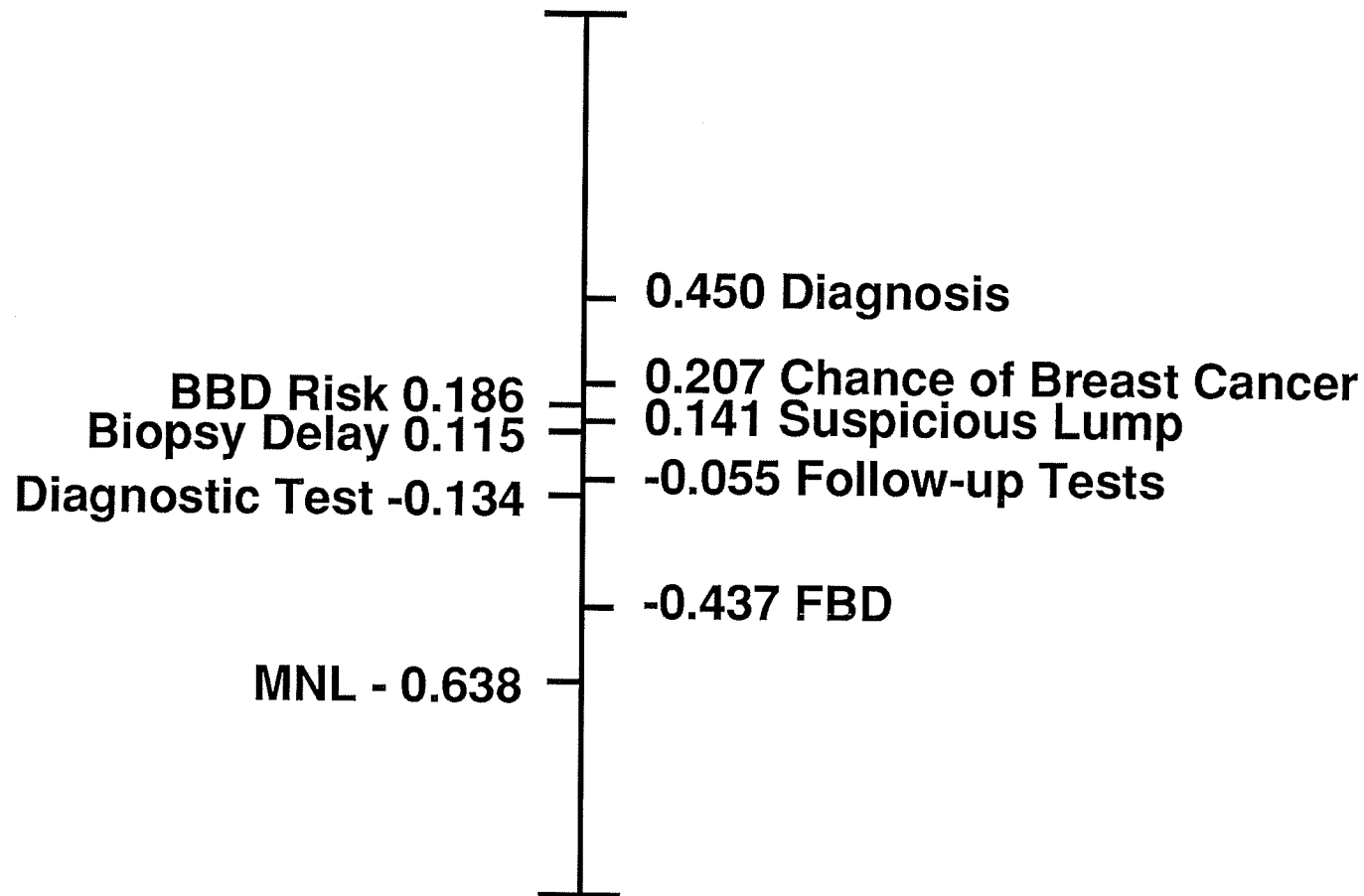
confidence intervals (Appendix L), and normal deviates matrices (Appendix M) for the total sample of benign breast biopsy patients are displayed in the assigned appendices. The Thurstone Scaling scores for Case V and the rescaled scores are presented in Appendix N and Appendix O respectively.

Figure 1 depicts the rank ordering of information needs for the benign breast biopsy sample (n=70). The most important information need (#1) related to when the patient would learn the diagnosis after the biopsy. The next four information needs on the profile (#5, #3, #4, #8) focused on the risk of developing breast cancer. Women wanted information related to their chance of getting breast cancer (#5), the risk associated with benign breast disease becoming malignant (#3), the reason that the lump in their breast was suspicious for breast cancer (#4), and information concerning the effect of a delay between scheduling the biopsy and developing breast cancer (#8). Interest in follow-up tests after a negative breast biopsy (#9) and the number of the tests needed to give a definite diagnosis (#6) were the sixth and seventh information needs, respectively, on the profile. Information about fibrocystic disease (#2) and the mammographic needle localization (MNL) (#7) were the least important information needs for this sample.

Profiles of information needs for sub-groups were compared using a test for equality of proportions using a Bonferroni correction. Internal consistency of an individual's comparative judgements was assessed by summing the number of circular triads



# INFORMATION NEEDS PROFILE FOR TOTAL SAMPLE OF BENIGN BREAST BIOPSY PATIENTS



in each subject's responses. A circular triad occurs when there is an inconsistent choice made by the respondent. For example, when presented with all possible pairs of three stimuli (1, 2, 3) it would be expected that if 1 was chosen as more important than 2, and 2 more important than 3, then 1 would also be judged to be more important than 3. A circular triad occurred when 3 was judged more important than 1. Appendix P shows the list of the circular triads for the study sample.

The range of circular triads chosen by any subject varied from -3.5 to 21.5, with a mean of 5.66 (SD=6.67), and a median of 3.5. Criteria for the maximum number of circular triads for a set of nine items is 30 (Sloan et al., 1994). Analysis of the number of circular triads (Appendix Q) illustrates complete consistency among raters since 100% of the participants met the criteria. Thirty-six (51.4%) subjects made fewer (3.5) than the mean (5.66) number of circular triads while 57 subjects (81.4%) made choices resulting in 10.5 or less circular triads. Guilliksen and Tukey's index of scalability provided an estimate of reliability (.78) for the information needs scale.

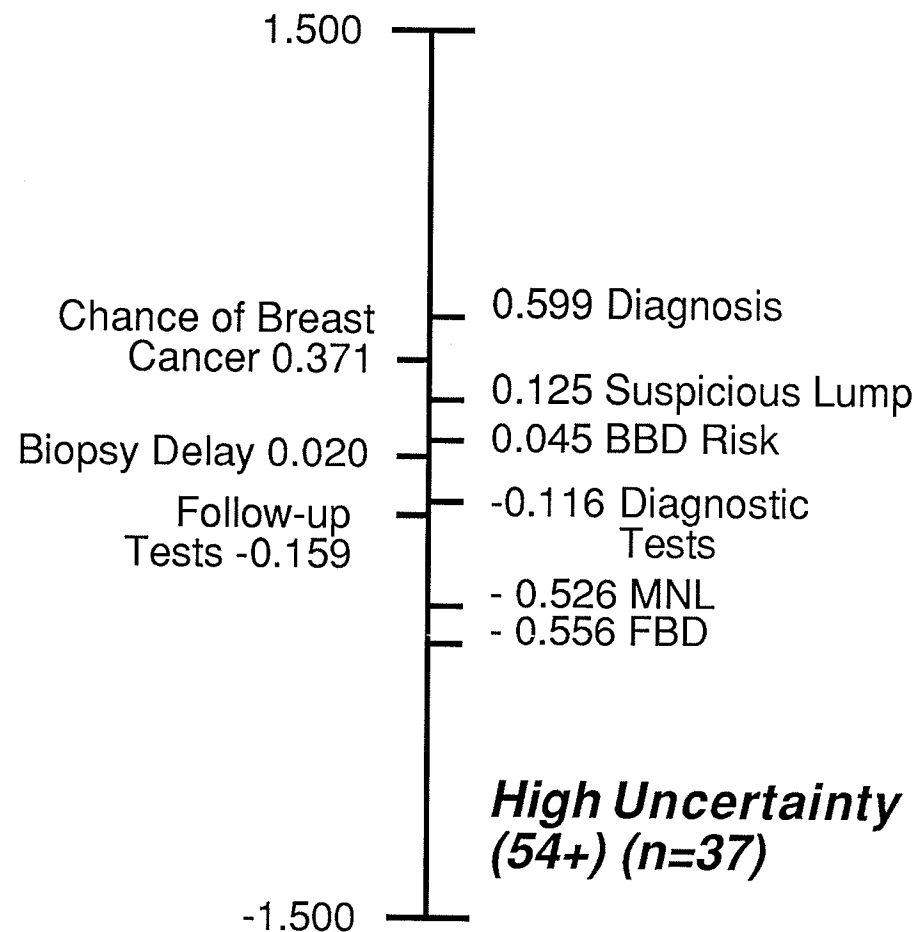
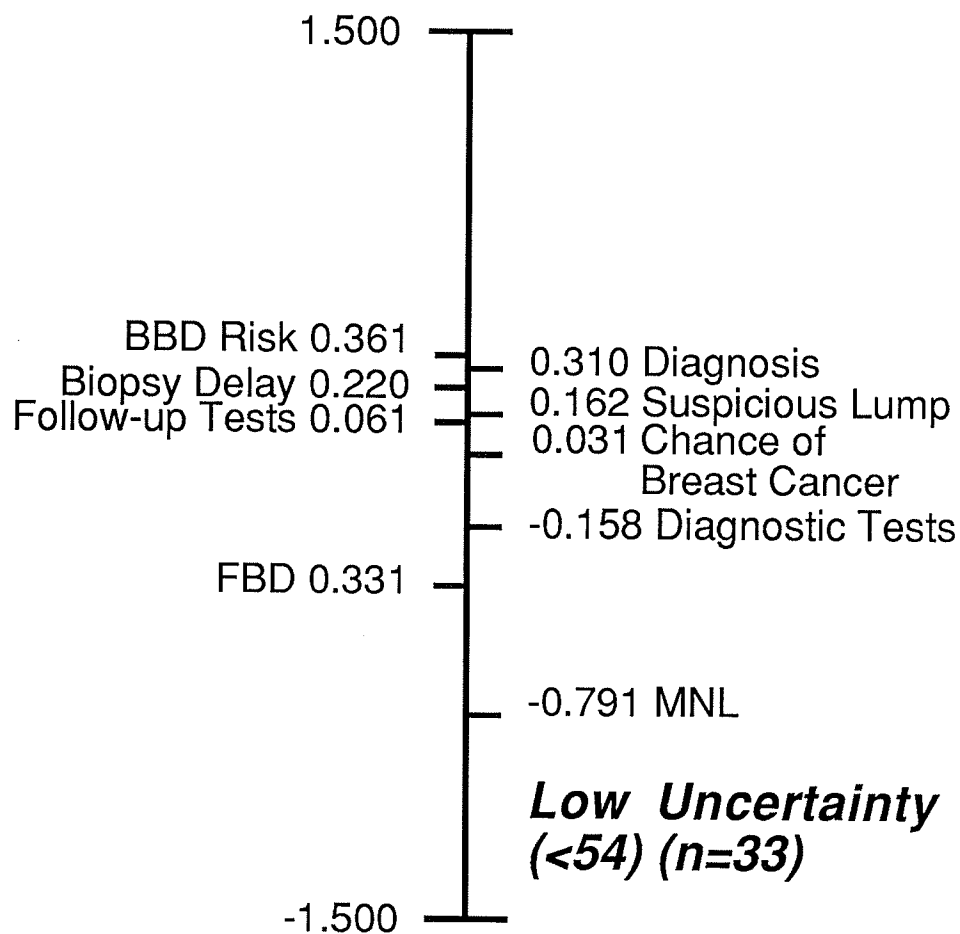
Kendall's Coefficient of Agreement (zeta) was calculated to measure the degree of consistency among subjects in judging the importance of different types of information. Zeta was calculated to determine if the number of circular triads chosen was a result of probability or contradictory judgement. The zeta coefficient ranges from 0 to 1 with a higher number representing fewer circular triads. The closer the zeta value is to 1, the

closer the subjects were to complete agreement about the relative importance of different types of information. The test for Kendall Zeta for the study sample ( $n=70$ ) resulted in a mean of .967 ( $SD=0.093$ ), indicating excellent agreement. The high Kendall's zeta demonstrates consistent comparative judgements of the most important information needs chosen by the benign breast biopsy subjects. Kendall's Coefficient of Agreement, calculated for the sample of 70 subjects with each rating nine items, was 0.132 ( $\chi^2=375.368$ , 37.603 df,  $p=0.00$ ).

Profiles of information needs were determined for women with higher and lower levels of uncertainty and anxiety. The MUIS-C Form and STAI total scale scores were split at the median score (MUIS-C Form = 54), (state anxiety = 51), and (trait anxiety = 36) to define high and low uncertainty and anxiety sub-samples, respectively. The number of patients in each of the uncertainty and anxiety sub-samples ranged from 33 to 37. The Thurstone scaling program was run on each of the sub-samples ( $n=6$ ) to provide information need profiles for women who expressed various levels of uncertainty and anxiety during the breast biopsy experience.

Thirty-three subjects comprised the low uncertainty and 37 patients made up the high uncertainty group (Figure 2). The low uncertainty sample (median < 54) was the only group to choose a different information need as the most important information. Information about the meaning of benign breast disease in terms of its risk for developing into breast cancer (#3) was rated as

# INFORMATION NEEDS PROFILES FOR LOW AND HIGH UNCERTAINTY GROUPS



more important than the information about how long after the biopsy the patient finds out if the lump is benign or malignant (#1). Information about the nature and number of tests needed to diagnose and provide follow-up care for benign breast disease were interspersed among the information needs about the risk of developing breast cancer for the low uncertainty group.

The high uncertainty group profile was similar to the total sample (n=70) profile in that high uncertainty patients grouped information in the same categories, although the order and spacing within the categories sometimes differed. Patients with high uncertainty were most interested in knowing when they would learn the diagnosis (#1) and secondly were concerned with information related to the chance of getting breast cancer (#5). The next two information needs were the same as those in the total sample profile except the order was switched, making information about what makes a lump suspicious for breast cancer (#4) the third most important information need, and the meaning of benign breast disease in terms of its risk for developing into breast cancer (#3) placed fourth on the profile.

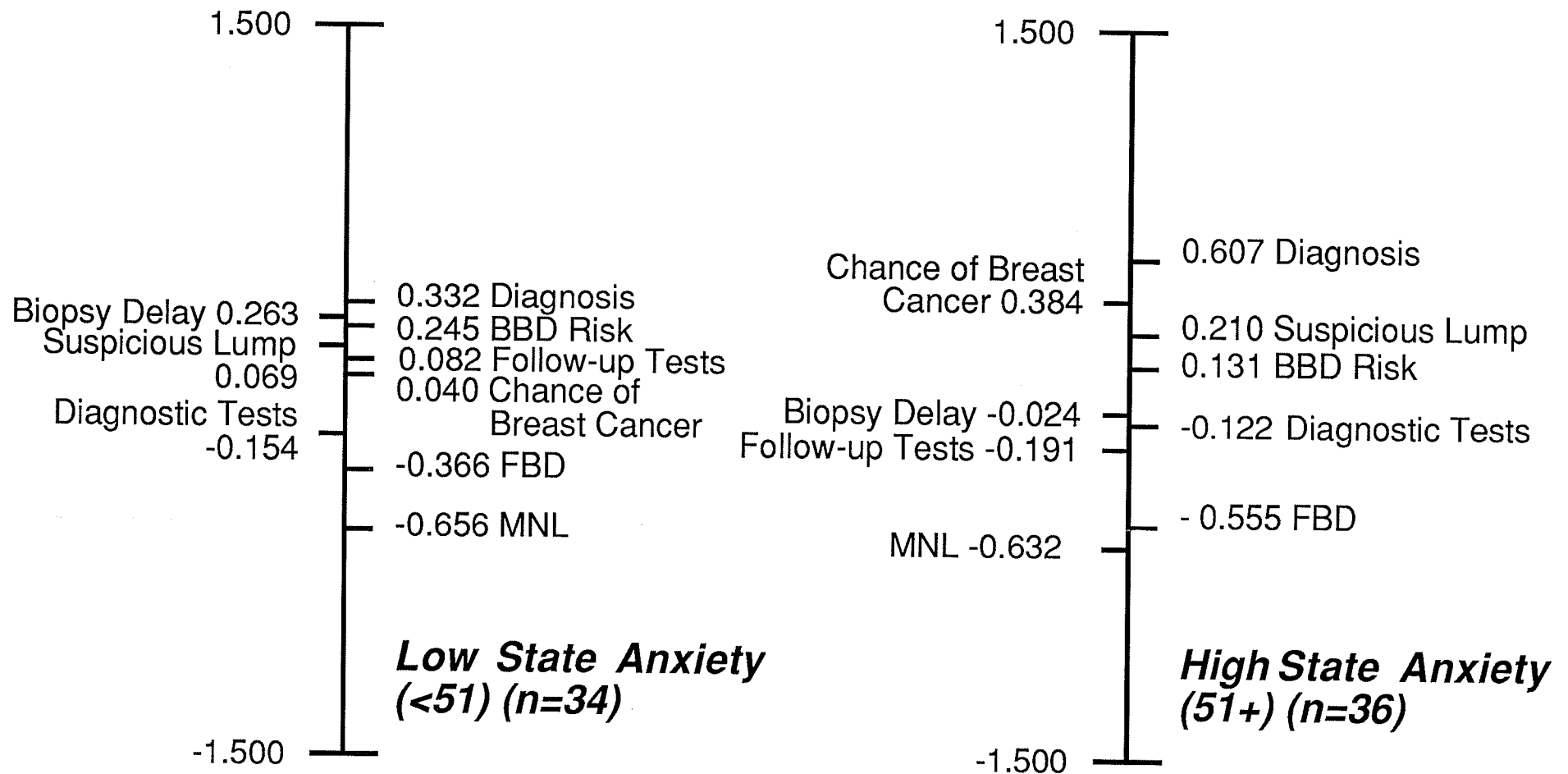
Both the total sample and the high uncertainty group chose how long one can wait before having the biopsy and being in real danger of getting breast cancer (#8) as the fifth most important information need. Information about the tests were in the reverse order in the high uncertainty group from the total sample profile. However, information about the number of tests need to give a definite diagnosis (#6) and the need for follow-up tests

after a negative biopsy (#9) were deemed less important than information about the risks associated with developing breast cancer; as in the total profile. Unlike the low uncertainty group and the total sample profile, the high uncertainty group ranked information about the mammographic needle localization procedure (#7) above information about fibrocystic disease (#2).

The low state anxiety group contained 34 subjects and the high state anxiety group consisted of 36 subjects (Figure 3). Both state anxiety groups ranked information related to how long after the biopsy they would know the diagnosis (#1) as the most important information need and information about fibrocystic disease (#2) and the mammographic needle localization procedure (#7) as the least important information needs; in eighth and ninth position on the profile respectively.

The high state anxiety group chose information about the risks of developing breast cancer (#5, #4, #3, #8) as the next four most important information needs after finding out the diagnosis (#1), followed by information related to the number of tests needed to give a definite diagnosis (#6) and follow-up tests after a negative breast biopsy (#9). The high anxiety group profile was the same as the high uncertainty profile except that the high uncertainty group reversed the order of the last two information needs. Information about the mammographic needle localization procedure was more important than information about fibrocystic breast disease for high uncertainty patients but less important for the high state anxiety sample. The low state

# INFORMATION NEEDS PROFILES FOR LOW AND HIGH STATE ANXIETY GROUPS



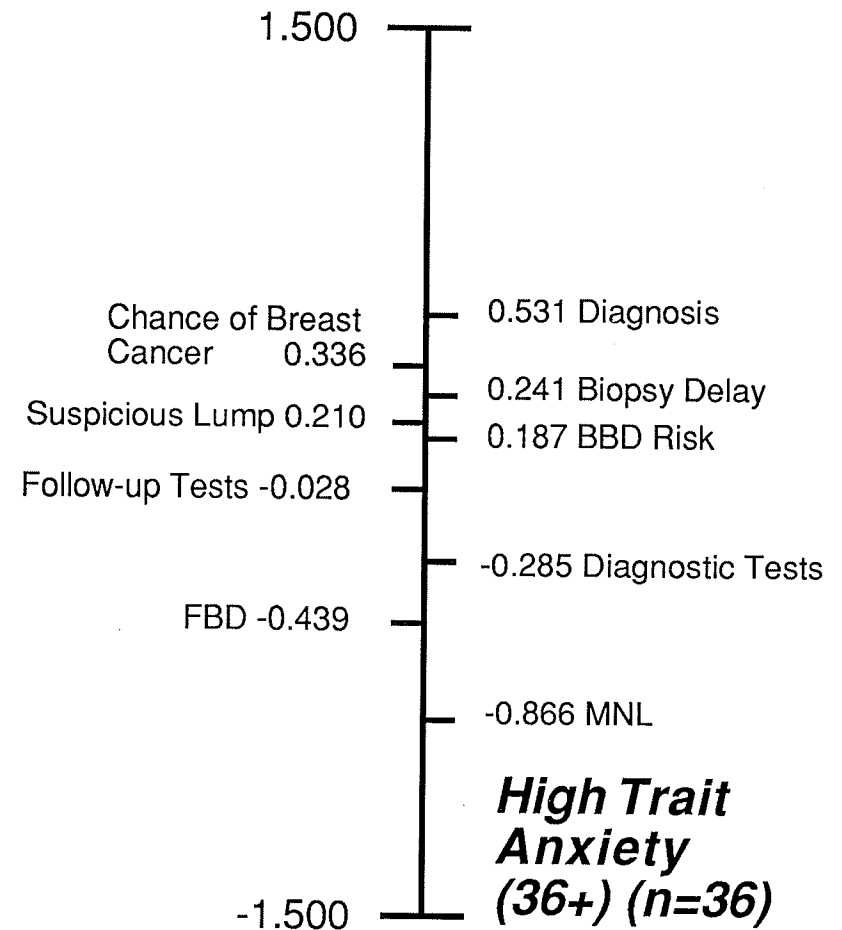
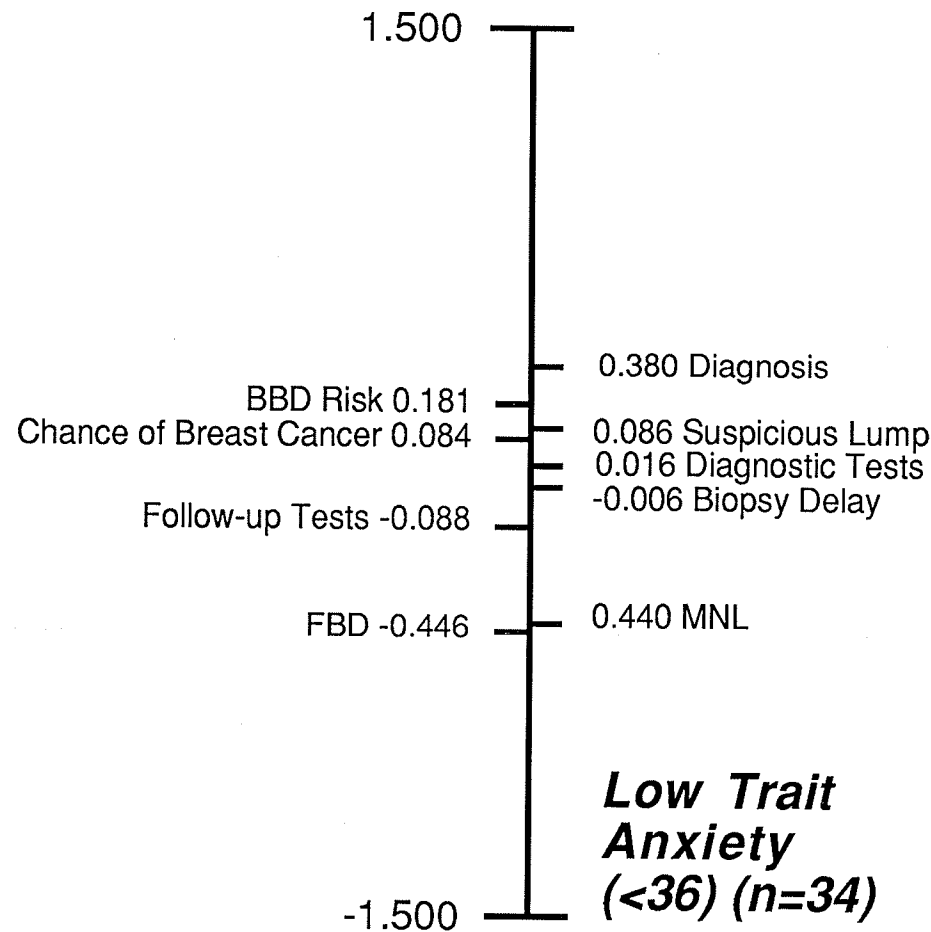
anxiety group, like the low uncertainty group, were more variable in the middle rank choices, mixing the desire for information about the risk of developing breast cancer with information about tests.

Profiles for the low trait anxiety (n=34) and the high trait anxiety (n=36) subjects are displayed in Figure 4. The high trait anxiety sample categorized the information needs in a similar manner as the total profile and the high uncertainty and high state anxiety groups. However, the order and spacing of information needs within the risk for breast cancer and test categories differed from the high uncertainty and high state anxiety group profiles. Information about when the patient would learn the diagnosis (#1) was most important and information about one's chances of developing breast cancer (#5) was ranked second for all high variable groups. Information about the need for follow-up tests (#9), the number of tests required to diagnose a lump (#6), fibrocystic disease (#2), and the mammographic needle localization procedure (#7), were in the same descending order as the total sample profile.

Differences in the high trait anxiety group and the total sample were noticed only in the rank order of the third, and fourth, and fifth information needs related to breast cancer risks. Women with high trait anxiety wanted information about how long they could wait before having a biopsy and being in real danger of getting breast cancer (#8) prior to information about what makes a lump in their breast suspicious (#4) and the meaning



# INFORMATION NEEDS PROFILES FOR LOW AND HIGH TRAIT ANXIETY GROUPS



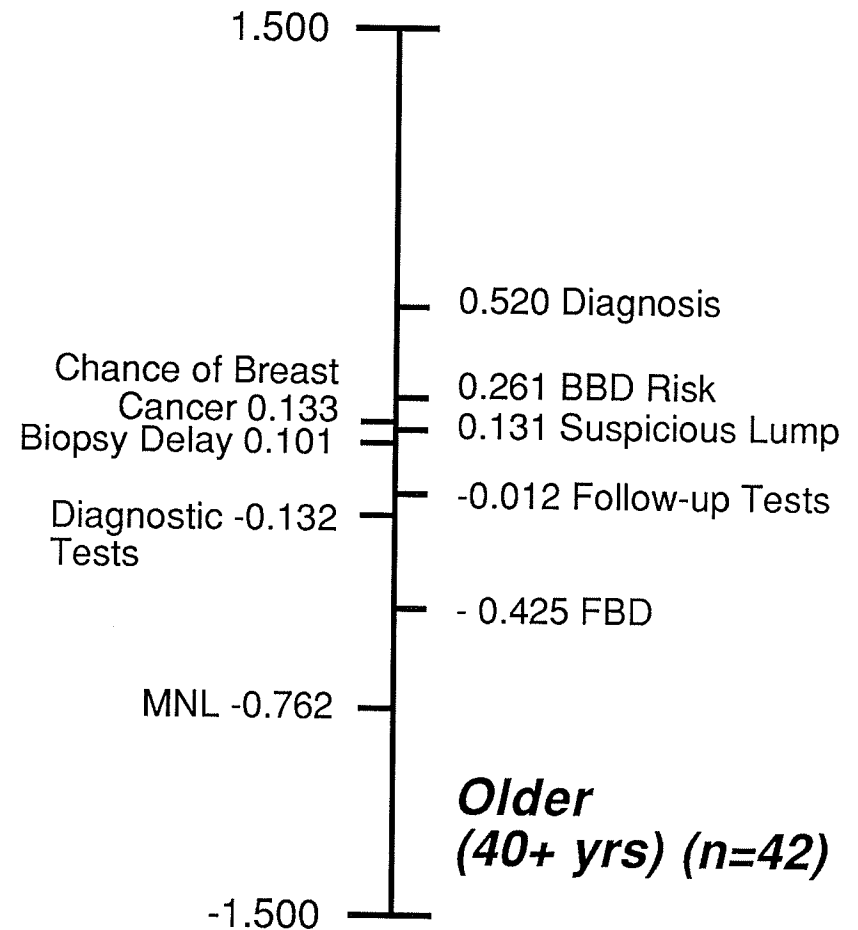
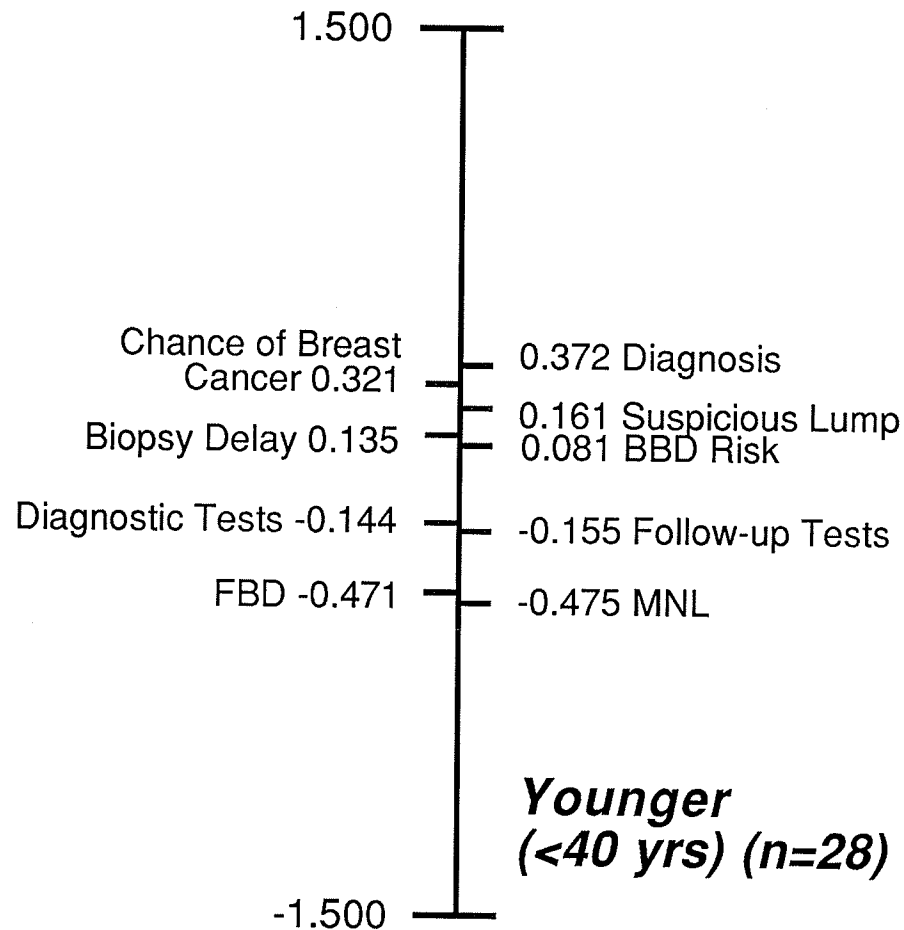
of benign breast disease in terms of its risk for developing into breast cancer (#3). Women in the total sample profile reversed this ranking to include #3, #4, and then #8.

The sample was also split by the variables of age category and experience with a loved one who had breast cancer. Profiles of information needs were determined for women who were less than 40 years of age (n=28), 40 years or older (n=42), had a relative or friend with breast cancer (n=41) and were not familiar with a breast cancer experience (n=29). Figure 5 shows the profiles for women of different ages.

Women in both age group categories ranked information about when they would learn the diagnosis (#1) as most important and information about fibrocystic disease (#2) and the mammographic needle localization procedure (#7) as least important. Although both groups chose information about breast cancer risks as more important than information about the diagnostic tests, the rank order of specific information needs varied between young (<40 years) and older (40+) women.

Younger women were more concerned with the immediate threat of breast cancer. They wanted to know what their chances of getting breast cancer were (#5) and what made the lump in their breast suspicious for developing into breast cancer (#4). The older group were more interested in the meaning of benign breast disease in terms of its risk for developing into breast cancer (#3) before knowing their chance of getting breast cancer (#5). Younger women had a similar pattern as high state anxiety

# INFORMATION NEEDS PROFILES FOR YOUNGER AND OLDER WOMEN

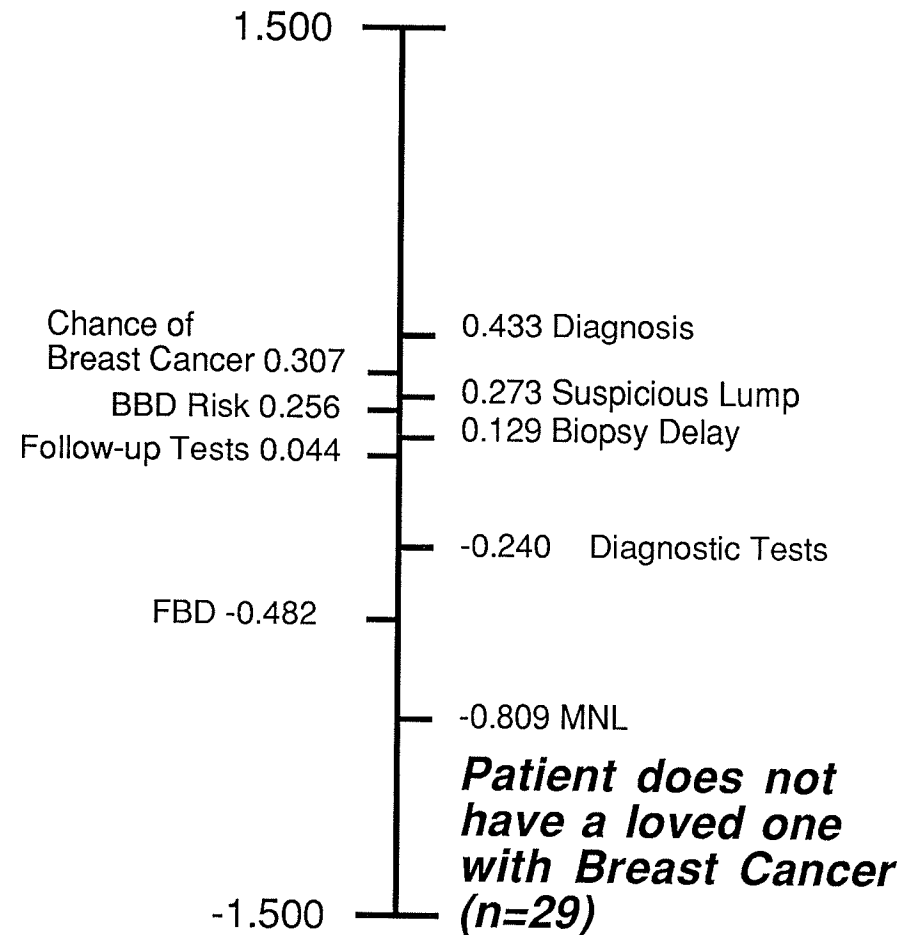
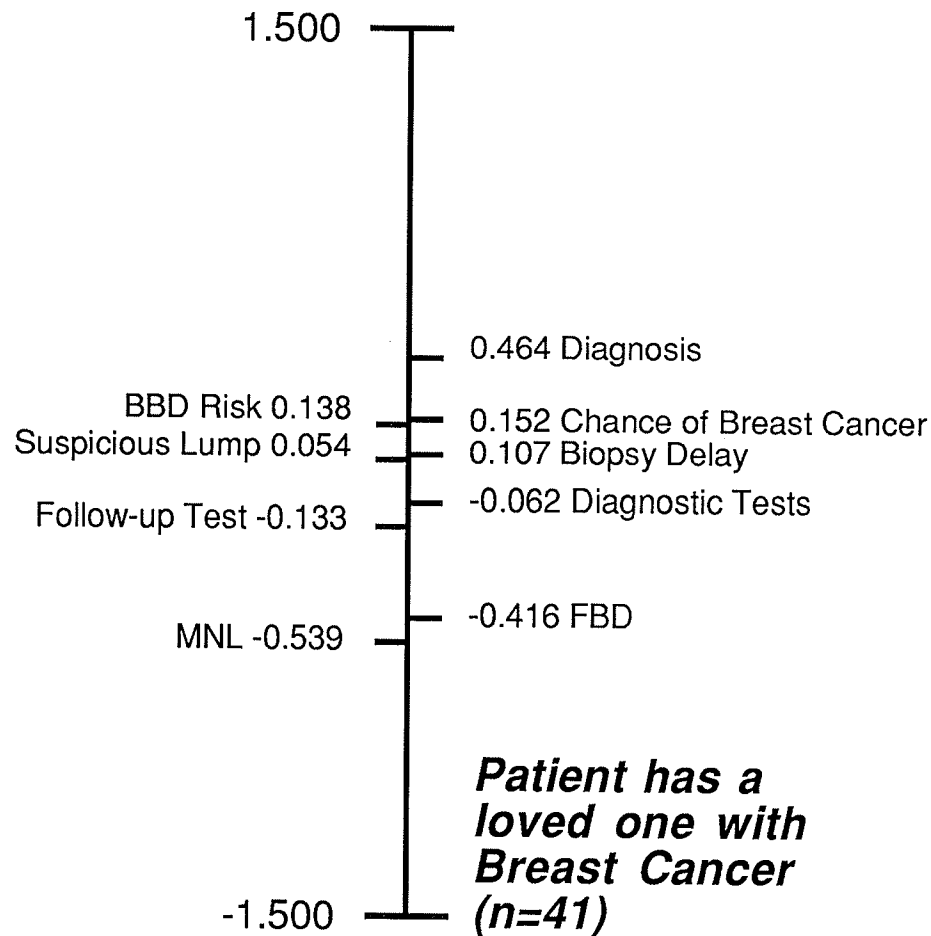


patients except that the younger women reversed the order of the fourth information need: how long one can wait before having the biopsy and being in real danger of getting breast cancer (#8) which was followed by the fifth information need: the meaning of benign breast disease in terms of its risk for developing into breast cancer (#3).

The younger group were also more interested in knowing the number of tests required to give a definite diagnosis (#6) before needing the information about the follow-up tests after a negative biopsy (#9). The older women reversed the rank order and widened the space between the two kinds of information they desired about tests. Perhaps the younger group were less familiar with the breast biopsy experience than the older group. This may have made them more interested in information about the immediate event rather than management of benign breast disease in general.

Figure 6 displays the rank order of information needs of women who had experience with a loved one having breast cancer. Twenty-nine subjects did not know a loved one with a breast cancer diagnosis while 41 women were familiar with the breast cancer experience. Both groups ranked learning about the diagnosis (#1) and information about the chance of getting breast cancer (#5) as the first and second most important information needs and information about fibrocystic disease (#2) and the mammographic needle localization procedure (#7) as eighth and ninth information needs respectively.

# INFORMATION NEEDS PROFILES FOR LOVED ONE CATEGORY



Both groups ranked information about the risks associated with breast cancer as the third, fourth, and fifth most important information need but in different orders. Women who did not have a loved one with a breast cancer diagnosis wanted information about what makes the lump suspicious for breast cancer (#4), followed by information about the meaning of benign breast disease in terms of its risk of developing into breast cancer (#3), and then information about waiting to have the biopsy and being in danger of getting breast cancer (#8). The order for the middle three information needs changed to #3, #8, and #4 for women who knew a loved one diagnosed with breast cancer.

Women who did have previous experience with a loved one's breast cancer diagnosis wanted to know about the number of tests needed to give a definite diagnosis (#6) before knowing about follow-up tests (#9). This order was reversed for those who did not have a loved one with a breast cancer diagnosis with a wider space between the two information needs. Women who knew a loved one with breast cancer may have felt that the breast cancer could happen to them since it had already touched their lives through a loved one's experience. This may have focused more attention on the need to achieve a definitive diagnosis before learning about benign breast disease care.

One qualitative question asked patients to note any other types of information that were important to them during their breast biopsy experience. Fifteen subjects (21.4%) responded to the open-ended question with comments collapsing into four

themes. The four themes included:

- 1) information about the surgical procedure,
- 2) the delay between the doctor scheduling and performing the breast biopsy,
- 3) concerns related to risks associated with follow-up benign breast care, and
- 4) the biopsy as a confirmation of a benign condition.

Five subjects (33.3%) who responded to the question were concerned about the actual surgical breast biopsy procedure. Anxiety about the biopsy related to the post-operative pain assessment, care of the suture line, the amount of tissue being excised, the meaning of a surgical biopsy, and scars resulting from the procedure. Three respondents (20%) expressed anxiety and uncertainty due to the delay between the scheduling of the breast biopsy and that actual surgical procedure. One woman referred to the experience of waiting to have the biopsy as "a nightmare", one felt that a six week time interval was too long, and one subject felt uncomfortable with the delay between the mammographic needle localization and the biopsy procedure.

Four patients (26.6%) were interested in information related to follow-up care regimes for benign breast disease. Patients commented on numerous factors related to this category including a desire to understand what causes benign and malignant breast lumps. Concerns ranged from the future need for multiple breast biopsies, resulting cosmetic effect, impact on sexual satisfaction, to fears of recurrence in the same or opposite

breast. Clarification of the difference between mammographically diagnosed microcalcifications and breast lumps elicited many questions about the effects of breast cancer treatments from one respondent. Information about the costs of breast cancer treatments, fear and risk associated with losing a breast, and surgical reconstruction alternatives was requested.

Two patients (13.3%) felt that the breast biopsy was performed to confirm a benign condition diagnosed by the physician. One patient received specific criteria from the physician such as "a soft and mobile lump" that provided assurance of the benign outcome. Agreement between the family physician and surgeon about the benign nature of the breast lump helped patients buffer the anxiety related to the breast biopsy procedure.

#### Chapter Summary

The study sample results are generalizable to the target population including benign breast biopsy patients from the breast clinic and the surgeon's general surgery practice affiliated with two community hospitals in Winnipeg, Manitoba. Most patients were over 40 years of age, married, completed post secondary education, and resided in Winnipeg. A lump resulting in a fibrocystic breast disease diagnosis was the most common symptom determining the need for a breast biopsy. Over half of the patients knew a relative or friend who had a breast cancer diagnosis.

Profiles of information needs demonstrated that information



about the diagnosis was of primary importance to patients after a benign breast biopsy. Information related to the risks associated with developing breast cancer, in general and specifically related to benign breast disease, held the next highest ranking positions on the profile. Information about tests required for follow-up care and diagnosis, although less important than breast cancer risk information, were deemed more important than information about fibrocystic disease and the mammographic localization procedure.

Complete agreement in judgement of the information needs was determined through computation of Kendall's Coefficient of Agreement (zeta). Four themes emerged from the qualitative question. These included a desire for information about the surgical breast biopsy, delay between scheduling and performing the biopsy, risks associated with follow-up breast health care regimes, and the biopsy as a means of confirming a benign diagnosis determined by the physician.

Benign breast biopsy patients in the study experienced higher uncertainty and anxiety levels than normative data mean comparison samples. Profiles of information needs for women experiencing high uncertainty and high anxiety more closely followed the pattern for the total sample. Patients with high uncertainty and state anxiety tended to prefer information about the diagnosis and the risks associated with breast cancer initially, followed by information about the diagnostic and follow-up tests, and finally information about fibrocystic

disease and the mammographic localization procedure. Women with low uncertainty and state anxiety levels produced more variable profiles with information about the risks of developing breast cancer interspersed with knowledge about specific tests required for diagnosis or follow-up breast health care.

Profiles for younger women (<40 years) also grouped information about the risk of developing breast cancer as more important than diagnostic and follow-up test information. Younger women wanted information about the outcome of the breast biopsy before increasing their knowledge about benign breast disease and breast cancer in general. The impact of knowing a loved one with breast cancer did not change the groupings of information needs. Women wanted information about breast cancer risks before test information in both groups.

## CHAPTER FIVE: DISCUSSION

### Introduction

The information needs of women who had a benign breast biopsy and the levels of uncertainty and anxiety experienced were described in this thesis. Discussion and interpretation of the study findings will be delineated in this chapter in relation to the Mishel Uncertainty in Illness Model and research involving the concepts of information needs, uncertainty, and anxiety in breast disease. Limitations of the study and implications of the findings for future nursing research and nursing practice will also be discussed.

### Mishel Uncertainty in Illness Model

Mishel (1988) described the three components of the stimuli frame that affect the level of uncertainty experienced in an illness situation. The stimuli frame components of symptom pattern, event familiarity, and event congruence provide different types of information for the patient and contribute to the assessment of the uncertainty in an illness. Benign breast disease can present as an ambiguous pattern of transient symptoms, making evaluation of the severity of the symptom pattern confusing for both the patient and difficult for the clinical practitioner. Women in this study wanted confirmation of the diagnosis, clarification of the risk of developing breast cancer, and information about the meaning of the breast cancer symptom in terms of the specific risk for benign breast disease developing into a malignancy.

The second component of the stimuli frame in Mishel's Uncertainty in Illness Model is event familiarity. Event familiarity encompasses factors; such as the health care environment, complexity of cues, and novelty associated with the illness experience; that can serve to heighten the uncertainty. In this study, novelty associated with the diagnosis of a breast cancer symptom was assessed by whether or not a patient knew a relative or friend diagnosed with breast cancer. Study findings do not support Mishel's prediction however, since there was no significant relationship found between familiarity with the breast cancer experience and the level of uncertainty experienced.

Event familiarity may have been buffered in this study by a gender effect of the physicians in both settings. Women commented favourably on the quality of the care received from both female physicians. Uncertainty and anxiety levels may have been higher except for the time that both surgeons took to explain the diagnostic process for a breast lump. Patients appreciated the surgeons' willingness to answer any questions in an unhurried manner and in language easily understood. Patients also remarked on the comfort and trust they felt with the female physician-patient relationship. In MacFarlane and Sony's (1992) study of 42 women who had a benign breast biopsy, 31% believed that more time for communication with the physician would have reduced anxiety related with the biopsy.

Event congruence, the third stimuli frame component, refers

to the consistency between the expected and the experienced in an illness situation and is indirectly related to uncertainty. A biopsy to diagnose a breast cancer symptom does not usually (80%) result in breast cancer; however, the patient commences an ongoing evaluation of risk factors for breast cancer once a symptom is presented. The fear of breast cancer is overwhelming even though the chance of developing the disease remains low for women who are diagnosed with a benign breast condition.

The number of diagnostic tests and examinations required to determine whether or not the breast lump is benign or malignant fuels the uncertainty and anxiety experienced by the patient. As well, the resulting benign breast biopsy diagnosis does not necessarily resolve the emotional turmoil for the patient. Participants in the focus group to determine the nine most important information needs of women after a benign breast biopsy stated that many unresolved concerns needed to be addressed once the imminent threat of breast cancer had been allayed (Deane, submitted).

### Information Needs

The sample in this study is representative of female patients who had a benign breast biopsy within two Manitoba community hospital surgeons' practices. The mean age of 41 years (SD=13.38) of this sample is similar to the younger control group (<40 yrs) of "near miss" benign breast disease patients in Luker et al.s (1995) study of information needs of women newly diagnosed with breast cancer. Luker et al.'s (1995) study sample

had 7.3% of breast cancer patients under the age of 40 years and 52.5% of the benign group in the younger age cohort. Benign breast disease patients in this study tended to be younger (median=43) and with more formal education (70%=high school or more) than women in Degner et al.'s (1995) study of information need of women with breast cancer (median age=58, 57.2%=more than high school education).

Women in this study, first and foremost, wanted to know the diagnosis of the breast biopsy before any other type of information. Shaw et al.'s (1994) study of women having a breast biopsy and their significant others supported this finding. MacFarlane & Sony (1992) also found that women were most concerned with the diagnostic outcome of the biopsy. These patients however, also requested information about cancer statistics which was the second most important information need for the study sample.

Information about the risks of getting breast cancer composed the next four information needs on the profile in the study sample. These information needs ranged from an interest in the knowing her chance of getting breast cancer (#5), understanding the meaning of benign breast disease in terms of its risk for developing into breast cancer (#3), determining what makes the lump in her breast suspicious for malignancy (#4), to knowing if delaying the biopsy increases the risk of a malignancy (#8). Information about follow-up tests for a benign breast disease diagnosis (#9) was more important than knowing how many

tests were needed to give a definite diagnosis (#6).

Information about fibrocystic breast disease (#2) and the mammographic needle localization procedure (#7) were deemed to be least important. Women in the focus group determined that information about the mammographic needle localization (MNL) was important and should be included in the information needs questionnaire. Although not all the women in the focus group had experienced a MNL, the anxiety and concerns expressed by those who did may have convinced all the focus group participants of the importance of this type of information. It may be that the fears associated with having to care for a needle protruding from one's breast en route to a biopsy in another hospital seemed overwhelming to the participants. One patient requested more information on the open-ended question about the delay between the MNL and the biopsy. Only the high uncertainty group and low trait anxiety group raised the position of this information need from ninth to eighth position for the sub-group profiles.

Mishel (1984) found a significant correlation between uncertainty and lack of information which led to an assumption that information was actually a dimension of uncertainty. Owens et al. (1985) found a small but significant relationship between knowledge and prompt symptom reporting. Women expressed an interest in knowing about the different types of conservative treatment options for breast cancer, stating that this information would have allayed fears and positively affected presentation of the breast cancer symptom to a health

professional. MacFarlane and Sony's (1992) retrospective study of the discovery of a breast lump, using a modified version of the trait portion of the STAI tool, found a statistically significant relationship between age, time of delay in symptom presentation, and stress levels. Subjects (45%) felt that nurses could help in reducing hospital anxiety during the breast biopsy experience.

Benign breast biopsy patients in a focus group conducted by the author expressed a need to review information about the benign diagnosis with the nurse (Deane, submitted). Patients stated that they were so anxious about the diagnosis that they were unable to remember anything else the physician explained to them at that time. However, patients were interested in acquiring more information after knowing the diagnosis without interfering with the doctor's clinic schedule. Participants believed that nurses were capable of providing this type of information and wanted more supportive and educative nursing care after the diagnosis. Hallberg and Erlandsson (1991) found that repetition of unambiguous information, given in everyday language, was a necessity for helping coronary patients cope with the uncertainty related to heart disease.

### Uncertainty

Mishel (1981) found that patients undergoing rule-out diagnostic procedures experienced higher uncertainty levels than those being treated for confirmed diagnoses. Benign breast biopsy patients in this study reported higher uncertainty levels



(mean=55.36, SD=11.86) than normative data for mixed cancer cases (mean=41, SD=10.7) but lower uncertainty scores than for normative data (mean=60, SD=17.1) for all samples studied using the Mishel Uncertainty in Illness Scale - Community Form. Women in this study experienced heightened uncertainty and anxiety related to the threat of breast cancer.

Studies have shown that patients with benign disease often experience high levels of uncertainty and anxiety related to their illness. Bailey and Nielsen (1993) found that uncertainty in women with rheumatoid arthritis was significantly correlated with uncertainty appraised as a danger. Uncertainty related to the inability of patients to determine when a flare of the symptoms would occur. Warrington and Gottlieb (1987) found that women having a hysterectomy for benign disease experienced higher levels of uncertainty and anxiety pre-operatively than on subsequent post-operate days during hospitalization. Benign breast biopsy patients are also unable to determine if and when the benign condition will turn malignant. High levels of uncertainty and anxiety of women experiencing a benign breast biopsy have implications for nursing care related to assessment and interventions that provide support throughout the diagnostic and follow-up phases.

Researchers have found that even though uncertainty and anxiety were correlated with each other, they were not related to demographic variables such as age (Northouse et al., 1995), education, or number of previous hospitalizations (Warrington &

Gottlieb, 1987). Only education, in Northouse et al.'s (1995) study of patients and husbands prior to a breast biopsy, was related to distress. However, this was thought to be related to lack of information and familiarity with medical procedures rather than formal education. In the benign breast biopsy study only the age variable nearly approached significance (1.8398,  $df=55.6$ ,  $p>.07$ ) when correlated with the uncertainty scores (MUIS-C Form). MacFarlane and Sony (1992) found a statistically significant relationship between age (29 to 39 years) and anxiety. Younger patients may be less familiar with medical procedures and more anxious about the threat of breast cancer.

Although uncertainty and anxiety are theoretically common psychological expressions in illness situations, relationships between these concepts have only recently been empirically studied. Shaw et al. (1994) found that uncertainty experienced in relation to a breast biopsy contributed to feelings of distress and that patients endeavoured to gather information in order to reduce the anxiety. Northouse et al. (1995) found uncertainty to be an important aspect of the women's distress prior to a breast biopsy with subjects expecting information to decrease the uncertainty and anxiety. Hirst and Whitehead (1984) suggested that uncertainty about the final diagnosis from a benign breast biopsy caused the anxiety.

Wong and Bramwell (1992) used the Mishel Uncertainty in Illness Scale and the State-Trait Anxiety Inventory to explore uncertainty and anxiety for 25 Canadian women who had a

mastectomy. Data was collected pre-operatively (1 to 2 days) and post-operatively (1 to 2 weeks). A significant positive correlation between uncertainty and anxiety was found only at the post-discharge time. Findings from this study suggest that uncertainty and state anxiety are significantly correlated.

Positive significant relationships were also found between total scores in the MUIS-C Form and STAI in the benign breast biopsy sample. Statistically significant positive correlations were found between uncertainty and state anxiety scores (.44039,  $p < .01$ ), uncertainty and trait scores (.35281,  $p < .01$ ), and state and trait anxiety scores (.32199,  $p < .01$ ). Identification of the factors of uncertainty and anxiety that influence each variable would provide valuable information for nursing assessments and interventions during the breast biopsy diagnostic process.

### Anxiety

This sample of women having a benign breast biopsy experienced heightened anxiety associated with the surgical procedure. The mean sample scores for state anxiety (51.67,  $SD=14.40$ ) exceeded the mean values for normative data of adult females (35.20,  $SD=10.61$ ). Trait scores for the sample (mean=36.13,  $SD=9.20$ ) were similar to normative trait values (mean=34.79,  $SD=9.19$ ) for adult females. Anxiety in women with benign breast disease has been reported to be higher than that experienced by other females (Hughes et al., 1986; Hughson et al., 1988; MacFarlane & Sony, 1992; Magery et al., 1977; Northouse et al., 1995; Scott, 1983).

Hughes et al. (1982) found that increased anxiety was associated with a biopsy of a breast cancer symptom in 107 women who were diagnosed with benign breast disease (n=140). Benign breast biopsy patients were found to have more depression and psychosocial stress than breast cancer patients. The researchers queried about the nature of the relationship between depression and psychosocial stress and its affect on the development of benign breast disease. Hughson et al. (1988) also found that benign breast biopsy patients experienced higher levels of psychosocial morbidity than both breast cancer patients and cholecystectomy patients. However, although higher anxiety was associated with a breast biopsy than for routine surgery, it was not statistically significant.

Various studies found that increased anxiety resulted in patients' decisions to delay presentation of a subsequent breast cancer symptom to a healthcare professional (Barrere, 1992; Hirst & Whitehead, 1984, Owens et al., 1985). Cognitive capacities are one of the antecedents of uncertainty determined by Mishel (1988). Scott (1983) advocated that increased anxiety negatively affected one's cognitive abilities. General reasoning ability and judged duration, which is the capacity to process information, were positively correlated with heightened anxiety prior to learning the diagnosis. Results of benign breast biopsy study showed that state anxiety, that is anxiety experienced during the breast biopsy experience, was also heightened.

Because of the nature of ambulatory care, patients in an

outpatient clinic receive most of the information about breast disease during the diagnostic phase. The high anxiety levels associated with the benign breast biopsy experience may suggest that comprehension could be diminished during the biopsy period when decision-making may be crucial. Barrere (1992) outlined a breast biopsy support program useful in assessing and providing information and emotional support during the biopsy experience.

The benign breast biopsy, considered to be a minor surgical procedure, can cause major emotional turmoil in the patient's life. Benedict et al. (1994) assessed recalled anxiety from the discovery to diagnosis of a benign breast mass in 238 women. Findings show that 58% of women reported severe and 32% moderate worry related to the diagnosis of the breast lump. The heightened anxiety related to learning the definitive diagnosis and the surgical procedure, justifies the need for a nursing intervention to support benign breast biopsy patients throughout the diagnostic and follow-up phases of breast health care (Barrere, 1992; Hirst & Whitehead, 1984).

Patients in the benign breast biopsy study requested information about the surgical procedure more than any other kind of information not included in the Information Needs Questionnaire. Nurses must be aware of the amount of information given at this intense time and ensure that comprehension and retention of important information is continually assessed. Patients may need ongoing reviews of the benign breast disease information related to follow-up care at subsequent clinic

visits.

### Limitations

External validity is compromised in this study due to the lack of a random sampling procedure. Probability sampling is the preferred choice with descriptive studies and a lack of probability sampling can inhibit the use of inferential statistics and generalizability of results. The determination of the data approximating a normal distribution permitted the use of parametric tests on the non-probability sample data.

The use of self-report instruments, with their inherent biases, may have compromised the reliability and validity of the study findings. The generic nature of the MUIS-C Form and STAI instruments sometimes caused women to ponder the actual meaning of the statement in relation to the breast biopsy experience. However, both instruments have achieved acceptable reliability coefficients in this study consistent with previous normative data. Validity has also been previously established for the MUIS-C Form and the STAI instruments.

The Information Needs Questionnaire, developed in a focus group prior to the study, involved patients from three months to two years after a breast biopsy. The consistency of the patient perceptions of the information needs determined as "most important" supports the stressful nature of the breast biopsy experience. Even though the two groups (>3 months and <3 months) may actually represent two different populations, agreement of the rank order and choice of the most important information needs

was unanimously achieved by participants during the focus group.

A social desirability bias may have occurred if subjects attempted to please the researcher and provide subjectively perceived socially appropriate answers. The chance of a physician bias was minimized by recruiting subjects from two sites. A selection bias may have occurred due to lack of random sampling and patients with similar perceptions may have comprised the quota sample. However, the excellent response rate, evidenced by only four refusals resulting in a sample of 70 subjects, does not indicate a selection bias.

The retrospective nature of the study may result in findings that are influenced by maturation of subjects' knowledge about benign breast disease. Subjects' recall of information needs important to them at the time of the breast biopsy may also be biased by the retrospective design. Study results cannot be generalized beyond the breast biopsy patients with a benign outcome from the ambulatory care breast clinic and surgeon's office.

#### Implications for Future Research

This study will serve to expand nursing knowledge related to the information needs and levels of uncertainty and anxiety in women who have experienced a benign breast biopsy. Further understanding of uncertainty related to a benign breast biopsy will be provided as well as an appreciation of the relationship between uncertainty and anxiety associated with a benign breast biopsy procedure. Future research should explore the

relationship between uncertainty and anxiety for women having a benign breast biopsy with the intent of determining which antecedents of the Mishel Uncertainty in Illness Model influence the anxiety experienced. Distinguishing the influence of specific antecedents will have implications for nursing practice.

A prospective design would provide confirmation of the study results. Replication of this study with a larger sample will validate the findings and improve generalizability of the results. As well, research to determine nurses' understanding of benign breast disease and its risk for developing into breast cancer will support the information needs of nurses caring for patients having breast biopsy procedures. Investigation of the peri-operative nurses' perceptions of the level of uncertainty and anxiety experienced by women having a benign breast biopsy on an outpatient basis will provide a foundation for developing effective nursing interventions.

Women expressed a desire for information throughout the diagnostic process. The kind and amount of information they felt they could cope with varied at different stages of the diagnostic process. Initially women were only concerned with knowing the diagnosis. However, interest in understanding the complexities of benign breast disease and its associated risk with the development of breast cancer surfaced after the imminent threat of breast cancer was alleviated. Women with benign breast disease require diagnostic stage-specific information that may affect their experience of uncertainty and anxiety during the



breast biopsy procedure. Research to determine the information needs of women who experience low uncertainty and low anxiety may provide insights into effective coping mechanisms for women during this intense time.

Information needs of women awaiting a benign breast biopsy should be studied in terms of their effect on the levels of uncertainty and anxiety experienced prior to knowing the definitive diagnosis. Qualitative and quantitative research of women who have just learned that they need a breast biopsy, women awaiting surgery in the ambulatory care unit, and women after the biopsy but before the diagnosis is known could help to differentiate which kinds of information are valuable at each stage in the diagnostic process.

#### Nursing Practice Implications

Nursing interventions must serve to educate women about the meaning of breast symptoms and the appropriate healthcare behaviours. Results from this study will provide valuable information to the breast clinic nurse, ambulatory care nurse, peri-operative nurse, and clinical nurse specialist in caring for women having a benign breast biopsy. Collaboration between these roles will ensure that quality, cost-effective nursing care could be provided to a large population of women by the existing staff levels. The incidence of breast biopsy with the associated heightened anxiety and illness implications of a prolonged stress response provide support for delineating a nursing consultation intervention. An enhanced nursing role for the breast clinic

nurse will promote supportive, facilitative, quality nursing care for patients with benign breast disease.

Presently nursing assessments occur prior to the physician examination in the breast clinic and encompass information about the nature of the breast problem, gynaecological history, and lifestyle factors contributing to breast disease. The nurse's role should also address the patient's response to health problems through a nursing consultation following the physician examination. The goals of providing emotional support and information about the informed consent, surgical procedure, screening techniques, and risks associated with breast disease fall within the realm of nursing. These goals can be met in a timely, appropriate manner by the nurse in conjunction with the physician's assessment and diagnosis of the patient's breast lump.

Patients scheduled for a breast biopsy traditionally receive a package of information before leaving the breast clinic and then teaching by the surgical day care unit nurses on the day of surgery. The breast clinic nurse could provide interval support and facilitate a patient's ability to cope with the anxiety between the scheduled and performed breast biopsy. Generally, only patients scheduled for a lumpectomy or mastectomy receive individual pre-operative instruction from the breast clinic nurse. Nursing care during the breast biopsy experience could provide emotional support for the patient and encouragement of information seeking behaviours while waiting for the diagnosis.

Pre-operative instruction has been associated for the past two decades with positive outcomes for the post-surgical patient (Hathaway, 1986). Three meta-analysis conducted by Devine and Cook, (1983); Hathaway, (1986); and Mumford et al. (1982) have supported the effects of pre-operative instruction on positive post-operative outcomes (Hathaway, 1986). Hathaway's (1986) meta-analysis of 68 studies (2413 experimental and 1605 control subjects) found an inverse relationship between the level of fear/anxiety and a favourable post-operative outcome. Individual pre-operative instruction was purported to be more effective than group instruction. However, many surgical day care units use group pre-operative instruction sessions to improve efficiency.

Patients could benefit from emotional support and information provided at the time the biopsy is scheduled from the breast clinic nurse. Literature documenting the extreme concern and anxiety evoked by the discovery of a breast lump and need for a rule-out diagnostic procedure provides support for the enhanced role of the breast clinic nurse (Hughes et al., 1986; Hughson et al, 1988; Lierman, 1988; Mishel, 1988; Scott, 1982). Hathaway (1986) promotes the role of the nurse in identifying the patient's level of anxiety and providing individualized pre-operative instruction to support the patient throughout the diagnostic phase.

A nursing consultation in a private, designated room within the breast clinic would allow the clinic nurse to assess the patient's concerns and fears related to the pending breast

biopsy. Nursing consultation could provide emotional support, breast disease and treatment information, answer questions related to the consent, and give feedback for ongoing psychosocial and information needs of the patient.

An answering machine with a private line to the nurse could ensure that the patient has a direct contact and prompt support available while waiting to have the biopsy and during subsequent treatment of her breast disease. A Focus Group conducted to determine information needs of benign breast disease patients having a breast biopsy supports the enhanced role of the breast clinic nurse. Patients expressed a desire to have a resource nurse available during the diagnostic and treatment phases to provide information, emotional support, and feedback on instructions about diagnostic tests, treatment and follow-up benign breast disease care (Deane, submitted).

A nursing consultation intervention could have positive implications for the breast clinic in the provision of holistic, interdisciplinary care. The breast clinic nurse would have a specified office within the breast clinic to conduct routine pre-assessments of new clinic patients and provide lifestyle education related to diet, exercise, breast cancer risk factors, and screening techniques for all breast disease patients. This role would facilitate efficient functioning of the breast clinic and support the physician by meeting psychosocial and informational needs of breast disease patients.

A nursing consultation intervention would further develop

the role of the nurse in caring for breast disease patients and provide justification for financial support of a Clinical Nurse Specialist role. A Clinical Nurse Specialist could provide education, administration, and research skills that contribute to positive outcomes of the breast clinic and promote cost-effective management of breast health care.

#### Chapter Summary

Women who have a benign breast biopsy experience heightened uncertainty and anxiety related to the threat of breast cancer. Nurses must respond to the patient's need for accurate information and emotional support during the intense diagnostic time through provision of quality nursing care. Future research must determine nurses' perceptions of patients' emotional experiences during a benign breast biopsy and understanding of breast cancer risks associated with benign breast disease.

Evaluation of the factors influencing uncertainty and anxiety prior to the breast biopsy will provide information to develop interventions to support women who are waiting for a definitive diagnosis of a breast lump. Nursing research could improve knowledge about breast disease patients and ensure development of appropriate and effective interventions. Quality nursing care during the breast biopsy experience will affect the patient's future behavioural and health care choices associated with breast health.

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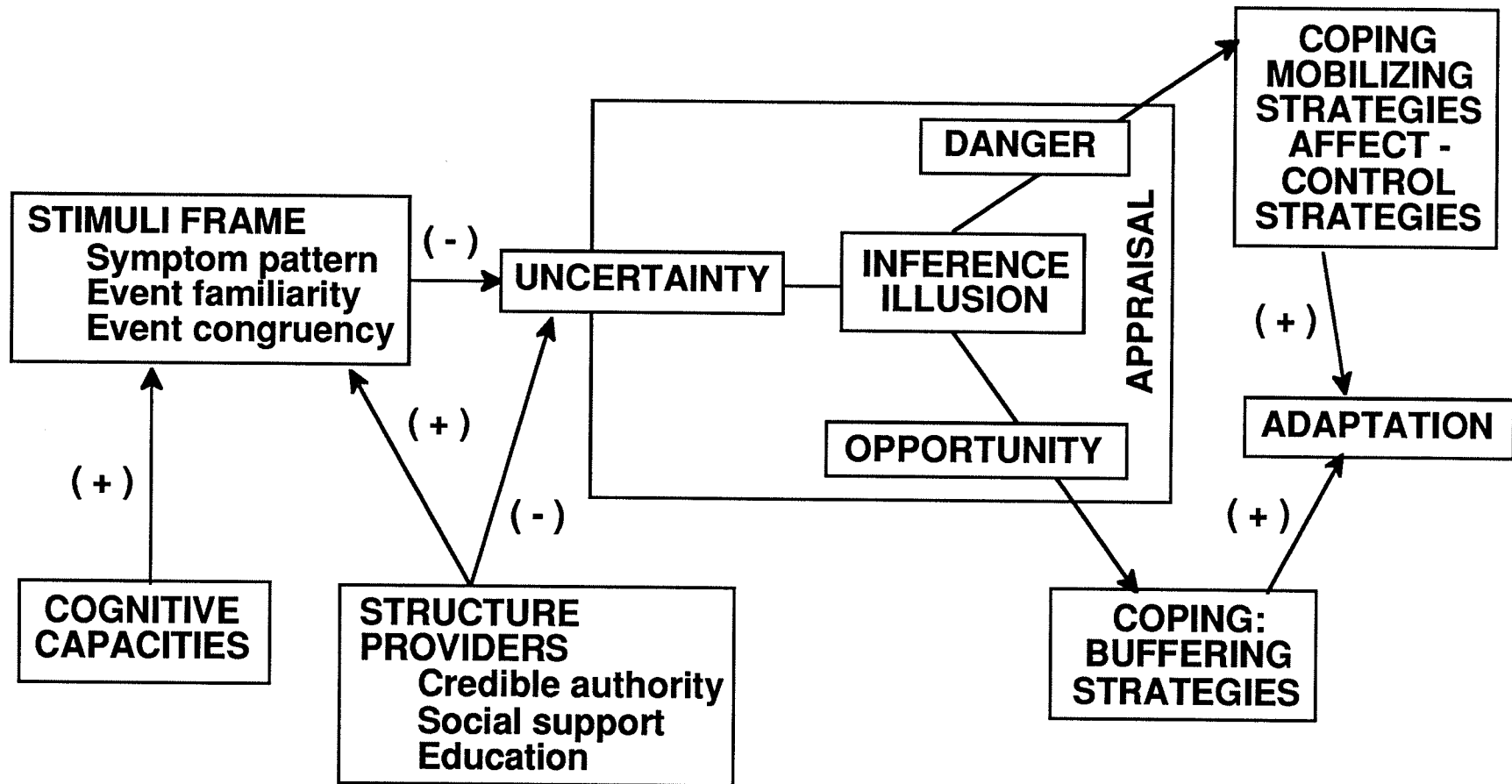
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## Appendix A

### MISHEL UNCERTAINTY IN ILLNESS MODEL

# UNCERTAINTY IN ILLNESS MODEL



## APPENDIX B

### INVITATION TO PARTICIPATE

My name is Karen Deane and I am a Master of Nursing student at the University of Manitoba. I would like to invite you to participate in a research thesis study titled: **"A Descriptive Study of the Information Needs of Women Experiencing Uncertainty and Anxiety Related to a Negative Breast Biopsy"**.

I am interested in obtaining your permission to ask you about your breast biopsy experience. I will be conducting a survey that takes approximately 20-30 minutes to complete.

## APPENDIX C

### CONSENT TO PARTICIPATE

You are invited to participate in a research thesis study titled: **"A Descriptive Study of the Information Needs of Women Experiencing Uncertainty and Anxiety Related to a Negative Breast Biopsy"**. The research study will be conducted by Karen Deane, RN, a Master's of Nursing student at the University of Manitoba. The goal of the thesis study is to describe the information needs, uncertainty, and anxiety of women experiencing a breast biopsy with a benign outcome. This study has been approved by the Ethical Review Committee of the Faculty of Nursing.

Participation in the study is voluntary and you are under no obligation to participate. Your care is not affected by whether you choose to participate in the study or not. You may refuse to answer any questions or withdraw from the study at any time.

Participants will be asked to complete four questionnaires about information needs, uncertainty, anxiety, and background information. The survey will be completed only once and takes approximately 20-30 minutes to complete. The research nurse will be present to answer questions you may have. Nine information needs will be presented in pairs for a total of 36 paired comparisons. You will be asked to choose which information need in each pair was more important to you when you had your breast biopsy. A second questionnaire will ask you questions about uncertainty in illness. A third questionnaire will ask about anxiety you experience normally and during your breast biopsy. Some personal background questions will complete the survey.

The information you give in the survey will be kept confidential. Only the researcher and thesis advisor will have access to the data. The questionnaires will have a code number and not your name and will be kept in a locked file for seven to ten years before being destroyed. Individual results will not be reported only grouped responses.

There may be no direct benefits to you personally, but participation in the study will provide information to help future women experiencing a breast biopsy.

A copy of the results will be available for your interest if you include your address.

Date \_\_\_\_\_ Participant \_\_\_\_\_

Witness \_\_\_\_\_

Address \_\_\_\_\_

**APPENDIX D**

**FOCUS GROUP ARTICLE**

Title Page

A Focus Group to Determine Information Needs  
of Women After a Benign Breast Biopsy

Karen A. Deane, RN, MN

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Text pages: 14

Figures: 2

Karen A. Deane, RN, MN was a research assistant in the St. Boniface General Hospital Nursing Research Office and a graduate student in the Faculty of Nursing at the University of Manitoba at the time of the study. Dr. Lesley F. Degner, RN, PhD, is a professor in the Faculty of Nursing at the University of Manitoba, Winnipeg, Manitoba, Canada.



A FOCUS GROUP TO DETERMINE THE INFORMATION NEEDS  
OF WOMEN AFTER A BENIGN BREAST BIOPSY

ABSTRACT

A focus group research study was conducted at a Canadian Community Hospital Breast Clinic to determine information needs of women who had experienced a benign surgical breast biopsy. One focus group interview with nine Breast Clinic patients who had a benign breast biopsy provided the researcher with findings related to the experience of a benign breast biopsy. Nine of the most important information needs for women during the diagnostic phase of a breast lump were determined. Information needs related to the types of benign breast disease, the meaning of risk associated with benign breast disease, and the diagnostic tests needed to evaluate a breast lump emerged from the focus group discussion as most important.

**KEY WORDS**

**Focus Group, Benign Breast Biopsy, Information Needs**

A Focus Group to Determine the Information Needs  
of Women After a Benign Breast Biopsy

INTRODUCTION

Women scheduled for breast biopsy experience considerable uncertainty and anxiety related to diagnosis of a breast lump. The process for determining the pathology of a breast lump involves a diagnostic triplet consisting of physician breast examination, mammogram, and fine needle aspiration. Three negative results from a diagnostic triplet provide a 98% to 99% accuracy rate. However, one suspicious or positive result warrants a surgical breast biopsy (Palmer & Tsangeris, 1993). The surgical breast biopsy is the only means of achieving a definitive diagnosis for a suspicious breast lump (Shaw et al., 1994).

Many questions arise during the diagnostic phase for a breast lump. Information related to tests and risks associated with breast cancer (MacFarlane & Sony, 1992) is valuable to women awaiting diagnosis of a breast lump. Information about many aspects of the diagnostic process need to be answered during a very compressed and anxious time for women having surgery on an outpatient basis. Anxiety and uncertainty escalate as a woman waits and ponders the meaning of the surgical outcome for her life.

Patient care should address the information needs of women awaiting a surgical breast biopsy. One approach to elicit feedback on information important to these patients is to conduct a focus group with women who have already undergone a benign breast biopsy. Lederman (1990) identified five assumptions about the nature of focus groups that support the use of this design in nursing

research. The assumptions include:

- 1) individuals are important sources of information,
- 2) people can verbalize thoughts and feelings,
- 3) a group's dynamic can generate authentic information,
- 4) group interviews are superior to individual interviews, and
- 5) the facilitator helps recover forgotten information.

The purpose of this study was to conduct a focus group to determine the most important information needs for women who have had a benign breast biopsy.

#### PRESENT STATE OF KNOWLEDGE

Focus group interviews were initially employed in marketing research to gather consumer opinions on product characteristics, advertising themes, and service delivery (Fontana & Frey, 1994). A focus group is a qualitative research technique defined as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (Kruger, 1988). A focus group consists of six to twelve people with an experience in common who share their ideas, feelings, and perceptions about a given event (Kruger, 1988).

A homogeneous group of participants promotes self-disclosure which Kruger (1988) viewed as crucial in attaining the goal of the focus group. The participants should be unfamiliar to one another but be aware of the common event they share. This level of familiarity will provide a comfortable and trusting setting in which to openly exchange personal perceptions related to a specific experience.

Although focus groups originated in the social sciences in the 1930's and were used as an exploratory marketing technique in the 1950's, they are becoming more common in nursing research endeavours (Kingry et al. 1989; Nyamathi & Shuler, 1990). In nursing, focus groups have been conducted to study factors related to the care of patients with quadriplegia (Bach & McDaniel, 1993); the elderly (Gray-Vickery, 1993); breast cancer survivors (Wyatt & Liken, 1993); women with AIDS (Nyamathi & Shuler, 1990); quality of care issues (Ambler Peters, 1993); attitudes towards student nurse assessments (Lankshear, 1993); nurse retention programs (Bartels DesRosier & Cavanaugh Zellers, 1989); and patient satisfaction (DeWolf, 1985; Horan & Pohlod, 1986). A focus group can facilitate the discovery of how people feel about an experience as well as provide valuable information about the group's attitudes and opinions related to a sensitive topic (DeWolf, 1985).

Empirical knowledge related to information needs of women experiencing benign breast biopsy is limited. However, existing research has suggested that this patient population is an appropriate and important group to study. Shaw, Wilson, & O'Brien (1994) conducted a qualitative study to determine the information needs of women and significant others prior to a breast biopsy. Subjects' uncertainty related to the diagnostic outcome resulted in distress that was alleviated only by confirmation of the benign diagnosis. Accurate, appropriate, and timely information for patients awaiting a benign breast biopsy may be effective in reducing anxiety and uncertainty experienced during the diagnostic process (Shaw et al., 1994).

Current research also suggested that women experience high levels of anxiety with a pending breast biopsy. Women undergoing breast biopsy have heightened anxiety levels as compared to general surgery patients (Hughson, Cooper, McCardle, & Smith, 1988; Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; & Scott, 1983). Although approximately 80% of all breast biopsies are negative, the woman's diagnostic journey for evaluation of the breast lump is not a benign experience due to the threat of breast cancer.

Northouse et al. (1995) studied the emotional distress of women and significant others prior to a breast biopsy. Although the sample included women with both benign and malignant diagnoses, the findings showed that the women regardless of the diagnostic outcome experienced significant levels of distress before the biopsy. Anxiety levels were found to be three times higher than for the normal population. Uncertainty, concurrent distress, lower levels of education, and hopelessness accounted for 42% of the variance in the women's distress.

Anxiety can result in poor compliance with early detection measures, such as breast self-examination and mammography screening, as well as delay in presentation of symptoms to an appropriate health care practitioner (Barrere, 1992; Calcan, 1985; Lauver, 1992; Owens, Duffy, & Ashcroft, 1985). Accurate information may decrease anxiety and facilitate the promotion of healthy lifestyles. Owens et al. (1985) found that women would have presented the breast cancer symptom more promptly to a health care professional if they had known about conservative treatments such as lumpectomy. Treatment choice, morbidity, and mortality outcomes can be affected by detection time.

Mishel (1981) found that patients undergoing diagnostic procedures to rule-out a carcinoma perceive more uncertainty than medical and surgical patients with determined diagnoses. Uncertainty in breast disease may be related to the surgical procedure itself, the threat of breast cancer, and the risks of developing breast cancer. A woman with a benign breast biopsy result requires education and supportive nursing care related to benign breast disease and follow-up care for her individual risk factors (Barrere, 1992, Shaw et al., 1994). The surgical breast biopsy procedure, generally performed on an out-patient basis, challenges the nurse to provide emotional support, breast health education, peri-operative care, and follow-up information during the patient's brief, but emotionally intense, surgical encounter.

#### SAMPLE RECRUITMENT

Ten female patients in a Canadian Community Hospital Breast Clinic who had experienced a benign breast biopsy were recruited from three age categories (<40 yrs, 40-60 yrs, >60yrs) related to the pre, peri, and post-menopausal stages. The breast clinic nurse selected names of potential patients from the medical record file and telephoned patients who met the study criteria that included:

- 1) experienced a benign breast biopsy,
- 2) over 18 years of age,
- 3) could read and understand English,
- 4) not being treated for a psychiatric problem.

The clinic nurse requested permission to provide the names and telephone numbers of patients who agreed to hear about the study. The project was

explained to potential participants by telephone and confirmation of the date and location of the focus group was obtained by the researcher. Although all ten patients agreed to participate in the focus group, one was unable to attend, leaving a sample size of nine.

#### PROCEDURE

In general, a focus group is conducted to facilitate understanding of feelings, attitudes, and opinions related to a particular experience common to all participants. Focus groups consist of six to twelve participants, unfamiliar to each other, and usually of the same sex, who agree to share feelings about a common experience in up to four interview sessions lasting approximately two hours each. Traditionally, the moderator guides the focused discussion with four to five open-ended questions ensuring that all subjects have the opportunity to participate in the discussion until saturation of the feelings, opinions, and information about the topic of interest is achieved.

Specifically, the focus group in this study was conducted to determine nine of the "most important" information needs of women who had experienced a benign breast biopsy. A modified, structured format involving completion of a demographic and information needs questionnaires followed by a group discussion was employed. The information needs questionnaire was developed by the researcher and consisted of 31 questions, derived from the literature and clinical experience, related to the breast biopsy experience. The questions were set in a Likert format with choices of very important, important, somewhat important, and not important. Seven categories of questions in the information



needs questionnaire included:

- 1) benign breast disease,
- 2) surgical breast biopsy,
- 3) diagnostic tests,
- 4) ambulatory care surgery,
- 5) post-discharge biopsy care,
- 6) breast cancer risk factors, and
- 7) breast cancer treatments.

The nine participants were welcomed with refreshments, name tags, and parking ticket reimbursement by K.D. who served as a moderator. The moderator introduced herself describing her academic and professional experience related to benign breast disease followed by an explanation of the purpose and expectations of the focus group study. Participants were asked to read and sign a disclaimer form prior to the start of the focus group.

The focus group was conducted in two parts. In the first part the individuals completed the demographic and information needs questionnaires (see Figure 1) while the second phase consisted of a group discussion to derive nine of the "most important" information needs. After completion of the demographic and information needs questionnaires, a count was taken to ascertain how many participants chose each information need as "very important". Only one information need was selected unanimously as "very important" by all nine of the participants.

A discussion of the remaining information needs chosen as "very

important" by at least 55% (n=5) of the participants followed. The information needs selected as "most important" from the "very important" choices were listed on a large blackboard for easy viewing. A general consensus of the nine information needs determined as "most important" by all the participants was achieved.

## FINDINGS

### Demographic Results

Age of participants ranged from 36 to 65 years old with a mean of 49 years. Five (55%) of the women completed education beyond high school. The remaining four women were equally distributed in the less than high school and high school categories. Five of the nine women (55%) were of Canadian background, one was Jewish, one French Canadian, one German Canadian, and one of Slovenian ethnic origin.

All of the participants had breast biopsy surgery as a Surgical Day Care patient. It was interesting to note that for five (55%) of the women, the biopsy was their first experience as a day surgery patient. All but one participant had at least one family member diagnosed with breast cancer. Four participants had the breast biopsy within the previous two months and the remaining five within the past two years.

### Information Needs Results

The nine information needs were identified from within three of the seven categories as "most important" information needs. The three categories included information about: 1) the types of benign breast disease, 2) the meaning of risk

associated with benign breast disease, and 3) the diagnostic tests required to evaluate a breast lump (see Figure 2). Information related to an ambulatory breast biopsy procedure and breast cancer treatment was deemed less important during the diagnostic phase for a breast lump. The following discussion of the nine "most important" information needs chosen by the focus group participants does not represent a rank ordering.

1) Types of benign breast disease

When the participants discovered in discussion that fibrocystic disease is only one of many types of benign breast disease, they all decided that it was very important to understand exactly what this diagnosis means. Participants wanted to be able to distinguish among various benign breast disease diagnoses such as simple cyst, fibroadenoma, papilloma, mastitis, hematoma or fat necrosis resulting from trauma to the breast.

2) Meaning of risk associated with benign breast disease

The first information need naturally led to questions about the risk associated with different types of benign breast disease. The second information need identified was: what is the meaning of benign breast disease in terms of its risk for developing into breast cancer? Participants wanted to understand how certain changes in the breast tissue were related to more or less risk of developing into breast cancer.

The third information need identified was: what makes a lump in my breast suspicious for breast cancer? This related to the individual risk factors that contributed to an increased concern by the physician about the patient's breast

lump. The fourth information need chosen was: what are my chances of getting breast cancer? Knowledge about the average woman's risk for developing breast cancer (1:9 during one's lifetime) was important as a reference point for understanding other personal risk factors.

Women also wanted to understand risk from a temporal context with concerns stemming from the time delay between scheduling and performing the biopsy. The fifth information need identified was: how long can I wait before having a breast biopsy and being in real danger of getting breast cancer? The importance of eliminating the risk as soon as possible was exemplified by group support for one woman's decision to get a second opinion when a breast biopsy was not recommended by her family physician, and another subject choosing to decline having the mammographic needle localization procedure at a preferred institution if it meant a delay in scheduling the surgical biopsy.

Anxiety related to anticipation of the diagnostic procedure elicited dramatic behaviours. Previous experience with a loved one dying from breast cancer resulted in preparation of a will after the surgery was scheduled for one participant. All participants agreed that clear information about the risk of leaving a lump in one's breast would have allayed some of the anxiety while awaiting the breast biopsy and diagnosis.

### 3) Diagnostic tests required to evaluate a breast lump

A number of concerns about the diagnostic tests and process for determining a definitive diagnosis were raised. The sixth information need selected was: how long after my biopsy will I know if my lump is benign or

malignant? This was the only information need chosen unanimously as 'most important' by all the focus group participants and was considered to be of primary importance.

Participants chose: how many tests are needed to give a definite diagnosis? as the seventh information need. Group discussion illumined the confusion, anxiety, and uncertainty experienced while undergoing unfamiliar tests and not knowing the value of each result in relation to other tests. The women were unsure if needing more tests meant that the chances of having breast cancer were higher or not.

The eighth information need identified was: what is involved in the mammographic needle localization procedure? Participants developed a new information need to address the purpose, care, and procedure involved in the mammographic needle localization procedure. Experiences ranged from painful insertion of the wire without a local to no discomfort with a local, fear of dislodging the wire during transportation between hospitals, and feeling abandoned as they arrived early in the surgical day care unit.

The ninth information need chosen as 'most important' was: do I need follow-up tests or exams if the biopsy is negative? Women expressed concern about not understanding the pathology report beyond the fact that they did not have cancer. Lack of this type of knowledge inhibited understanding the rationale for appropriate follow-up care for benign breast disease. Women felt unclear and confused about the purpose of subsequent appointments.

In summary the nine 'most important' information needs for women

experiencing a breast biopsy with a benign result related to the types of benign breast disease, the meaning of risk associated with a benign breast condition, and the diagnostic tests required to evaluate a breast lump. The most important information needs chosen by the focus group participants are outlined in Figure 2.

### DISCUSSION

Focus group research designs offer a cost-effective and efficient means of procuring information about topics of a sensitive nature such as breast disease. Information derived from focus group research designs can provide valuable insights into nursing care issues such as the experience of women having a benign breast biopsy. Generalizability of focus group study findings is not possible due to the nature of the qualitative research design. However, the results can support quantitative studies in various ways. Focus groups can aid in instrument development by ensuring face and content validity and can enhance the interpretation of quantitative findings.

Findings of the focus group determined key information needs of women having a benign breast biopsy on an out-patient basis. The focus group participants were most concerned with understanding the nature of benign breast disease, the risk of benign breast disease developing into breast cancer, and the number and type of diagnostic tests required to confirm a definitive diagnosis. Information related to breast cancer treatment (surgical, chemotherapy, and radiation) was perceived to be important after the diagnosis was known.

A shared meaning of the anxiety and uncertainty was experienced by all the women in the focus group who had undergone a breast biopsy with a benign

outcome. Women unanimously wanted to know first and foremost when the diagnosis of the breast lump would be verified. Shaw et al. (1994) also found that the priority information need for breast biopsy patients was identification of the pathology of the lump.

A general consensus of the issues related to important information needs for women awaiting a benign breast biopsy was evident regardless of the length of time since each woman's own benign breast biopsy procedure. Participants acknowledged the value of the role of the breast clinic nurse in providing emotional support and follow-up breast care information. Barrere (1992) found a breast biopsy support program valuable for women experiencing a breast biopsy.

Women expressed a desire to have comprehensive information throughout all the steps of the diagnostic process, from discovery of the breast lump through follow-up care. Information about what to expect from the tests, surgery, post-operative care, and follow-up treatment at the time of being scheduled for the breast biopsy, but before leaving the breast clinic, was deemed important. Previous research supports the importance of accurate information to reduce uncertainty (Northouse et al., 1995), dispel myths (Owens et al., 1985), and to facilitate healthy breast care behaviours (Barrere, 1992).

Adequate, appropriate, and timely information was perceived by the participants as helpful in decreasing anxiety and uncertainty and assisting with coping with the intense emotions prior to the surgical breast biopsy. Findings in studies by Hughson et al. (1988), Scott (1983), and Mishel (1981) support the high levels of anxiety and uncertainty experienced by women awaiting a breast biopsy.

Northouse et al. (1995) found that women with lower levels of education experienced significantly greater levels of anxiety prior to a breast biopsy due to unfamiliarity with the procedure.

The findings in the focus group are consistent with the literature and clinical reports. Support for research related to the experience of women awaiting a benign breast biopsy and the importance of the breast clinic and peri-operative nursing role is provided. The focus group findings have clinical implications for the importance of the information and support roles of nurses caring for women undergoing a benign breast biopsy.



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Figure 1

**INFORMATION NEEDS FOR PATIENTS**  
**AWAITING DIAGNOSIS OF A BREAST LUMP**

<b>INFORMATION NEED</b>	<b>Very Important</b>	<b>Somewhat Important</b>	<b>Not Important</b>
1.What is fibrocystic breast disease?			
2.What do pain &/or tenderness in my breast mean?			
3.Does a mammogram show if a lump is benign or malignant?			
4.Can the doctor tell by the feel of my breast lump if it is benign or malignant?			
5.What does a fine needle aspiration show?			
6.Does any one breast symptom increase my chance of risk for breast cancer?			
7.Am I more prone to cancer now that I have breast lumps?			
8.How many tests are needed to give a definite diagnosis?			
9.How long does breast biopsy surgery take?			
10.Will I feel anything with the local anesthetic?			

<b>INFORMATION NEED</b>	<b>Very</b> <b>Important</b>	<b>Somewhat</b> <b>Important</b>	<b>Not</b> <b>Important</b>
-----------------------------	---------------------------------	-------------------------------------	--------------------------------

11. Will I have pain  
after my surgery?

12. How long will I be  
in the hospital?

13. How long does the  
local anesthetic  
(freezing) last?

14. What kind of bandage  
care will I need to  
do at home?

15. How long before my  
stitches come out?

16. How long after my  
biopsy will I know  
if my lump is benign  
or malignant?

17. What precautions  
should I take after  
my breast biopsy?

18. What makes a breast  
lump suspicious for  
breast cancer?

19. What are the possible  
complications from a  
breast biopsy surgery?

20. How different will my  
breast look after my  
biopsy procedure?

21. What are my chances  
of getting breast  
cancer?

<b>INFORMATION NEED</b>	<b>Very</b>	<b>Somewhat</b>	<b>Not</b>
	<b>Important</b>	<b>Important</b>	<b>Important</b>

22.What are the different reasons for lumpectomy or mastectomy?

23.What are side effects of chemotherapy?

24.How does radiation therapy work?

25.What information do nodes give my doctor?

26.What treatments are needed for breast cancer?

27.Will I be more susceptible to lumps in the other breast?

28.Do breast problems have a relation to other 'women' problems eg. uterus, ovaries?

29.If my breast biopsy is negative and I get another lump next year, do I have to go through this procedure again?

30.How long can we wait before having a biopsy and being in real danger of getting breast cancer?

31.Do I need follow-up tests or exams if the biopsy is negative?

Figure 2

**INFORMATION NEEDS OF WOMEN AFTER A BREAST BIOPSY**

A) The types of benign breast disease:

1. What is fibrocystic disease?

B) The meaning of risk associated with benign breast disease:

2. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
3. What makes a lump in my breast suspicious for breast cancer?
4. What are my chances of getting breast cancer?
5. How long can we wait before having a biopsy and being in real danger of getting breast cancer?

C) The diagnostic tests required to evaluate a breast lump:

6. How long after my biopsy will I know if my lump is benign or malignant?
7. How many tests are needed to give a definite diagnosis?
8. What is involved in the mammographic needle localization procedure?
9. Do I need follow-up tests or exams if the biopsy is negative?

**INFORMATION NEEDS QUESTIONNAIRE**

This questionnaire will ask you to choose which kind of information was important to you while you were waiting to have your breast biopsy. Nine information needs have been paired with each other, for a total of 36 paired comparisons. **Please circle the number of the information need that was more important to you during your breast biopsy experience.** Look at each of the pairs separately and don't worry about which information need you chose in the previous pairs. You may feel there is a lot of repetition but the information needs are paired together only once.

1. How long after my biopsy will I know if my lump is benign or malignant?
2. What is fibrocystic disease?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
9. Do I need follow-up tests or exams if the biopsy is negative?
4. What makes a lump in my breast suspicious for breast cancer?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
5. What are my chances of getting breast cancer?
7. What is involved in the mammographic needle localization procedure?
6. How many tests are needed to give a definite diagnosis?
1. How long after my biopsy will I know if my lump is benign or malignant?
2. What is fibrocystic disease?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
9. Do I need follow-up tests or exams if the biopsy is negative?
4. What makes a lump in my breast suspicious for breast cancer?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
5. What are my chances of getting breast cancer?



CODE # \_\_\_\_\_

7. What is involved in the mammographic needle localization procedure?
6. How many tests are needed to give a definite diagnosis?
1. How long after my biopsy will I know if my lump is benign or malignant?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
4. What makes a lump in my breast suspicious for breast cancer?
2. What is fibrocystic disease?
5. What are my chances of getting breast cancer?
9. Do I need follow-up tests or exams if the biopsy is negative?
6. How many tests are needed to give a definite diagnosis?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
7. What is involved in the mammographic needle localization procedure?
1. How long after my biopsy will I know if my lump is benign or malignant?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
4. What makes a lump in my breast suspicious for breast cancer?
2. What is fibrocystic disease?
5. What are my chances of getting breast cancer?
9. Do I need follow-up tests or exams if the biopsy is negative?
6. How many tests are needed to give a definite diagnosis?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
7. What is involved in the mammographic needle localization procedure?

CODE # \_\_\_\_\_

1. How long after my biopsy will I know if my lump is benign or malignant?
4. What makes a lump in my breast suspicious for breast cancer?
5. What are my chances of getting breast cancer?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
6. How many tests are needed to give a definite diagnosis?
2. What is fibrocystic disease?
7. What is involved in the mammographic needle localization procedure?
9. Do I need follow-up tests or exams if the biopsy is negative?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
1. How long after my biopsy will I know if my lump is benign or malignant?
4. What makes a lump in my breast suspicious for breast cancer?
5. What are my chances of getting breast cancer?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
6. How many tests are needed to give a definite diagnosis?
2. What is fibrocystic disease?
7. What is involved in the mammographic needle localization procedure?
9. Do I need follow-up tests or exams if the biopsy is negative?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
1. How long after my biopsy will I know if my lump is benign or malignant?
5. What are my chances of getting breast cancer?

CODE # \_\_\_\_\_

6. How many tests are needed to give a definite diagnosis?
4. What makes a lump in my breast suspicious for breast cancer?
7. What is involved in the mammographic needle localization procedure?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
2. What is fibrocystic disease?
9. Do I need follow-up tests or exams if the biopsy is negative?
1. How long after my biopsy will I know if my lump is benign or malignant?
5. What are my chances of getting breast cancer?
6. How many tests are needed to give a definite diagnosis?
4. What makes a lump in my breast suspicious for breast cancer?
7. What is involved in the mammographic needle localization procedure?
3. What is the meaning of benign breast disease in terms of it's risk for developing into breast cancer?
8. How long can we wait before having a biopsy and being in real danger of getting breast cancer?
2. What is fibrocystic disease?
9. Do I need follow-up tests or exams if the biopsy is negative?

Are there any other types of information that were important to you during your breast biopsy experience?

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# APPENDIX F

## ROSS MATRIX FOR OPTIMAL ORDERING OF PAIRS

### The Ross Matrix Format

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-n	n-4	4-2	2-5	5-3	3-6	6-4	4-7
4-(n-1)	(n-1)-5	5-n	n-6	6-2	2-7	7-3	3-8
5-(n-2)	(n-2)-6	6-(n-1)	(n-1)-7	7-n	n-8	8-2	2-9
6-(n-3)	(n-3)-7	7-(n-2)	(n-2)-8	8-(n-1)	(n-1)-9	9-n	

### The Ross Matrix Applied

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-9	9-4	4-2	2-5	5-3	3-6	6-4	4-7
4-8	8-5	5-9	9-6	6-2	2-7	7-3	3-8
5-7	7-6	6-8	8-7	7-9	9-8	8-2	2-9
6-1		7-1		8-1		9-1	

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APPENDIX G- Mishel Uncertainty in Illness Scale-Community Form

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APPENDIX H- State Trait Anxiety Inventory

**APPENDIX I**

**DEMOGRAPHIC QUESTIONNAIRE**

# DEMOGRAPHIC QUESTIONNAIRE

CODE # \_\_\_\_\_

- 1) AGE:.....
- 2) MARITAL STATUS: Married..... (1)  
Widowed..... (2)  
Divorced..... (3)  
Common-Law..... (4)  
Never Married..... (5)
- 2) EDUCATION: Less than high school..... (1)  
High school diploma..... (2)  
More than high school..... (3)
- 3) USUAL RESIDENCE: Winnipeg..... (1)  
Other..... (2)
- 4) OCCUPATION: Homemaker..... (1)  
Secretary..... (2)  
Teacher..... (3)  
Nurse..... (4)  
Retired..... (5)  
Other..... (6)
- 5) ETHNICITY: English Canadian..... (1)  
Ukranian..... (2)  
French Canadian..... (3)  
English British..... (4)  
German..... (5)  
Aboriginal..... (6)  
Other..... (7)
- 6) DATE OF YOUR BREAST BIOPSY: Day \_\_\_\_\_  
Month \_\_\_\_\_  
Year \_\_\_\_\_
- 7) HORMONE USE: Birth Control Pills..... (1)  
Estrogen Replacement..... (2)  
Other..... (3)
- 8) LENGTH OF HORMONE USE:  
Less than 1 year..... (1)  
1-5 years..... (2)  
5-10 years..... (3)  
Over 10 years..... (4)
- 9) BREAST SYMPTOM:  
Lump or thickening in breast..... (1)  
Nipple discharge..... (2)  
Change in breast skin or nipple..... (3)  
Other..... (4)



CODE\_\_\_\_\_

10) DO YOU HAVE A FRIEND OR FAMILY MEMBER  
DIAGNOSED WITH BREAST CANCER?

Yes..... (1)  
No..... (2)

11) IF YES TO QUESTION (10), WHO HAD BREAST CANCER?

Mother..... (1)  
Sister..... (2)  
Grandmother..... (3)  
Aunt..... (4)  
Cousin..... (5)  
Other..... (6)

12) WHERE DID YOU HAVE YOUR BREAST BIOPSY DONE?

Misericordia Hospital..... (1)  
Victoria Hospital..... (2)

13) BREAST BIOPSY DIAGNOSIS:\_\_\_\_\_

## APPENDIX J

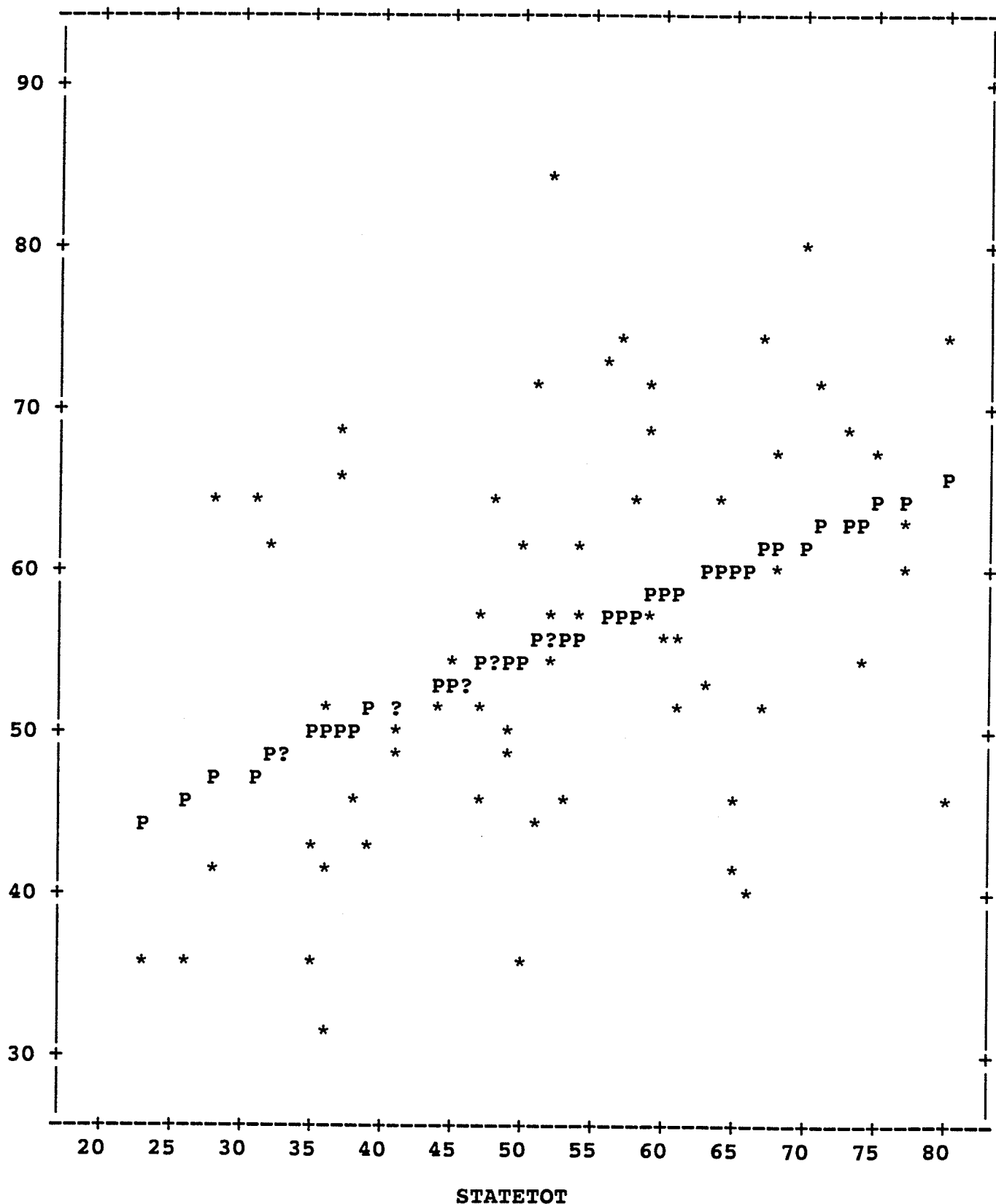
### SCATTER PLOT OF CORRELATION OF UNCERTAINTY AND ANXIETY

Benign Breast Biopsy Study  
 Uncertainty and Anxiety Correlation - Alpha

5

8:54 Tuesday, April 2, 1996

ED



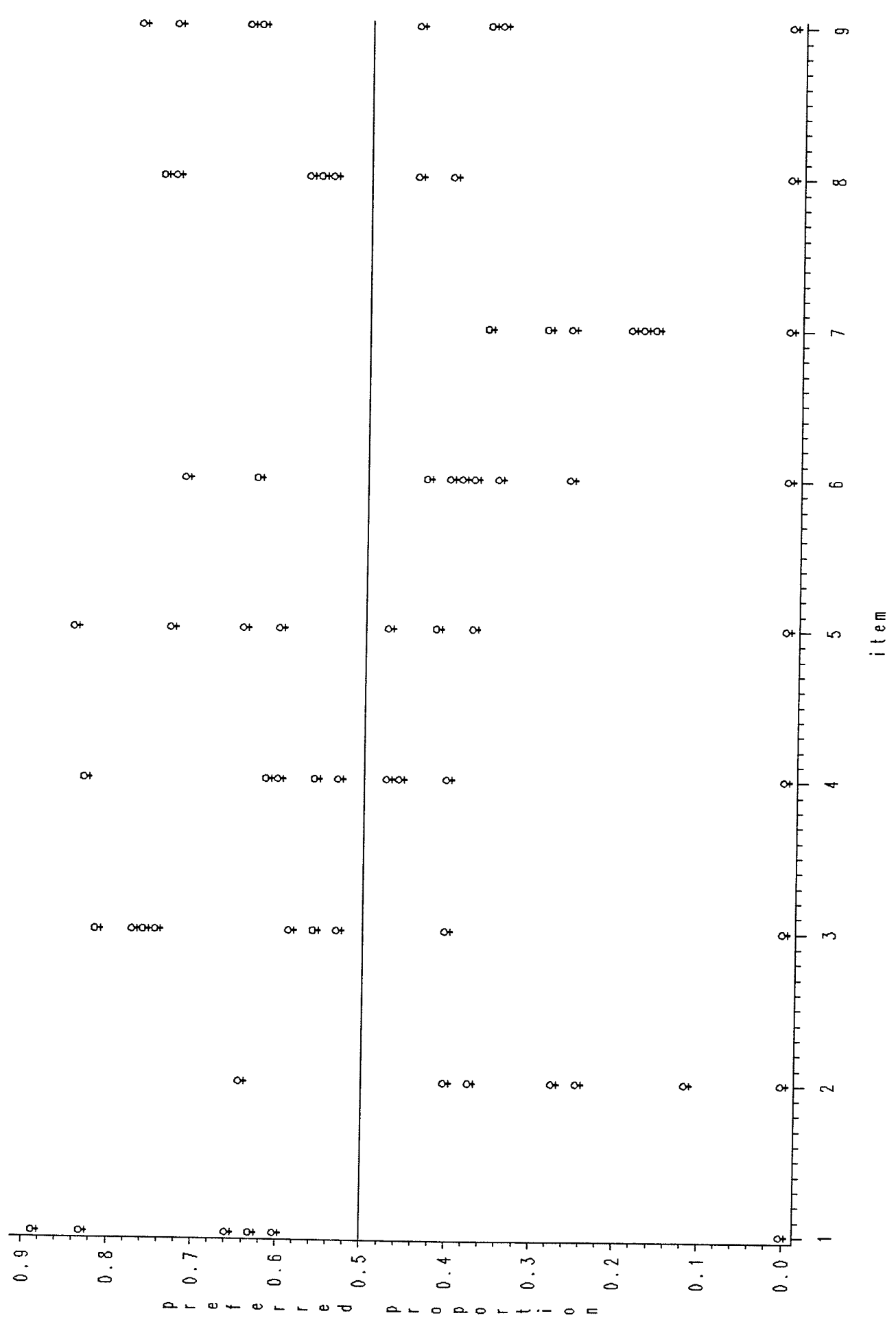
f=stai\_mui.sas

authors=bhm & kad

APPENDIX K

PREFERRED PROPORTIONS

RESULTS OF THURSTONE SCALING: CASE V



f=infodata.sas

Authors: kad, bhm, & jas

Benign Breast Biopsy Study  
PROPORTIONS MATRIX FOR CASE V

5

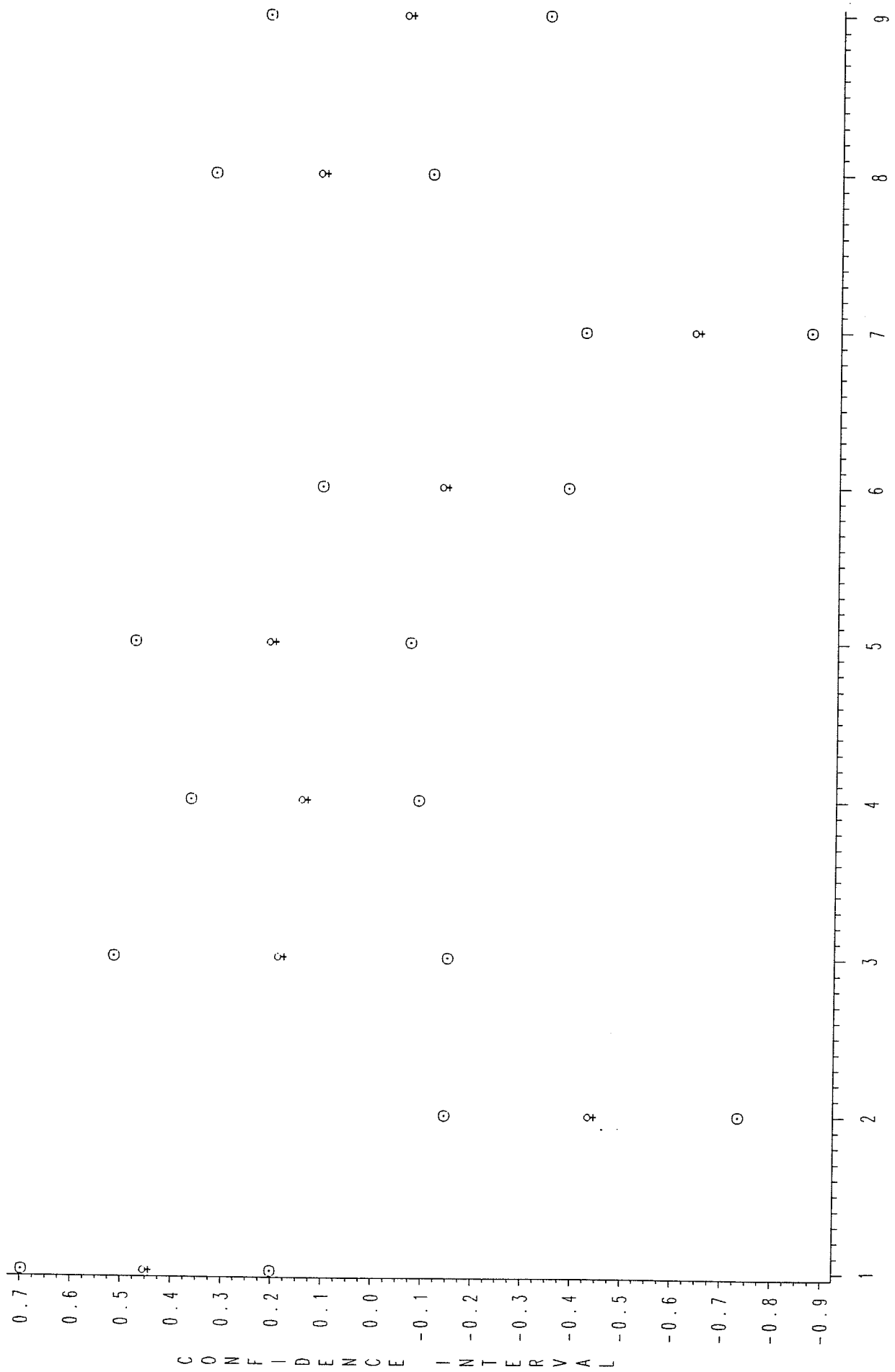
16:04 Wednesday, March 27, 1996

PROB1	PROB2	PROB3	PROB4	PROB5	PROB6	PROB7	PROB8	PROB9
0.00000	0.88571	0.60000	0.60000	0.62857	0.65714	0.82857	0.60000	0.65714
0.11429	0.00000	0.24286	0.40000	0.27143	0.37143	0.64286	0.27143	0.27143
0.40000	0.75714	0.00000	0.52857	0.58571	0.74286	0.81429	0.55714	0.77143
0.40000	0.60000	0.47143	0.00000	0.52857	0.61429	0.82857	0.45714	0.55714
0.37143	0.72857	0.41429	0.47143	0.00000	0.60000	0.84286	0.60000	0.64286
0.34286	0.62857	0.25714	0.38571	0.40000	0.00000	0.71429	0.42857	0.37143
0.17143	0.35714	0.18571	0.17143	0.15714	0.28571	0.00000	0.25714	0.35714
0.40000	0.72857	0.44286	0.54286	0.40000	0.57143	0.74286	0.00000	0.55714
0.34286	0.72857	0.77143	0.44286	0.35714	0.62857	0.64286	0.44286	0.00000

## APPENDIX L

### CONFIDENCE INTERVALS

# CONFIDENCE INTERVALS FOR SCALE VALUES: CASE V



ITEM

f=infodata.sas Authors: kad, bhm, & jas



APPENDIX M

NORMAL DEVIATES

**Benign Breast Biopsy Study**  
**NORMAL DEVIATES MATRIX FOR CASE V**

4

16:04 Wednesday, March 27, 1996

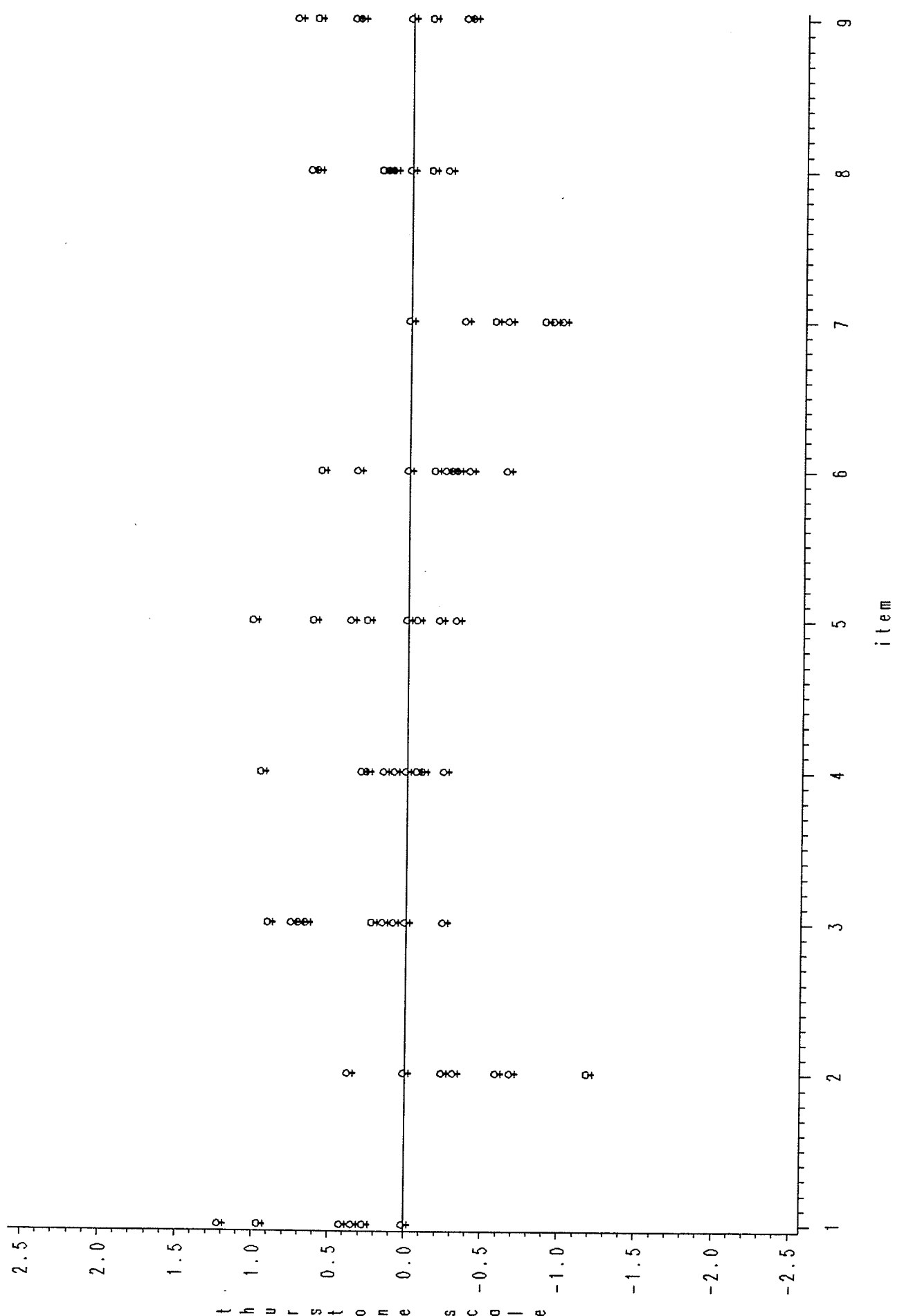
OBS	SCORE1	SCORE2	SCORE3	SCORE4	SCORE5
1	0.00000	-1.20405	-0.25335	-0.25335	-0.32807
2	1.20405	0.00000	0.69714	0.25335	0.60850
3	0.25335	-0.69714	0.00000	-0.07168	-0.21653
4	0.25335	-0.25335	0.07168	0.00000	-0.07168
5	0.32807	-0.60850	0.21653	0.07168	0.00000
6	0.40468	-0.32807	0.65218	0.29051	0.25335
7	0.94854	0.36611	0.89380	0.94854	1.00627
8	0.25335	-0.60850	0.14373	-0.10763	0.25335
9	0.40468	-0.60850	-0.74356	0.14373	0.36611

OBS	SCORE6	SCORE7	SCORE8	SCORE9
1	-0.40468	-0.94854	-0.25335	-0.40468
2	0.32807	-0.36611	0.60850	0.60850
3	-0.65218	-0.89380	-0.14373	-0.74356
4	-0.29051	-0.94854	0.10763	-0.14373
5	-0.25335	-1.00627	-0.25335	-0.36611
6	0.00000	-0.56595	0.18001	0.32807
7	0.56595	0.00000	0.65218	0.36611
8	-0.18001	-0.65218	0.00000	-0.14373
9	-0.32807	-0.36611	0.14373	0.00000

## APPENDIX N

### THURSTONE SCALING SCORES

RESULTS OF THURSTONE SCALING: CASE V



f=infodata.sas      Authors: kod, bhm, & jas

APPENDIX O

RESCALED SCORES

# RESCALED THURSTONE SCALING SCORES FOR CASE V

ITEM #	SCALE VALUE
1	15.136795424
5	13.056027741
3	12.871588176
4	12.48669573
8	12.263691832
9	10.792239022
6	10.108780261
2	7.5042285733
7	5.7799532397

note: higher score means a more preferred item

APPENDIX P

LIST OF CIRCULAR TRIADS

**Benign Breast Biopsy Study  
CIRCULAR TRIADS ANALYSIS**

16

16:04 Wednesday, March 27, 1996

IS	D	MAXTRIAD	DCRIT	ZETA	DF	CHI	PVALUE	RATER
1	19.5	30	27.2445	0.35000	20.16	23.36	0.72020	CONSISTENT
2	-1.5	30	27.2445	1.05000	20.16	56.96	0.99998	CONSISTENT
3	1.5	30	27.2445	0.95000	20.16	52.16	0.99988	CONSISTENT
4	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
5	9.5	30	27.2445	0.68333	20.16	39.36	0.99359	CONSISTENT
6	-0.5	30	27.2445	1.01667	20.16	55.36	0.99996	CONSISTENT
7	1.5	30	27.2445	0.95000	20.16	52.16	0.99988	CONSISTENT
8	-0.5	30	27.2445	1.01667	20.16	55.36	0.99996	CONSISTENT
9	9.5	30	27.2445	0.68333	20.16	39.36	0.99359	CONSISTENT
0	6.5	30	27.2445	0.78333	20.16	44.16	0.99846	CONSISTENT
1	2.5	30	27.2445	0.91667	20.16	50.56	0.99980	CONSISTENT
2	-2.5	30	27.2445	1.08333	20.16	58.56	0.99999	CONSISTENT
3	8.5	30	27.2445	0.71667	20.16	40.96	0.99597	CONSISTENT
4	1.5	30	27.2445	0.95000	20.16	52.16	0.99988	CONSISTENT
5	5.5	30	27.2445	0.81667	20.16	45.76	0.99906	CONSISTENT
6	12.5	30	27.2445	0.58333	20.16	34.56	0.97614	CONSISTENT
7	13.5	30	27.2445	0.55000	20.16	32.96	0.96410	CONSISTENT
8	-1.5	30	27.2445	1.05000	20.16	56.96	0.99998	CONSISTENT
9	2.5	30	27.2445	0.91667	20.16	50.56	0.99980	CONSISTENT
0	5.5	30	27.2445	0.81667	20.16	45.76	0.99906	CONSISTENT
1	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
2	9.5	30	27.2445	0.68333	20.16	39.36	0.99359	CONSISTENT
3	3.5	30	27.2445	0.88333	20.16	48.96	0.99966	CONSISTENT
4	-1.5	30	27.2445	1.05000	20.16	56.96	0.99998	CONSISTENT
5	19.5	30	27.2445	0.35000	20.16	23.36	0.72020	CONSISTENT
6	13.5	30	27.2445	0.55000	20.16	32.96	0.96410	CONSISTENT
7	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
8	-1.5	30	27.2445	1.05000	20.16	56.96	0.99998	CONSISTENT
9	0.5	30	27.2445	0.98333	20.16	53.76	0.99993	CONSISTENT
0	-2.5	30	27.2445	1.08333	20.16	58.56	0.99999	CONSISTENT
1	19.5	30	27.2445	0.35000	20.16	23.36	0.72020	CONSISTENT
2	3.5	30	27.2445	0.88333	20.16	48.96	0.99966	CONSISTENT
3	-1.5	30	27.2445	1.05000	20.16	56.96	0.99998	CONSISTENT
4	19.5	30	27.2445	0.35000	20.16	23.36	0.72020	CONSISTENT
5	0.5	30	27.2445	0.98333	20.16	53.76	0.99993	CONSISTENT
6	0.5	30	27.2445	0.98333	20.16	53.76	0.99993	CONSISTENT
7	2.5	30	27.2445	0.91667	20.16	50.56	0.99980	CONSISTENT
8	1.5	30	27.2445	0.95000	20.16	52.16	0.99988	CONSISTENT
9	5.5	30	27.2445	0.81667	20.16	45.76	0.99906	CONSISTENT
0	7.5	30	27.2445	0.75000	20.16	42.56	0.99749	CONSISTENT
1	3.5	30	27.2445	0.88333	20.16	48.96	0.99966	CONSISTENT
2	1.5	30	27.2445	0.95000	20.16	52.16	0.99988	CONSISTENT
3	7.5	30	27.2445	0.75000	20.16	42.56	0.99749	CONSISTENT
4	2.5	30	27.2445	0.91667	20.16	50.56	0.99980	CONSISTENT
5	16.5	30	27.2445	0.45000	20.16	28.16	0.88985	CONSISTENT
6	0.5	30	27.2445	0.98333	20.16	53.76	0.99993	CONSISTENT
7	4.5	30	27.2445	0.85000	20.16	47.36	0.99944	CONSISTENT
8	11.5	30	27.2445	0.61667	20.16	36.16	0.98439	CONSISTENT
9	8.5	30	27.2445	0.71667	20.16	40.96	0.99597	CONSISTENT
0	-0.5	30	27.2445	1.01667	20.16	55.36	0.99996	CONSISTENT
1	5.5	30	27.2445	0.81667	20.16	45.76	0.99906	CONSISTENT
2	-0.5	30	27.2445	1.01667	20.16	55.36	0.99996	CONSISTENT

f=infodata.sas

Authors: kad, bhm, & jas



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S	D	MAXTRIAD	DCRIT	ZETA	DF	CHI	PVALUE	RATER
3	-2.5	30	27.2445	1.08333	20.16	58.56	0.99999	CONSISTENT
4	7.5	30	27.2445	0.75000	20.16	42.56	0.99749	CONSISTENT
5	6.5	30	27.2445	0.78333	20.16	44.16	0.99846	CONSISTENT
6	0.5	30	27.2445	0.98333	20.16	53.76	0.99993	CONSISTENT
7	-3.5	30	27.2445	1.11667	20.16	60.16	0.99999	CONSISTENT
8	12.5	30	27.2445	0.58333	20.16	34.56	0.97614	CONSISTENT
9	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
0	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
1	3.5	30	27.2445	0.88333	20.16	48.96	0.99966	CONSISTENT
2	2.5	30	27.2445	0.91667	20.16	50.56	0.99980	CONSISTENT
3	20.5	30	27.2445	0.31667	20.16	21.76	0.63689	CONSISTENT
4	3.5	30	27.2445	0.88333	20.16	48.96	0.99966	CONSISTENT
5	21.5	30	27.2445	0.28333	20.16	20.16	0.54190	CONSISTENT
6	13.5	30	27.2445	0.55000	20.16	32.96	0.96410	CONSISTENT
7	-0.5	30	27.2445	1.01667	20.16	55.36	0.99996	CONSISTENT
8	-3.5	30	27.2445	1.11667	20.16	60.16	0.99999	CONSISTENT
9	10.5	30	27.2445	0.65000	20.16	37.76	0.98993	CONSISTENT
0	-3.5	30	27.2445	1.11667	20.16	60.16	0.99999	CONSISTENT

## APPENDIX Q

### ANALYSIS OF CIRCULAR TRIADS

Benign Breast Biopsy Study  
CIRCULAR TRIADS ANALYSIS

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# CIRCULAR TRIADS

D	Frequency	Percent	Cumulative Frequency	Cumulative Percent
-3.5	3	4.3	3	4.3
-2.5	3	4.3	6	8.6
-1.5	5	7.1	11	15.7
-0.5	5	7.1	16	22.9
0.5	5	7.1	21	30.0
1.5	5	7.1	26	37.1
2.5	5	7.1	31	44.3
3.5	5	7.1	36	51.4
4.5	1	1.4	37	52.9
5.5	4	5.7	41	58.6
6.5	2	2.9	43	61.4
7.5	3	4.3	46	65.7
8.5	2	2.9	48	68.6
9.5	3	4.3	51	72.9
10.5	6	8.6	57	81.4
11.5	1	1.4	58	82.9
12.5	2	2.9	60	85.7
13.5	3	4.3	63	90.0
16.5	1	1.4	64	91.4
19.5	4	5.7	68	97.1
20.5	1	1.4	69	98.6
21.5	1	1.4	70	100.0

RATER	Frequency	Percent	Cumulative Frequency	Cumulative Percent
CONSISTENT	70	100.0	70	100.0