"Big Deal:"

The Lived Experience of Having A

Breast Biopsy With

Benign Results

By

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#### Abstract

TITLE: "Big Deal:" The Lived Experience of Having a

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According to the American Cancer Society, one of every nine women in the United States will develop breast cancer. Women facing diagnostic breast biopsy procedures must cope not only with the surgery, but also the threat of potentially fatal disease, unpleasant treatment, and sometimes potentially disfiguring surgery. Though much is known about how women live with breast cancer, little is known about women's lived experience of having a breast biopsy when the results are benign.

Therefore, the purposes of this retrospective, exploratory, descriptive study were to describe women's experience of having a breast biopsy under general anesthesia when the pathology results were benign, to describe the actions those women interpreted as helpful and not helpful during the experience, and to understand the impact the experience had on the women's lives. Eight women, 40 to 59 years old, were interviewed individually three and one half to eight weeks after surgery. Interviews were tape recorded and transcribed verbatim. Transcriptions were then read and analyzed, using constant comparative

analysis techniques for qualitative data.

Findings indicate that women described their breast biopsy along a continuum from "totally big deal" to "no big deal," with five of them reporting some degree of "big deal" and three saying the experience was "no big deal." Aspects of the "big deal" appraisal were concerns about the possible diagnosis of cancer, surgery, and self-image. Several factors contributing to "big deal" appraisal included personal characteristics, personal knowledge of women with cancer, and congruency between expectations and experience related to physical sensations, support, minimization of the procedure, and emotional response. Another major theme was the behaviors women used to cope, including cognitive, social, practical, and affective coping behaviors. Women also described behaviors of health care professionals and others that were helpful and not helpful to them during their breast biopsy experience. The greatest impact of the breast biopsy experience on women's lives was the sense of threat experienced in the preoperative phase. No woman reported feeling that the experience would have a long-term impact on her life.

# TABLE OF CONTENTS

Pa	ge
ACKNOWLEDGEMENTS i	ii
ABSTRACT	V
TABLE OF CONTENTS	ii
LIST OF TABLES	
LIST OF FIGURES	
CHAPTER	
I. INTRODUCTION	1
Statement of Problem	
Significance to Nursing	
II. REVIEW OF LITERATURE	
Concerns of Patients Having Outpatient	,
Surgery	7
Literature Deleted to December 1	
Overview/Summary Articles	10
Personal Experience and Search	.U
for Meaning	.2
Response of Family Members to Women's	
Breast Cancer	
Uncertainty in Illness	
Supportive Relationships 2	
Caring	1
Social Support 2	2
Summary of Review of Literature 2	5
Tentative Conceptual Perspective 2	7

	viii
	Purpose and Research Questions 28
III.	METHODS
	Design
	Sampling Procedure and Sample
	Characteristics
	Protection of Human Subjects
	Data Collection and Management Procedures 37
	Data Analysis
IV.	RESULTS AND DISCUSSION
	Research Question 1: The Experience 43
	Big Deal
	Aspects of "Big Deal" Appraisal 51
	Concerns Related to Possible
	Diagnosis of Cancer 51
	Concerns about Surgery 55
	Concerns about Self-Image 57
	Factors Contributing to "Big Deal"
	Appraisal
	Personal Characteristics 61
	Personal Knowledge 64
	Congruency Between Expectations and
	Experience 65
	Emotional Response 65
	Physical Sensations 67
	Perceived Lack of Support 67
	Minimization

bummary and comparison wit	n ·	th	e					
Literature					•	•		76
Coping Behaviors	•	•			•	•		77
Cognitive Coping Behaviors	•	•	•	•			٠.	80
Information Seeking .	•							80
Self Talk	•	•		٠			•	87
Controlling Thoughts .	•	•		•	•	•		88
Putting Life On Hold .	•	٠	•	•		٠	•	90
Social Coping Behaviors .					•	•		90
Practical Coping Behaviors	•			•			•	93
Affective Coping Behaviors	•			•				95
Summary and Comparison with	ı t	he	3					
Literature	•			•	•	•		95
Memorable Events	•		•		•	•	•	97
Mammograms	•							97
Localization	•			۰				99
Experiences Women Did Not Talk	Ab	ου	ıt	•	v		1	.00
Research Question 2: Actions by Ot	he	rs	3	•		•	1	.00
Research Question 3: Impact on Lif	е		•				1	.06
Summary of Results	•	•					1	.08
V. IMPLICATIONS FOR THEORY, RESEARCH,								
AND PRACTICE			•		•	•	1	12
The Research Subject Experience .	•	•			۰		1	12
Limitations of the Study	•	•			•		1	13
Similarities to Other Findings in Re								
Theoretical Literature		•					1	15

	Suggestions for Research
	Implications for Nursing Practice 11
REFERENC	ES
APPENDIC	
A.	Subject Selection Form
В.	Introductory Letter
c.	Telephone Interview Guide
	Consent Form
E.	Initial Interview Guide

# LIST OF TABLES

1.	Number of Women Ages 40-59 Having A Breast
	Biopsy at the Study Hospital During the Data
	Collection Period
2.	Characteristics of Women in the Sample 35
3.	Factors on Which Groups Differed 60
4.	Personal Characteristics and Factors That Did Not
	Influence Women's Appraisal 63
5.	Examples of Four Types of Coping Behaviors 79
6.	Characteristics, Actions, and Behaviors
	Two or More Women Described as Helpful 102
7.	Summary of Findings

# LIST OF FIGURES

1.	Investigator's interpretation of Lazarus and Folkman's
	(1984) theory of primary and secondary cognitive
	appraisal in response to events, with resulting coping
	process reaction
2.	Stress, appraisal, and coping in the experience of a
	breast biopsy with benign results

#### CHAPTER 1

## INTRODUCTION

## Statement of the Problem

According to the American Cancer Society, one of every nine women in the United States will develop breast cancer. During 1992, an estimated 180,000 new cases of breast cancer will be discovered in American women and 46,000 women will die due to breast cancer. For the state of Oregon, the estimated number of new cases of breast cancer is 2,100 in 1992, with estimated deaths numbering 550. Breast cancer is second only to lung cancer as cause of death among American women (American Cancer Society, 1992).

According to Kleinman (1988) illness and symptoms have inescapable symbolic meanings and significance that are determined by each culture and time period. "People vary in the resources they have available to them to resist or rework the cultural meanings of illness. These meanings present a problem to patient, family, and practitioner every bit as difficult as the lesion itself" (p. 26). Cancer, at this time in Western culture, is one of the most feared and dreaded diseases (Kleinman, 1988; Lierman, 1988; Benner & Wrubel, 1989) and is viewed by some people as "death, suffering, and destructiveness" (Hilton, 1988, p. 222). The diagnosis of cancer is often experienced as stigmatizing (Kleinman, 1988; Lierman, 1988). An example of the impact

cultural meaning has on individuals is the difficulty that some people have getting or keeping a job after they have been diagnosed as having cancer (Gates, 1991). A possible diagnosis of cancer creates terror and a sense of horror, and is accompanied by the fear of a lingering and untimely death and the threat of disfiguring treatment with accompanying loss of body- and self-image. Therefore, the experience of diagnostic workup may cause great distress and alterations in coping (Kleinman, 1988; Benner & Wrubel, 1989).

Detection of changes in breast tissue may be by self breast exam, clinical breast exam performed by a health care professional, or screening mammography. While changes in breast tissue may be discovered using these techniques, a definitive diagnosis of breast cancer must be made by examination of tissues collected by fine needle aspiration or biopsy techniques (Stein & Zera, 1991). The American Cancer Society recommends that "all suspicious lumps should be biopsied for a definitive diagnosis, even when the mammography findings are described as normal" (American Cancer Society, 1992, p. 9). Although the majority of suspicious breast changes are benign, the biopsy experience itself may not be a benign one. Women facing breast biopsy must cope not only with surgery but also the threat of potentially disfiguring mastectomy or lumpectomy surgery and

fatal disease (Hughson, Cooper, McArdle, & Smith, 1988; Nielsen & East, 1990).

Devitt (1989) reported the incidence of Canadian women referred to a single consulting surgical practice for further evaluation of suspected breast disorders. Of the 2,923 women referred, 2,532 (87%) were what he called "false alarms." He summarized his perception of the women's experience of having "false alarms" following a self-discovered change in breast tissue:

The anxiety due to these false alarms can only be fully appreciated by those who have endured it. There is a tendency to forget that a woman must live with her anguish while she confirms that a symptom is really there and does not disappear either later or with her next menses. When the symptom does not disappear, her anxiety increases and she seeks an appointment with her first contact physician. There is invariably some delay in obtaining this. The excessive waiting and sometimes offhand, or less than caring, receptionists, technicians, nurses, and physicians, add to her fears. This morbidity cannot be meaningfully measured but it is an enormous public health problem that must be addressed.

Breast biopsies that yield benign results are a failure of the clinical diagnostic process, but some are necessary because of the limitations of our

diagnostic methods. However, to subject a woman and her family to the strain of a false alarm of "possible breast cancer" is cruel and possibly insensitive (Devitt, 1989, p. 1257-1258).

Devitt's opinion alluded to the anguish women experience related to the discovery and waiting and indicated that the "morbidity cannot be meaningfully measured" for this experience regardless of the final diagnosis. Hughson et al. (1988) reported that patients having breast biopsy were more vulnerable to preoperative morbidity (anxiety, depression, irritability, lethargy, social dysfunction, and inability to work) than patients having cholecystectomy surgery. Patients who had benign results were generally younger and also the most distressed.

It was my clinical perception that breast biopsy procedures were performed very frequently. To check the validity of that perception, I conducted a three week survey at a local 450 bed nonprofit urban medical center in June, 1990. Findings confirmed that women in this area experience breast biopsy procedures with benign results and that the process includes delays similar to those described by Devitt (1989). During the survey period, of the 33 women having breast biopsy procedures performed by 10 different surgeons, 28 (85%) were "false alarms (benign results), while 5 (15%) also had lumpectomy or mastectomy procedures. This rate is similar to Devitt's (1989) finding that 87% were "false

alarms." The time between scheduling the procedure and having the breast biopsy ranged from 0 to 22 days (mean = 7 days, SD = 6 days). For the five women requiring surgery for breast cancer, the time elapsed between scheduling the breast biopsy and having the lumpectomy ranged from 0 days (scheduled as frozen section, possible mastectomy) to 15 days. Of the 13,247 surgical procedures performed at the medical center during 1990, 475 (4%) were breast biopsy procedures and 136 (1%) were lumpectomy or mastectomy procedures. Therefore, while breast biopsy procedures seemed to occur frequently, they were only a small percentage of the total number of procedures performed.

## Significance to Nursing

Because breast cancer has been called primarily a disease of aging (Baker, 1991) and the population of the United States is aging, nurses can expect to work with many women who have been, are, or will be in the process of being diagnosed as having breast cancer. Little is known about women's lived experience of having a breast biopsy when the results are benign. "Lived experience", a term used by van Manen (1990), is defined in this study as the description of the perceived experience after time has passed to allow reflection. "Lived experience" also includes the continued impact the experience has on the individual and her relationships with others.

Nurses need to understand what women expect and view as helpful in order to be able to provide care that improves patient welfare and satisfaction. One way to discover what women expect and view as helpful is to ask them. With knowledge of how women interpret the experience of having a breast biopsy, nurses will be able to act with increased thoughtfulness, practical resourcefulness, and tact (van Manen, 1990).

#### CHAPTER II

## REVIEW OF LITERATURE

Abundant information, written by both health professionals and lay authors, is available about breast cancer risk factors, diagnostic procedures, treatment options, and the impact of treatment on women and their family members. Although breast biopsy is a commonly performed procedure, women's perceptions of the experience of having a breast biopsy with benign results have not been reported in the literature. The trajectory of events from prediagnosis to recovery from breast biopsy surgery and discovery of the diagnosis is complex and involves an interruption in normal life activities, dealing with multiple health care professionals, coping with the stress of facing a potentially life-threatening disease with unpleasant treatment options, and the physical and emotional stresses of outpatient surgery. Uncertainty seems to underlie the entire experience. To gain some preliminary insight into topics which seemed logically consistent with the breast biopsy experience, literature was reviewed related to concerns of patients having surgery on an outpatient basis, breast cancer, uncertainty, and the caring and support aspects of relationships.

Concerns of Patients Having Outpatient Surgery

Little research has been reported about concerns of
patients having surgery on an outpatient basis even though

the number of such surgeries performed each year is increasing markedly. Frisch, Groom, Seguin, Edgar, and Pepler (1990) studied 41 pairs of subjects, each consisting of a patient who had surgery on an outpatient basis and the support person assisting them in the immediate postoperative period at home. The surgeries included laparoscopic tubal ligation, arthroscopy, carpal tunnel release, and Dupuytren's release. Using questionnaires which subjects completed at home and returned by mail and telephone interviews on the second and seventh postoperative days, the researchers obtained an understanding of their experience of ambulatory surgery and recovery at home. Three themes emerged across all the types of surgeries. The first theme related to signs and symptoms during recovery: discomfort, swelling, bruising, nausea, grogginess, and depression. The second theme related to the helper's presence or absence. The third theme was that previous surgery experience affected the subjects' expectations and plans for recovery. Whether these findings can be generalized to women having breast biopsy procedures is unknown.

Caldwell (1991a), using an open-ended question, interviewed 76 adult patients having surgery for the first time about the most important concerns related to their outpatient surgery. A limitation of this study is that demographic information about patient gender and types of

surgical procedures was omitted. Data were collected preoperatively. Six areas of concern were identified: professional care (availability, continuity of care after discharge, competence, and quality), information (not having enough, having too much, not knowing enough to ask the right questions), the process of surgery (the surgery itself, the preoperative wait, fear of being discharged too soon, fear of anesthesia), health outcomes (fear of the unknown, the possibility of malignancy, fear of recurrence, the probability that more surgery would be required), recovery process (fear of pain and complications after discharge, fear of being dependent on others, fear of being unable to care for dependents, concern about the effect the surgery would have on the ability to carry out their usual daily activities), and personal vulnerability (feelings of anger or embarrassment). A finding important to this study is that local anesthesia generated its own type of concerns different from general anesthesia. The concerns related to local anesthesia were reported in a general way and referred to patients wanting to be "knocked out."

The findings of the two studies demonstrated that people having surgery on an outpatient basis reported a variety of concerns in both the preoperative and postoperative phases of their experiences. The concerns expressed were different in the two phases. While preoperative concerns related to the process of surgery and

recovery, health outcomes, and personal issues, the postoperative concerns focused on recovery issues. It was unclear whether women having breast biopsies were included in the preoperative study (Caldwell, 1991a). It was also unknown if women having breast biopsy surgery have the same concerns in the preoperative and postoperative phases of the breast biopsy experience.

Literature Related to Breast Cancer

Numerous books and articles, by both research and lay authors, have been written about women's experiences with breast cancer. The focus of this review is on women's experience with breast cancer including overview/summary articles; personal experience and search for meaning; and response of family members to women's breast cancer.

Women's personal histories, including their knowledge of cancer and the experiences of family and friends, shape their illness experience during all its phases and determine what is stressful to them (Benner & Wrubel, 1989). The lived experience of breast biopsy when the results are benign has not been reported in the research literature.

## Overview/Summary Articles

Stein and Zera (1991) presented an overview of the incidence, risk factors, diagnostic measures, and staging of breast cancer as well as treatment options and concerns of nurses fulfilling the perioperative role when caring for women having breast surgery for cancer. The complex issues

faced by women related to the diagnosis and treatment options of their breast cancer were summarized; however, no mention was made of women's perceptions of the experience and the impact that diagnosis and treatment had on the women as individuals. The experience of breast biopsy was mentioned only as the means for obtaining tissue to allow definitive diagnosis.

Nielsen and East (1990) presented a similar summary focused on breast biopsy. They indicated that breast biopsy is a 30 to 60 minute procedure, performed on an outpatient basis unless contraindicating pre-existing medical conditions exist. Breast biopsy can be part of a one-step (biopsy and mastectomy combined) or two-step procedure. Again, the human experience was missing from their discussion of the breast biopsy procedure.

An example of a summary article in a lay publication is the recent article by Drexler (1991). She included breast anatomy and development, common breast conditions, procedures used to diagnose breast cancer, types of breast cancer, prognostic tests, and a discussion of the politics of breast cancer focusing on the need for funds to provide screening mammograms for women with low incomes.

Description of the lived experience of having a breast biopsy when the results are benign is missing from lay publications as well as professional literature.

# Personal Experience and Search for Meaning

Women respond to the possible diagnosis of cancer with "terror and a sense of horror and even betrayal" (Benner & Wrubel, 1989, p. 270), anxiety, anger, guilt, depression, and fear (Benner & Wrubel, 1989; Baker, 1991; Lierman, 1988). Cawley, Kostic, and Cappello (1990) discovered that 55% of 160 subjects who had breast conserving surgery for early stage cancer responded positively to the question, "Did you find the surgery upsetting in any way?". The major areas of concern related to the diagnosis of cancer and its implications, fear of anesthesia, being hospitalized, and delays in scheduling the surgery. These concerns related to the presurgical period and may be present in women facing breast biopsy procedures.

Lierman (1988) used a semistructured guide when interviewing a convenience sample of 20 women one month following mastectomy for breast cancer. The purpose of this retrospective study was to examine women's responses to the discovery of breast symptoms. Women were asked to describe their breast symptom, how and when it was initially discovered, what the experience of discovery was like for them, what they did when they discovered the breast symptom, and when they first sought medical help. Women's responses varied from seeking help from their physician very soon following the discovery to preparing for death. Delay in help-seeking ranged from less than one week to seven years.

Lierman identified both emotion-focused and problem-focused coping patterns in women responding with both early and delayed help-seeking behaviors. Emotion-focused coping referred to "cognitive maneuvers" used to "change the meaning of the situation without changing it objectively" (Lierman, 1988, p. 353). "Problem-focused coping strategies are directed at defining the problem, generating alternative solutions, weighing alternatives, choosing among them, and finally performing some action specifically directed at the situation" (Lierman, 1988, p. 353). These definitions are based on the work of Lazarus and Folkman (1984). For some women who delayed help-seeking, fear of loss of control over one's life, being a burden on others, and a need to maintain control and independence seemed to be important. Implications for nurses arising from the study included helping women to develop new coping skills, being advocates to encourage and assist women to ask questions, and realizing that some women do not wish to participate in diagnostic and treatment decision-making.

In a descriptive, qualitative study, Moch (1990) conducted open-ended interviews of a convenience sample of 20 women who had lumpectomy or mastectomy for cancer. The purpose of this study was to describe the experience of health for women diagnosed with breast cancer. Interviews were analyzed using constant comparative methods. Six themes related to the experience of breast cancer were

identified: getting information and making choices, coping with the physical aspects, dealing with lack of control or possible recurrence, being hopeful about the prognosis and optimistic about life, changing relatedness, and identifying meaning and adding new perspectives about life. A finding of importance was that 80% of these women spoke about changes in their perspective about life. "Many women spoke of profound realizations about what was important in their lives" (Moch, 1990, p. 1430).

Similar results emerged from analysis of interviews conducted within six months of cancer diagnosis with 30 randomly selected patients (10 men and 20 women) (O'Connor, Wicker, & Germino, 1990). Two-thirds (18) of the sample had breast cancer and the others had either lung or colorectal cancer. The six themes that emerged from content analysis of interview transcripts were seeking an understanding of the personal significance of the cancer diagnosis; looking at the consequences of the cancer diagnosis; review of life; change in outlook toward self, life, others; living with the cancer; and hope. An additional finding was that the "search for meaning appears to be both a spiritual and psychosocial process" (O'Connor et al. 1990, p. 174).

Women with breast cancer must work through uncomfortable, negative emotions before coming to acceptance. Examples of the emotions women experience appeared in an article in a lay publication in which Ann

Jillian, an actress, and Betty Ford, wife of former president Gerald Ford, spoke of their reactions to breast cancer. They referred to having feelings of having failed, being at fault, taking the blame, shock, grieving, loss of femininity, anger, and eventually acceptance (Casey, 1991).

The results of these qualitative studies indicate that women dealing with known cancer diagnosis report a variety of concerns; cope with the discovery of cancer symptoms in a variety of ways; and experience a variety of feelings, for example, anger, shock, feeling at fault, and hope. It is unknown if women facing possible cancer diagnosis as determined by the pathology results of breast biopsy have similar concerns, coping mechanisms, and feelings.

# Response of Family Members to Women's Breast Cancer

Northouse and Swain (1987) used three instruments to measure three aspects of the psychosocial adjustment after mastectomy for breast cancer: the Affects Balance Scale to measure mood, the Brief Symptom Inventory to measure symptom distress, and the Psychosocial Adjustment to Illness Scale to measure role functions. Subjects included 50 women who had mastectomy for breast cancer and their husbands.

Subjects were interviewed 3 days after surgery and again 30 days later. Results indicated that women's breast cancer had an impact on the family system as evidenced by the finding that husbands reported levels of distress and exhaustion similar to that of their wives. An important

implication of this finding is that both the patients and their husbands need support.

Northouse (1989a) reported an additional aspect of the same study in which the women and their husbands were interviewed separately at 3 days and 30 days after the mastectomy procedure. The purposes of these parts of the study were to describe the emotional concerns of patients and their husbands in the hospital and one month after discharge, to describe the initial reactions of patients and their husbands to seeing the mastectomy incision, to determine which phase of illness patients and their husbands perceived as most stressful, and to identify factors that helped patients and their husbands cope with the effects of illness immediately after surgery and at home. Structured interviews were tape recorded, transcribed and analyzed for themes and recurrent responses for each time period (i.e. in hospital and at home one month later). Results indicated that while women and their husbands were both concerned about survival, the way they expressed their concerns differed. Only a small percentage of husbands had difficulty viewing the mastectomy incision. Although husbands reported the hospitalization period as the most stressful, the women indicated that the preoperative period was more stressful than the period of hospitalization or the time at home after discharge. "Several factors apparently contribute to the stress before surgery: a pervasive sense

of uncertainty about their situation, bureaucratic scheduling problems that delay surgery, insufficient information about their condition, and the need to make overwhelming treatment choices with minimal contact or guidance during this time from health care professionals" (Northouse, 1989a, p. 283). Emotional support, religion, information, and attitude were factors that helped these women and their husbands cope with the effects of illness.

Northouse (1989b) administered the Affects Balance Scale, the Brief Symptom Inventory, and the Psychosocial Adjustment to Illness Scale to 43 women and 41 husbands of the original sample at 18 months post surgery. The purpose of this follow-up study was to assess subjects' ongoing psychosocial adjustment. Findings, consistent with the earlier study, indicated that psychosocial adjustment was an ongoing process. Husbands reported levels of distress that did not differ significantly from the level of distress reported by the patients across the three assessment times.

Baker (1991) in a book for lay persons, wrote of the responses that daughters have to their mother's breast cancer. She wrote poignant descriptions of individual reactions such as the fears of being abandoned, intimacy, childbirth, having their breasts touched, dying at the same age as their mothers did, denial, and loss of ability to trust.

# Uncertainty in Illness

As suggested by Northouse (1989a), a sense of uncertainty contributed to women's stress before breast surgery. Other authors have identified uncertainty in women's experience of gynecological (Mishel & Braden, 1987, Mishel & Braden, 1988) and breast cancer (Hilton, 1988; Northouse, 1989a; Spindler, 1991). Breast biopsy is performed to determine or rule out a definitive diagnosis of cancer. Breast biopsy is stressful and may reasonably be associated with uncertainty related to both the surgical experience and the prospect of having breast cancer.

Mishel has conducted a program of research related to uncertainty in illness. Uncertainty in illness has been defined in a variety of ways with some common elements emerging. Mishel (1984) referred to uncertainty as a cognitive state occurring when an event cannot be structured or categorized due to insufficient cues. Mishel and Braden (1988) expanded the definition to include the inability to determine meaning, values, and the future. Components of uncertainty in illness included ambiguity concerning the state of the illness, complexity concerning treatment and the system of care, lack of information concerning diagnosis and severity of illness, and unpredictability of the course of the illness and its outcomes. Hilton's (1988) definition included the time dimension indicating that uncertainty changes over time and is accompanied by various emotions

such as anxiety, fear, anger, wonder, frustration, helplessness, curiosity, and depression.

In an early study (Mishel, 1984) of 100 systematically selected medical patients, all but 3 male, in a Veterans Administration hospital, subjects were asked to complete three questionnaires designed to determine if uncertainty about symptoms, treatment, and outcome were major predictors of stress experienced by hospitalized patients. The three instruments included the Likert-format Mishel Uncertainty in Illness Scale to measure uncertainty, the Hospital Stress Rating Scale to measure psychosocial stress during hospitalization, and the Seriousness of Illness Rating Scale used for determining the seriousness of the primary diagnosis. Multiple regression analyses were used to construct a model showing the complex nature of the relationships of uncertainty and other factors (such as seriousness of illness, level of education, age, and prior hospitalization) on perceived stress during hospitalization. An acknowledged limitation to this study was limited generalizability of findings because few women were included.

Further studies conducted by Mishel and her colleagues have focused on testing and refining theories related to uncertainty in illness. Using a sample of 61 women receiving treatment for gynecological cancer, Mishel and Braden (1988) tested and refined a model of antecedents of

uncertainty. Antecedents were identified as the "stimuli frame" (symptom pattern and event familiarity) and "structure providers" (social support, education, and credible authority). In this study only the complexity and ambiguity aspects of uncertainty were included. Findings of this study indicate that event familiarity and credible authority reduced the complexity aspect of uncertainty and social support decreased the level of the ambiguity aspect of uncertainty. Using a sample of 100 women receiving treatment for gynecologic cancer, Mishel, Padilla, Grant, and Sorenson (1991) replicated an earlier study focusing on testing a model of the mediating function of mastery and coping on uncertainty in illness. These studies contributed to the development of theories of uncertainty in illness. The results call attention to the complexity of patients' experience of uncertainty.

The value of the studies related to uncertainty in illness lies in the description and identification of factors influencing the phenomenon of uncertainty. However, this research has been focused on persons with long-term diseases (chronic diseases or prolonged acute illness requiring hospitalization). A neglected population is persons experiencing a diagnostic surgical procedure.

# Supportive Relationships

The need for supportive relationships during times of illness has been well documented (Smith, Redman, Burns, &

Sagert, 1985; Mishel & Braden, 1987, 1988; Mishel, 1988; Hilton, 1988). Support can come from nurses and others in the patient's social network. Researchers have identified actions which patients perceive as caring or noncaring and have investigated the impact of dimensions of support provided by health care providers and other people on patients' illness experience.

### Caring

Nurses have the opportunity to make a difference in patients' experience of illness. According to Benner and Wrubel (1989), "When we are ill we want to feel cared for" (p. 399). Discovering the patient's concerns and acting to help them manage those concerns demonstrates caring. When nurses' actions match the patient's perceived need, the patient interprets the action as caring (Brown, 1986).

Although "caring" is difficult to define, reported research includes several common themes. Behavior interpreted as caring involves the patient being treated as an individual with unique qualities and needs (Brown, 1986; Gaut, 1986; Swanson-Kauffman, 1986) and the nurse being "present" with the patient in an emotionally engaging way (Grossman-Schultz & Feeley, 1984; Brown, 1986; Swanson-Kauffman, 1986). Being watchful, anticipating what the patient needs, and meeting those needs ("doing for") is another common aspect of caring (Brown, 1986; Swanson-Kauffman, 1986). Other themes of caring include providing

information, demonstrating professional knowledge and skill, assisting with pain control, spending more time with the patient than was necessary, and promoting patient autonomy (Brown, 1986).

In contrast to the studies of caring, Riemen (1986) used a phenomenological approach to analyze ten patients' descriptions of noncaring interactions. Specific actions the patients reported as noncaring were grouped into five categories: being in a hurry and efficient, doing a job, being rough and belittling, not responding, and treating patients as objects. These actions appear to be the antithesis of actions that patients perceive as caring.

## Social Support

Results of a descriptive study of 357 women (Smith et al., 1985) with recently diagnosed cancer (272 had breast cancer) indicated that the most important type of support was having someone listen to and talk with them about their illness. Other types of behaviors interpreted as beneficial were taking care of housework, preparing meals, and providing transportation. In this study, social support referred to "emotional and task-oriented activities that may buffer against the stressful effects of cancer" (p. 67). The authors recommended further research to evaluate the types of support tasks perceived as beneficial and detrimental. No detrimental behaviors were identified in this study.

In 1987, Mishel and Braden examined the relationship of social support to uncertainty in 44 women with gynecological cancer. The purpose of this correlational descriptive study was to determine the relationships among the variables of social support (affirmation, aid, and affect) and uncertainty (ambiguity, complexity, lack of information, and unpredictability) at three phases of illness (diagnosis, treatment, and stabilization). Three instruments were used: the Affect, Affirmation, and Aid subscales of the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1983); the 34-item Likert-format Mishel Uncertainty in Illness Scale; and the 45-question Psychosocial Adjustment to Illness Scale (Morrow, Chiarello, & Derogatis, 1978). Results indicated that the variables of social support (affect, affirmation, and aid) have varied impact on women's perception of uncertainty, psychological distress, attitude toward health care, and psychological adjustment during different phases of their illness. For example, affirmation during the diagnosis phase helped women clarify their situation resulting in lower levels of ambiguity. During treatment, affirmation and social interactions helped women reduce their sense of lacking control. In the stabilization phase following treatment, the aid component of social support assumed greater importance. Throughout the cancer experience, the individual dimensions of social support

assumed greater importance at different times and influenced different aspects of uncertainty.

Cawley, Kostic, and Cappello (1990) used a questionnaire to discover support needs of women choosing conservative surgery -- "just a lumpectomy"-- or primary radiation for early stage breast cancer. The subjects in this study reported that needs for support were not met, either preoperatively or postoperatively. Women did not receive psychosocial support from either their friends/family or the health care team. In their report the authors included a touching quotation from one of the 160 subjects responding to the data collection questionnaire:

I think it is difficult enough to have the diagnosis of "cancer of the breast," then the decision to have the lumpectomy performed and then to be treated as if there is really nothing wrong with you, because, after all, you have most of your breast . . . The treatment makes it very difficult, if not impossible, for women with lumpectomies to air any of their fears or thoughts or, sometimes, anger because the atmosphere seems to be that they really should not be feeling any of those feelings, because they still do have most of their breast (p. 93).

Minimization of the experience appeared to have increased this woman's sense of distress. She continued, "People seem to be under the impression that if you had 'just' a

lumpectomy then there's nothing wrong with you, . . . and your life should be the same as it always has been. I do wish there was some way of making this difficult period a little easier for many women" (p. 93). Although this study was of women having conservative treatment for diagnosed breast cancer, nothing has been reported about the caring and support needs of women during the experience of breast biopsy surgery itself.

### Summary of Review of Literature

Professional and lay literature includes information about the detection, diagnosis, treatment, and the response of women and their family members to the diagnosis of breast cancer. Literature about uncertainty in illness indicates there are multiple influences that have an impact on patients' psychological responses to situations where the meaning of illness-related events is unclear. about caring and social support aspects of supportive relationships demonstrates the positive, negative, and varied impact they have on patient perceptions of care and ability to cope. Conceptualizations of support have varied from descriptions of behavioral tasks termed supportive (Smith et al, 1985) to the theoretically-based categories of affect, aid, and affirmation support (Mishel & Braden, 1987). However, the nature and type of support needed and perceived by women having breast biopsy surgery has not been described.

Little is reported about the experience of people having surgery on an outpatient basis and virtually nothing is written about diagnostic surgery when a possible outcome is cancer or other potentially fatal or disfiguring condition. Nothing has been reported about the experience of women having breast biopsy under general anesthesia on an outpatient basis when the result is benign.

While the literature does not directly address the experience of breast biopsy, it does provide some guidance. Research descriptions of patients' preoperative surgical apprehension (Northouse, 1989a; Caldwell, 1991a) suggest that uncertainty is one part of the experience of surgical patients. The phenomenon called "false alarm" by Devitt (1989) also has the ambiguity component of uncertainty. Uncertainty has been described by Mishel (1988) in a middlerange theory in which the appraisal of uncertainty, mediated by social support, results in coping mechanisms and eventual adaptation. The phenomenon of anguish over the "false alarm" (Devitt, 1989) suggests that emotional distress is a result of the uncertainty appraisal. Minimization of the surgical procedure or diagnosis may be an example of ineffective support measures by health care professionals and others and may result in increased stress (Cawley et al., 1990).

### Tentative Conceptual Perspective

Previous research and theory development have included concepts which are possibly relevant to the experience of having a surgical procedure with diagnostic uncertainty. The applicability of the findings from existing research to women having breast biopsy when the results are benign was, at best, tentative. While it is not customary to use a conceptual framework to guide qualitative inquiry, a tentative conceptual perspective provides direction when some knowledge is available. The tentative conceptual perspective for this study included the concepts reported in the review of literature as tentative concepts, but did not preclude the discovery or development of other concepts or their linkages arising from the data (Stern, 1985).

The conceptual framework guiding the Mishel work seemed applicable for diagnosed diseases. It was, however, unclear whether there would be conceptual fit with the phenomenon of breast biopsy when results are benign. Thus, exploration of these concepts for fit with the experience of women undergoing breast biopsy to determine a diagnosis of cancer was tentative. While this framework provided a frame of reference to guide interviews exploring women's lived experiences, other important components from the empirical data could be allowed to emerge.

To use this tentative conceptual perspective with an empirically-grounded approach, several assumptions were

necessary. Women who have had breast biopsy procedures are the experts in the lived experience and can articulate their perceptions of what happened to them. They are able to articulate their perceptions of actions they interpret as helpful and not helpful in assisting them to cope effectively throughout their experience. These perceptions can help health care professionals become more effective, tactful, and thoughtful in working with other women undergoing breast biopsy procedures.

Purpose and Research Questions

Because of the gaps in the literature, a study was needed about the breast biopsy experience, the actions women perceive as helpful, and the impact of having breast biopsy surgery on women's lives. The purpose of this study was to describe the experience, helpful actions of others, and the impact of having a breast biopsy later diagnosed as benign. The specific research questions to be addressed were:

- 1. What is women's experience of having a breast biopsy procedure under general anesthesia on an outpatient basis like when the results are benign?
- 2. What actions by health care professionals and others do these women describe as helpful/not helpful?
- 3. What impact does the breast biopsy experience have on women's lives?

### CHAPTER III

### **METHODS**

### Design

A retrospective, exploratory, descriptive approach was used to discover women's perceived experience of having a breast biopsy for diagnosis when the results turned out to be benign. Women 40 to 59 years of age who experienced breast biopsy under general anesthesia on an outpatient basis and who had benign pathology results were interviewed three and one half to eight weeks after surgery. The interview format allowed participants to share the perspective and meaning that they attached to the experience and captured the scope and nature of their feelings (Patton, 1980). Although an interview guide was prepared, it was used only to assure that topic areas of concern were addressed (Patton, 1980). Open-ended questions encouraged the women to reflect on their experiences, thoughts, perceptions, feelings, concerns, and actions from the moment of discovering the need for surgery, through presurgery waiting, surgery, postoperative recovery, waiting for diagnosis, and since discovery of benign diagnosis. A conversational format allowed women to talk about their experiences in a natural progression, rather than a structured question and answer response. The interviews lasted from one to two and one half hours and occurred in a location mutually acceptable to the participant and

investigator. Seven women chose to come to the hospital where the breast biopsy had been performed for the interview and one interview was in the subject's home. Interviews were tape recorded, transcribed verbatim, and analyzed.

Sampling Procedure and Sample Characteristics

A purposive, convenience sample of eight women who had breast biopsy surgery at a single 450 bed urban nonprofit medical center were interviewed. Data collection continued until responses were no longer unique, demonstrating some redundancy of content, and the investigator had depleted time and financial resources available for this small research project.

Potential participants were identified through the hospital surgery schedule and selected according to the following inclusion and exclusion criteria. Initially 23 women were identified who were 40 to 59 years old, were having a breast biopsy under general anesthesia on an outpatient basis, and were under the care of the participating surgeons. Women 40-59 years old were selected for similarity of life work tasks and family developmental cycle tasks (Friedman & Miller, 1992). Patients having surgery under local anesthesia may have a different experience and different concerns (Caldwell, 1991a) and were therefore excluded. Of the 23 women originally identified, 4 had malignant pathology results and were therefore excluded. The original exclusion criterion of no previous

surgery within the last 10 years seemed important because of the finding by Frisch et al. (1990) that patients with previous experience of surgery may restructure their environments, relationships, or expectations based on that experience. The criterion was changed, however, based on finding that the first five potential subjects had to be excluded because of having surgery within the last 10 years. Therefore the criterion was revised to exclude women who had diagnostic surgery in the last 10 years. Other reasons for exclusion were previous breast biopsy  $(\underline{n}=2)$ , inability of the surgeon's office personnel to contact  $(\underline{n}=2)$ , the woman being "too busy"  $(\underline{n}=1)$ , and living outside the geographic area  $(\underline{n}=1)$ .

The office personnel of the consenting surgeons performed the initial screening of potential subjects using the inclusion criteria (Appendix A). Office personnel obtained the women's permission to be contacted by the investigator. Only those women with benign pathology who indicated willingness to participate were contacted by letter (Appendix B) which was mailed by the office personnel. The letter explained the study purpose, time requirements, and potential benefits. If a woman was interested in further information or wanted to participate in the study, she included a telephone number on the enclosed card and returned it to the investigator in the enclosed self-addressed, stamped envelope. Eight women

responded. Within one week of receiving the response, the investigator called to thank the woman for her interest, and determined if all inclusion criteria were met, using a telephone interview guide (Appendix C).

All participants were English-speaking without accents which could make transcription difficult or contribute to interpretive inaccuracies, had no prior history of breast cancer, had not had a previous breast biopsy, and lived within a 20-mile radius of the study hospital. Even with the changed criterion of no diagnostic surgery in the last 10 years, there were further misfits with the criteria. these cases both the surgeon's office and also the women during the preliminary telephone interview stated they met inclusion criteria. However, during the face-to-face interview, it was found that all women had undergone diagnostic or other surgery within the last 10 years that would have excluded them had they, or the surgeon's office, responded correctly to the original or revised screening criteria. Because this was discovered during the interview, the women were all included in the study and notation of the surgery was made.

During the telephone conversation, the investigator answered any questions the woman had, explained the interview format, including the need for tape recording the interview. If all criteria were met, demographic data, including the woman's age, educational background,

occupation, and perception of general health were obtained.

A mutually acceptable interview time and place were established.

Although it is not a goal of qualitative research to have a representative sample, it may be useful to notice how the study sample compared to the population from which it was drawn. Subjects were not representative of the total population at the study hospital because during the time of the study, there was a change in surgical practice to more frequent use of local anesthesia. This unanticipated change in practice occurred between the time of proposal development and completion of data collection. The total number of women ages 40 to 59 years having breast biopsy under general anesthesia during the period of subject recruitment was 37, 14 under the care of non-participating surgeons (Table 1). While the two participating surgeons each performed 7 or 16 breast biopsies for women ages 40-59, other surgeons performed 0-6 similar procedures each under general anesthesia. During the period of subject recruitment, 56 other women in this age group had breast biopsy surgery under local anesthesia, 53 performed by nonparticipating surgeons and 3 performed by the participating surgeons.

Number of Women Ages 40-59 Having A Breast Biopsy At the
Study Hospital During the Data Collection Period

Type of anesthesia	Participating surgeons $(\underline{n} = 2)$	Nonparticipating surgeons $(\underline{n} = 19)$
General anesthesia	23 (7 and 16/surgeon)	14 (0 to 6/surgeon)
Local anesthesia	3	53

Table 2
Characteristics of Women in the Sample

Sample Characteristics Valu	e or Frequency
Age (years)	
Range	40 to 59
Actual ages	40,42,43,45,46,48,51,59
Mean ( <u>M</u> )	47
Standard Deviation (SD)	6
Marital status	
Married	5
Divorced	2
Male partner	1
Highest level of education	
High school	2
Some college	2
Master's degree	4
Occupation	= ;
Homemaker	1
Part time work (sales, public relations)	2
Teacher	4
Other (electronics worker)	1

Ages of the eight participants ranged from 40 to 59 ( $\underline{M}$  = 47,  $\underline{SD}$  = 6) (Table 2). Seven women were less than 52 years of age, with six between 40 and 50. Five women were married; two were divorced; and one had a male partner. The levels of completed education were high school ( $\underline{n}$ =2), some college ( $\underline{n}$ =2), and a master's degree ( $\underline{n}$ =4). Occupations were reported as homemaker ( $\underline{n}$ =1), part-time paid work outside the home ( $\underline{n}$ =2), electronics worker ( $\underline{n}$ =1), and teacher ( $\underline{n}$ =4). When asked to describe their general health, women used the following terms: "above average" ( $\underline{n}$ =1), "good" ( $\underline{n}$ =5), "great" ( $\underline{n}$ =1), and "excellent" ( $\underline{n}$ =1). All women were Caucasian.

### Protection of Human Subjects

Institutional review board approval of study procedures was obtained from Oregon Health Sciences University.

Approval was also obtained from the nursing research committee and the institutional review board at the study hospital. Informed consent was obtained from each woman prior to interview (Appendix D). Confidentiality was maintained by identifying interviews with numbers and keeping the list of participants' names and numbers separate from the transcribed interviews. Transcribed interviews were read only by the investigator and research committee members and data were reported in such a way that no individual could be identified. Women were given the option of having the tapes returned to them or having the tapes

destroyed after the transcripts had been checked. One woman chose to have the tape returned to her. The master list was destroyed after the analysis of the transcripts was completed.

Data Collection and Management Procedures

Interviews occurred three and one half to eight weeks
after surgery to allow time for women to reflect on their
experiences. According to van Manen (1990, p. 10), "A

person cannot reflect on lived experience while living
through the experience." Interviews were conducted
individually and in order of subject availability between
February and July, 1992.

Before the interview began, the investigator reviewed the purpose of the study, the interview format, the fact that the interview would be tape recorded and transcribed, and the potential benefits to the woman and the health care profession. Women were also told the tape recorder could be turned off at any time they wished. The subject was then asked for informed written consent (Appendix D). Each participant signed two copies of the consent form; one was given to her, and one was kept by the investigator. The investigator then emphasized that the woman's information, thoughts, feelings, impressions, and point of view were valid and extremely important (Patton, 1980; Marshall & Rossman, 1989). During the interview, the investigator took occasional notes to provide nonverbal feedback to the woman

being interviewed that what she was saying was of great importance, to keep record of nonverbal behavior, and to help formulate new questions as the interview progressed (Patton, 1980).

Nondirective, open-ended questions were used to stimulate women to talk about the events and sensations they experienced from the time of either becoming conscious of a change in the breast or scheduling the first doctor visit at which they became aware of a breast change, to the present time. Their thought and feeling responses to events and sensations were elicited as well as their concerns, impressions, and actions. Questions were also used to solicit participants' perceptions of the actions that they interpreted as helpful and not helpful from health care providers, family, and friends. Each woman was asked to explain the effect the breast biopsy experience had on her life and the lives of people who were important to her and what it felt like to talk about her breast biopsy experience during the interview. Most women talked about the areas of researcher interest on the planned interview guide without the need to ask the specific questions on the Initial Interview Guide (Appendix E). Permission was requested at the end of the interview to contact the woman again if necessary to clarify data or to check interpretations. No subsequent contacts were needed. As data collection proceeded from one informant to another, the interviews

became more focused to explore emerging themes (Miles & Huberman, 1984) that became apparent in the data.

Interviews lasted from one to two and one half hours.

Immediately after each interview, the investigator recorded her impressions, insights, and feelings and also described the setting and the woman interviewed.

Interviews were transcribed verbatim from the tape recordings by an expert typist who was blinded to the identifying information. Transcripts ranged from 31 to 81 pages in length. Transcribed data were verified by the investigator by listening to the tape while reading the typed transcription. Concurrent data collection and analysis permitted refinement of the interview questions to verify or fill out emerging themes.

### Data Analysis

Data analysis was accomplished using constant comparative analysis methods (Patton, 1980; Strauss & Corbin, 1990; Woods & Catanzaro, 1988). Data analysis occurred in several phases, although the activities often occurred concurrently (Stern, 1985). Analysis was ongoing as transcribed interviews became available.

In the first phase, transcribed interviews were read and labeled with substantive codes, which were developed from the data. Substantive codes "label the substance of the data" (Stern, 1985, p. 155). After several interviews were read, a preliminary coding system was developed.

In the second phase, as transcribed interviews became available, all transcripts were reread and coded using the substantive codes developed in the first phase. When all interviews were completed, all transcripts were checked for all codes. From these coded data, themes were described and relationships between themes noted.

In the third phase, transcribed interviews were read and reread several times to maintain a sense of context and to look for themes, concerns, commonalties, relationships, and patterns both within and between subjects. Comparisons were made among the interviews, and frequently occurring or similar clusters of concerns were noted as themes. coded as relevant were examined to describe each theme and relationships among themes. Throughout data analysis, theoretical notes were kept to capture ideas and to record hunches, insights, and preliminary thoughts about relationships between themes (Lincoln & Guba, 1985; Stern, 1985). The core variable, "the central process that seems to dominate" (Stern, 1985), was identified. In the fourth phase, the literature was sampled to compare and contrast the concepts discovered in the data with findings from previous research.

Lincoln and Guba (1985) identified four scientific values and corresponding criteria for trustworthiness of qualitative research findings. They are, respectively, (a) truth value and credibility, (b) applicability and

transferability, (c) consistency and dependability, and (d) neutrality and confirmability. Trustworthiness of the study was maintained by several means. The credibility aspect of trustworthiness was maintained by allowing women to fully describe their experiences in their own words, taking as much time as they needed. Each interview concluded with an opportunity for the women to add anything they wanted. There was always a time of "debriefing" when the tape recorder had been turned off. For several women this time allowed them to reflect and expand on an area of importance to them. The investigator made notes during this time that were useful in identifying areas of emphasis.

A second way the credibility aspect of trustworthiness was maintained was that the research adviser served as "debriefer" to the investigator. Although Lincoln and Guba (1985) warn against having a member of the student's research committee serve in that function, it proved useful in this study. The adviser asked insightful questions and made useful suggestions. Several nurse peers at the study hospital also served the debriefer function.

Transferability was protected by providing "thick descriptions" (Lincoln & Guba, 1985) in the report. Each theme, category, and concept is supported and illustrated by data from the transcribed interviews. The data and descriptions of the sample will provide a basis for readers to make decisions about the appropriateness of applying the

findings to another population. Lincoln and Guba (1985) state the feasibility of transferring findings to other populations must be demonstrated by the one who chooses to apply the findings. Dependability and confirmability were maintained by the research adviser reviewing coded data and each step of the analysis process. Interpretations were constantly checked against the data. Thus, while all threats to trustworthiness cannot be eliminated, and the potential for investigator bias is present, actions designed to limit these threats were taken.

### CHAPTER IV

### RESULTS AND DISCUSSION

Women were asked to reflect on and describe their breast biopsy experience in order to determine answers to the three research questions. Results will be organized by answering the research questions in order. The question that generated the most data was the first research question. While the uncertainty concept was present in the data, many of the resultant themes seemed to be particularly consistent with much of the stress and coping literature. Themes will be presented with relevant literature and interpretation.

Research Question 1: The Experience

The first research question was, "What is women's experience of having a breast biopsy procedure under general anesthesia on an outpatient basis like when the results are benign?" During the interview, women focused on a variety of aspects in describing their experience. While there were many individual differences in the experience, there were also many common themes and repeated areas of concern. The following findings describe some of the common themes and repeated areas of concern that the women expressed. These themes include "big deal"-- "no big deal" (the core variable), coping behaviors, and memorable events. Aspects of "big deal" appraisal were concerns about cancer, surgery, and self-image. Women also reported factors contributing to

"big deal" appraisal which included personal characteristics, personal knowledge of other women with cancer, and congruence between expectations and experiences of support from family members, emotional responses, physical sensations, and a sense of minimization by self or others. Of the events reported, localizations and mammograms were the most memorable. Women described their coping as cognitive, social, practical, and affective. similarity between "big deal" findings and the Lazarus and Folkman (1984) literature on stress, appraisal, and coping was striking. That literature was therefore useful in explaining the "big deal" - "no big deal" theme as aspects that were part of women's appraisal of their experiences. Each of these themes will be defined, discussed, supported with examples from the data and with related literature. Because "big deal" - "no big deal" is the core variable, this theme, with its aspects and factors, will be described first. Coping and memorable events will follow. appropriate, relationships with other research findings will be described.

### "Big Deal"

"Big deal" - "no big deal" was a major theme and the core category. One way women described their breast biopsy experience was to use the descriptive term "big deal" with various other words along a continuum of "totally big deal" to "no big deal." Five of the eight women interviewed used

the term "big deal" and two referred to their experience as "no big deal." The remaining woman spoke of her experience as if it was "no big deal" but did not use the phrase. One of the two "no big deal" women referred to several aspects of her experience as if the experience really felt like a "big deal" to her.

"Big deal" was used to express women's retrospective cognitive appraisal of the breast biopsy experience. appraisal reflected the woman's evaluation of threat for potential harm or loss. According to Lazarus and Folkman (1984), "Cognitive appraisal is an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful" (p. 19). "Cognitive appraisal can be most readily understood as the process of categorizing an encounter, and its various facets, with respect to its significance for well-being. It is largely evaluative, focused on meaning or significance, and takes place continuously during waking life" (p. 31). Although Lazarus and Folkman (1984) referred to cognitive appraisal as occurring between the stressful event and the reaction, this process seemed to also fit the evaluative process used by women who are describing the breast biopsy experience retrospectively.

Lazarus and Folkman (1984) identified two forms of cognitive appraisal: primary and secondary (Figure 1).

Primary appraisal answers the question, "Am I in trouble or being benefited, now or in the future, and in what way?" (p. 31). Three kinds of primary appraisal were identified by Lazarus and Folkman: (a) irrelevant (the encounter has no implication for a person's well being), (b) benign-positive (the outcome of an encounter is construed as positive), and (c) stressful. Lazarus and Folkman also identified three aspects of the stressful appraisal: (a) harm/loss referring to situations where damage has already been done, (b) threat referring to harms or losses that have not yet taken place but are anticipated, and (c) challenge referring to the potential for gain or growth (p. 31-36). Women in this study reported concerns related to potential harm or loss, i.e. the "threat" aspect of stressful appraisal and the perceived harm they had undergone.

# FACTORS THAT AFFECT APPRAISAL

Personal Factors Commitments Beliefs

Time factors, Ambiguity, Novelty, Predictability, Event uncertainty, Timing in life cycle Situation Factors

### REACTION

(coping process) -emotion focus -problem focus

What can be done?

Secondary

EVENT

## **COGNITIVE APPRAISAL**

Primary

Am I: in trouble? being benefitted?

Now or in the future?

3 options:

-irrelevant (no implication)

-benign/ positive

-stressful

-harm/loss (already happened)

-threat (potential harm)

-challenge (potential gain)

Figure 1. Investigator's interpretation of Lazarus and Folkman's (1984) theory of primary and secondary cognitive appraisal in response to events with resulting coping process reaction. (Based on Stress. appraisal, and coping. by R.S. Lazarus and S. Folkman, 1984, New York: Springer Publishing Co.)

Women who referred to the breast biopsy experience as "big deal" seemed to have made a primary appraisal of threat. They expressed concerns focused on the threat of having cancer with the resulting implications for family future (possibility of increased risk of daughter/sisters getting cancer), financial concerns (loss of job and/or insurance), and the experience of having surgery (anesthesia, possible death). The perceived threat was expressed emotionally as well as intellectually. An interesting difference between women who described their experience as "big deal" and those who did not was that three of the five "big deal" women wept during the interview while none of the "no big deal" women expressed the same degree of emotionality.

Realization of "big deal" sometimes occurred on reflection, "I didn't think that just a little biopsy would be any big deal and it was a bigger deal than I thought it was." As another woman said, "And you know, in retrospect it can still look like a little deal because it was benign after all, wasn't it. And it was, it was remote that it wouldn't be [benign], you know."

The following excerpt from an interview illustrates several aspects of threat appraisal and factors that influenced it:

I'm glad you're doing this [research project], because the whole bottom line of this whole thing is it is not

a big deal procedure. You're not going to die having a biopsy. And so, it tends to get treated as nothing more than, I don't know; having a tonsillectomy or something like that for kids. And it's so much bigger than that because it, there's so much psychological stuff mixed in with it. I mean, it's how you look, it's are you going to die. I mean, cancer is the scariest thing to, to everybody I've met. To most people that's the scariest thing. And uh, and so everybody on the other side; on the health care side know that most of the people they see are not going to have cancer. Well, I mean you get used to it or something but it is [a] totally big deal for the person going through it. And I think even if I have another one it will be a big deal. I mean it isn't just that this was my first one.

Themes, aspects, and factors discovered in the data are shown in relationship to each other in an adaptation and extension of the Lazarus and Folkman (1984) model (Figure 2). Each section of the figure will be described in the following sections of this report.

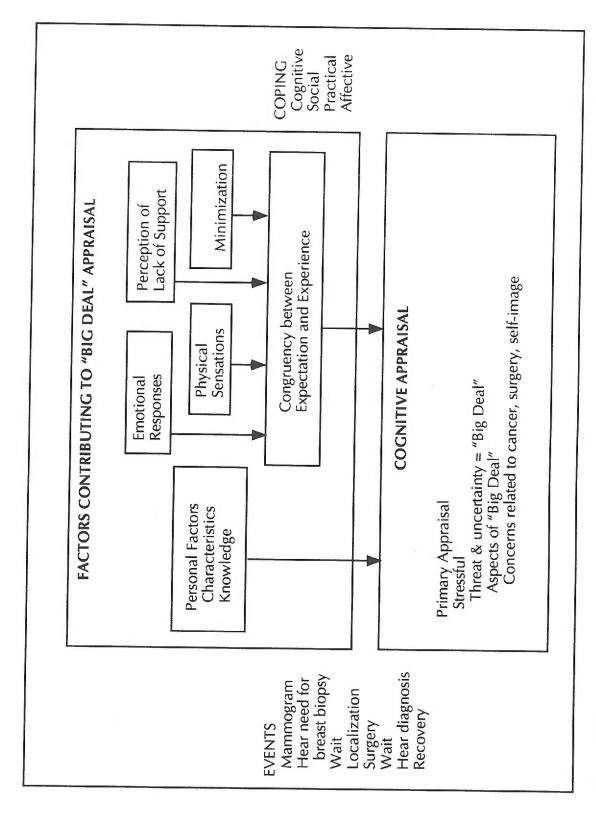


Figure 2. Stress, appraisal, and coping in the experience of a breast biopsy with benign results.

### Aspects of "Big Deal" Appraisal

Several aspects that seemed to influence the primary (threat) appraisal of "big deal" are seen in this excerpt:

(a) concerns related to possible diagnosis of cancer

("cancer is the scariest thing to everybody I've met"), (b)

concerns about surgery ("you're not going to die having a

biopsy"), and (c) self-image ("it's how you look"). These

and other aspects of "big deal" and factors contributing to
"big deal" are presented below.

Concerns related to possible diagnosis of cancer.

Concerns related to the possible diagnosis of cancer is defined as expression of worry about the impact a diagnosis of cancer would have on life. Women expressed a variety of concerns related to the possible diagnosis of cancer including these concerns: (a) uncertainty about how cancer would change their lives, (b) concern about the possibility of having radiation or chemotherapy, (c) increased risk of cancer for family members, (d) ability to maintain social roles, and (e) ability to continue to work and maintain financial stability.

Those women who referred to the experience as "big deal" expressed a variety of concerns related to the impact a diagnosis of cancer would have on their life and the lives of their family members. One expression of the depth of concern was the emotion displayed and described while discussing the concerns. Women used expressions such as:

"I think you worry. You always worry (crying). Is this, what's this going to mean? What kind of changes are going to take place in your life? I was scared." "My life would have been totally different [if the diagnosis was cancer] than the way it turned out." These concerns were consistent with Caldwell's (1991b) statement that diagnostic surgery may be the most threatening type of operative procedure in terms of potential outcome.

Although women did not use the term "uncertainty," it was a common undercurrent implied during interviews. Studies of uncertainty in chronic illness have demonstrated that it includes, in part, aspects of inability to determine meaning, values, and the future; ambiguity concerning the state of the illness; lack of information concerning diagnosis; and unpredictability of the course of the illness and its outcomes (Mishel & Braden, 1988). These studies indicate that uncertainty changes over time and is accompanied by a variety of emotions (Hilton, 1988). aspects were confirmed in this study of women having diagnostic breast biopsy procedures. Women's statements in the previous paragraph illustrate the sense of inability to determine the future because of the unknown diagnostic outcome. This was particularly evident in women's discussions about the highly stressful time between learning of the need for breast biopsy and having the surgery. For

one woman, the day of surgery was a temporary respite from worry. As she said:

I felt real relieved that the surgery was over and then the anxiety kind of starts to creep back in because you know you're going to have to go find . . . And even, even in your mind you're telling yourself, "Well, I'm, it's probably nothing.". . . But there's always that "what if?" And I, I don't think you could ever get rid of that.

Uncertainty was also implied in women's expressions of concern about possible radiation or chemotherapy treatments required if the diagnosis was cancer. One example is:

. . . that's a big deal, chemotherapy. And I know that people respond to that differently, but I know for some it can be very debilitating, and I know that, well I certainly, there's a really big chance that I could be one of those people who might have a very hard time with, a very exhausting time with chemotherapy. . . . What could I do to prepare myself for that?

This statement, while being another illustration of uncertainty, is also an illustration of Lazarus and Folkman's (1984) secondary appraisal, which answers the question, "What can be done (about the possibility of a cancer diagnosis)?"

Another type of concern about a possible diagnosis of cancer expressed by two women was the increased possibility of the daughter also having breast cancer later in life.

I feel like I don't want to get breast cancer because if I get breast cancer, then the risk to my daughter is much, much greater because my mother had breast cancer, then I will have had it, and then I will almost feel like she's almost doomed to get it. . . . And I don't know what kind of impact that would have with her life. Another woman said,

And I just wondered if uh, that I would be passing that [breast cancer] along to my daughter or if my sisters should be watching themselves more closely. . . . I worried for everybody because I thought that's not something you want to have happening in your family.

As previously reported, according to Baker (1991), adult daughters are influenced by their mother's breast cancer. Baker found that some women whose mothers had breast cancer reported having fears of being abandoned, intimacy, dying at the same age as their mothers did, and loss of ability to trust. Therefore, these women's concerns related to the impact on the family if the results of the breast biopsy indicated cancer are consistent with Baker's (1991) report.

Ability to maintain present social roles was another concern related to the possible diagnosis of cancer. For

example, one woman, who was the primary care provider for her chronically ill adult daughter, expressed concern about being able to continue that role. "I was concerned, you know, that I would be all right in order to care for her."

Another type of concern expressed related to the ability to work and maintain financial stability if the diagnosis was cancer. For example,

Job wise it would have been a disaster to me. . . . I was worried about the insecurity of, of whether, if I did have cancer. People lose insurance and all this kind of stuff. I mean financially this could have been just devastating to me. . . And I didn't make any plans based on that. I mean I was just sort of hoping that it would all turn out okay so I wouldn't have to.

This woman was unmarried and self-supporting, and being without income and/or insurance would have had a "devastating" impact.

In summary, women expressed concerns about the possible diagnosis of cancer related to a variety of aspects of their lives including the impact having cancer would have on their future and their ability to fulfill family, professional, and financial responsibilities. Underlying the expressions of concern was the unexpressed, common characteristic of uncertainty.

Concerns about surgery. Concerns about surgery is defined as expressions of concern or worry about the process

of surgery and anesthesia. These concerns included fears related to anesthesia (feeling uncomfortable with being out of control, concern related to feeling claustrophobic, concern about whether the anesthesiologist would take expressions of concern seriously) and fears related to the possibility of death due to some untoward event occurring during surgery. The element of uncertainty is evident in many of these concerns.

One woman who referred to her breast biopsy experience as "big deal" referred to the relief she experienced upon awakening in the post anesthesia care unit,

the anesthetic than I was the surgery. I was more worried about the anesthetic than I was the surgery. I was more worried about being asleep. They could do anything they wanted when I was asleep. I didn't think they were going to hurt me. . . . I just was glad that I was awake and that I didn't have any brain damage because they gave me the wrong stuff or anything like that. . . I don't like to not have control of what's going on with me. . . . So I knew that once I was asleep, I couldn't control anything until I woke up again. For me, I don't like that. . . . I was more worried about dying because of the anesthetic or a mistake happening during the surgery than I was of having breast cancer. . . I don't like to not have control of what's going on with me.

Another woman questioned whether her claustrophobia would be taken seriously.

I wanted to make sure that there was somebody there that knew that I was claustrophobic even if I told somebody, they never, if they believed you I don't know. But I did not want to be tied down, I didn't want to experience any of this fear. And I didn't want to come up from surgery where you can't really move and you're on your back. . . . I really am claustrophobic and that, that was scary. . . . Often people treat that rather lightly and so I just wanted an advocate.

In contrast, one woman who had experienced serious complications following abdominal surgery six years before the breast biopsy and now described her breast biopsy experience as "no big deal" said:

Anything can go wrong [in surgery] I'm sure. And I'm really not happy with any operation that you have to go through, because I'm sure anything can go wrong. But I really didn't think about it at that point. You know, you're at that point; I mean, what can you do? At that point you're there, that's it, you're already to go. Whatever happens, happens. So no, I didn't worry.

Concerns about self-image. Concern about self-image is defined as expressions of uncertainty or worry about loss of a breast and the potential impact that loss would have on psychological well-being and appearance. Self-image

concerns related to the way women felt about the possible psychological impact of having a breast (or part of one) removed, including the impact on appearance. To emphasize that breast surgery has greater impact than surgery on other parts of the body, one woman differentiated a breast biopsy from a biopsy on the arm.

But there's something different about a breast biopsy, it involves so many other emotional things than a lump on your arm. That's different than having a gouge out of your breast because of how it makes, how you feel about how you look for one thing. I mean you can't treat a lump in the breast like you do a lump someplace else. It's, and I don't know why but you can't. And, but it's because it's, it's too personal or too, too much tied up in what your self is. Maybe this is particularly sensitive because it's, it doesn't seem, it isn't a major medical procedure. But psychologically it really is a major thing. I mean not only the fact that you might have cancer but that you might be totally disfigured or something.

Women had different perceptions, however, about the relationship of their breast to self-image. One woman described her experience as "big deal," but also said, "I can do without a breast just fine thank you." She had other major concerns related to the diagnosis of cancer and the

possible impact of cancer on her ability to maintain her social roles.

In summary, the Lazarus and Folkman (1984) model of primary cognitive appraisal was useful in interpreting women's report of their breast biopsy experience. Women in this study reported their experience along a continuum of threat appraisal from "big deal" to "no big deal." Those five women who evaluated the experience as "big deal" also expressed concerns related to cancer, the surgery itself, and self-image. Uncertainty was expected to be found as a major theme, but it was not found to be the most prominent theme in this data. Uncertainty was present, however, in combination with, and overpowered by, threat of potential harm in the experience of these women.

### Factors Contributing to "Big Deal" Appraisal

Several factors seemed to contribute to women's description of the breast biopsy experience as "big deal" or "no big deal." Table 3 lists factors that differed between women in the "big deal" and "no big deal" groups. Many of these factors were personal demographic characteristics; while the last two factors emerged through the constant comparative data analysis. These factors will be reported in the following order: personal characteristics (demographic), and then the two emergent factors, personal knowledge of other women with cancer, and congruency between expectations and experience.

Table 3

Factors on Which Groups Differed

Factor	"Big Deal" $(\underline{n} = 5)$	"No Big Deal" $(\underline{n} = 3)$	
Age range (years)	40-51	45-59	
Ages	40,42,43,48,51	45,46,59	
Marital status			
Married	2	3	
Divorced	2	0	
Male partner	1	0	
Prior knowledge of change in breast	1	3	
Pain in breast	1	2	
Unexpected difficulties Uncontrolled Weeping	3	0	
Infection	1	0	
Number of pages in transcript	37,39,58,75,81	31,38,57	
Mother had cancer	4	0	
Breast	3	0	
Liver	1	0	
Perceived lack of support	4	1	
Experience minimized by self and/ or others	3	2	

Personal characteristics. Personal characteristics, as related to the "big deal" or "no big deal" appraisal, were noted during phase three of data analysis. As can be seen in Table 3, there were differences between the five women who referred to the breast biopsy experience as a "big deal" and the three who referred to the experience as "no big deal." Personal characteristics seemed to be of a demographic and/or personality nature. Demographic characteristics will be described first.

The women who said the experience was "big deal" were younger: three of them were in the early 40s, one was in the late 40s, and one was in the early 50s. Two of the women expressing "no big deal" were mid-40s and the other was late 50s. The finding that women in the "big deal" group were younger is consistent with the finding reported by Hughson et al. (1988) that on preoperative interview, younger patients who had breast biopsy with benign results reported more distress than did older patients.

Another difference between the groups related to marital status. All of the women in the "no big deal" group were married. Two of the women in the "big deal" group were married, two were divorced and living without a male partner, and one woman lived with a male partner.

The amount of time women knew about the change in their breast differed between the groups. Only one of the five women in the "big deal" group had been told about a breast

change prior to becoming aware of the need for a breast biopsy. She had been told at that time (six months before) to not be concerned about the change. The other four women in the "big deal" group had no prior knowledge of a change in their breast. However, all three women in the "no big deal" group had known of the change in their breast for periods ranging from 6 months to 2 years. Each of these women had been told by their physician to not be concerned about the change.

As previously discussed, all women who experienced unexpected emotional difficulties also described the experience as "big deal." Women who described the experience as "big deal" also had more to say in the interview, as reflected in the longer interview transcripts, possibly because of their perception that the experience caused greater threat or disruption in life.

Some personal characteristics did not seem to make a difference in the appraisal of "big deal" and "no big deal." As listed in Table 4, these factors include women's highest level of education, occupation, surgeon, and number of attempts made at wire placement during the localization procedure prior to surgery. The factors listed appear in proportionate numbers for the two groups, with the exception that more women in the "big deal" group had master's degrees and were teachers (n=3) than in the "no big deal" group (n=1).

Personal Characteristics and Factors That Did Not Influence
Women's Appraisal

Factor	"Big Deal" ( <u>n</u> = 5)	"No Big Deal" $(\underline{n} = 3)$
Highest education level		
High school	1	1
Some college	1	1
Master's degree	3	1
Occupation		
Homemaker	1	0
Part-time work	1	1
Electronic worker	O	1
Teacher	3	1
Surgeon		
A	2	1
В	3	2
Number of attempts during localization		
procedure	1,2,3,5,5	0,2,2+5,

Note. One woman in the "no big deal" group did not have localization and one woman had bilateral localization procedures.

Personal knowledge. Personal knowledge is defined as familiarity with a cancer experience because of knowing a female family member having cancer. Although two of the women in the "no big deal" group knew of women who had cancer, neither of these women had close personal knowledge of the details or were influenced by it. In contrast, four of the five women in the "big deal" group had mothers who had cancer (breast,  $\underline{n} = 3$ ; liver,  $\underline{n} = 1$ ). Of those four, two mothers were still living. The other woman in the "big deal" group had personal knowledge of an extended family member who had breast cancer. All of the women in the "big deal" group spoke of their personal knowledge of the cancer experience in terms of difficult aspects such as "I remember seeing her [grandmother's] scars and I just thought it was just the most terrible thing, you know. I couldn't imagine this ever happening, you know, or having it happen to me or anybody else. I just thought it was a terrible thing." Another woman explained,

And so it [having a breast biopsy] gave me another little view on my mother. Because as far as she's the classic example of "everything is always just fine." And she's a very healthy person and a very vital person, but everything isn't always just fine but she would never tell you that. So I discovered one more time when things weren't just fine. I mean it must have been a horrible experience that she went through.

This daughter reported that her mother was "convinced that it was malignant" when she told her mother about the upcoming breast biopsy procedure.

Congruency between expectations and experience. Congruency between expectations and experience is defined as degree of fit between what women anticipated and their perceptions about the breast biopsy experience. It served as a filter to evaluate experiences of (a) emotional response (b) physical sensations, (c) emotional support from the significant male partner or other family members, and (d) minimization of the breast biopsy experience. there was discrepancy or mismatch between what was expected and what was experienced, rather than congruency, there were unmet expectations, unexpected difficulties, and unanticipated feelings. Discrepancy between expectations and experience seemed to contribute to "big deal" appraisal. For some women the perceived discrepancy had a physical or emotional impact. Two of the women with unmet expectations were surprised by feelings of anger and disappointment. Women who described an emotional episode also talked about unmet expectations and dissatisfaction related to support from a significant male. Each experience filtered through expectations will be discussed in more detail in the following sections.

Emotional response is defined as feelings experienced and/or expressed in reaction to events. An unexpected

difficulty that was disturbing to women was unexpected emotional discharge. Emotional discharge seems to be associated with a "big deal" appraisal. All three women who described an emotional episode during the postoperative period also described the breast biopsy experience as "big deal." These women described episodes of uncontrollable weeping which disturbed them. For one woman, shooting pains in her affected breast caused her to think, "I'm afraid something's wrong. Something is really wrong. I'm not getting better." She had expected to be completely healed in one week. Because her experience did not match her expectation, she became worried enough to return to the surgeon for evaluation. Her surgeon reassured her that she did not have infection. Hours after leaving the surgeon's office she had an episode of uncontrollable weeping, after which the pain was relieved and she began to feel better. As she said, "the whole experience just kind of came to a head then, you know." For another woman the emotional impact included "surges of anxiety."

And then afterwards there were some after effects from all this. I remember that even though I found out when I did, which was really quite soon after the procedure about the, it being benign. I, you know, the stress level was reduced . . . and yet I still had anxieties and I, I couldn't figure out why that was, you know, I just kept going through these surges of anxiety . . .

I could not stop crying and it was like I had no control over it . . . I could force it to stop for awhile and it wasn't going to stop and I wasn't crying about anything . . . . It wasn't like something specific had triggered that.

She also reported about a colleague who shared having a similar emotional release after a breast biopsy. Having the colleague talk with her about the similar experience was comforting to this woman.

Physical sensations is defined as the feelings of discomfort or pain associated with the breast biopsy experience. Three women described experiencing breast pain or tenderness. The following excerpt is typical of descriptions of pain/tenderness. "I didn't have a whole lot of pain. I experienced a little more when I went back to work because I really didn't do anything the weekend. . . . It was like I'd get these little, stabbing little pains." Another woman described her pain as "kind of shooting pains." The occurrence of pain was not strongly associated with a "big deal" appraisal, as two women who discussed pain in their postoperative period described their experience as "no big deal."

Surprisingly, pain other than anticipated was not always associated with the "big deal" and "no big deal" appraisal. This finding does not fully support the Lazarus and Folkman (1984) theory of stress and appraisal. Pain

that was different or longer lasting than anticipated could be interpreted as threat (potential harm) according to Lazarus and Folkman (1984). For two of the three women, pain was reported as different than expected; however, they did not interpret that breast biopsy experience as "big deal." One of these two women who used the term "no big deal" seemed to express other concerns and behaviors that were more consistent with the "big deal" appraisal of the other five women. The overall "big deal" appraisal may be so complex and have so many varied aspects that individual factors (such as unexpected pain) are not enough to result in an overall appraisal of "big deal." Instead, the appraisal of "big deal" may be based more on the combinations of factors and the perceived importance or potential harm of those factors to the individual.

Another aspect of physical sensations is the length of time women anticipated healing would take. Women's expectations were not always realistic. For example, one woman anticipated being completely healed and back to normal within one week. When she continued to have pain after one week, she interpreted the pain as indicating she was experiencing a complication and became concerned enough to return to her doctor. This woman also experienced an episode of uncontrolled weeping after learning her pain was part of the normal healing process.

Perceived lack of support is defined as the woman's sense that the emotional aid provided by persons significant to her did not meet her expectations or satisfy her need. discrepancy contributing to "big deal" appraisal was women's perceived lack of support from the male partner and other family members. All three of the "no big deal" women were married and none of them talked much about the husband's role in psychological support. All three were quite matter of fact in their descriptions of the breast biopsy experience. Of the five women who described the breast biopsy experience as "big deal," two were married, one was divorced, one had a male partner, and one had a male friend (Table 3). Those women who were dissatisfied with the support provided by the husband/ partner spent a lot of time talking about that concern. The importance of this support factor was demonstrated by the emotion (tears and anger) expressed during telling about that lack of support. A factor contributing to the perception of lack of support was unfulfilled expectations or the discrepancy between expectation and experience. Women who were not disappointed and did not express dissatisfaction did not say anything about expecting reassurance. For example, one woman in the "no big deal" group talked about the way her husband routinely responds, "He just views things, like well, it will be okay, you know. So, it was fine." On the other hand, women who had unmet expectations for verbal

reassurance were disappointed and experienced dissatisfaction. As one woman in the "big deal" group said:

I did not feel that I got enough support from my husband, and I don't know whether that is because men don't know what to say. Or because it's just my husband's temperament. I just wanted him to say, I wanted him to tell me, "Well, if you have breast cancer that's okay. I'll love you anyway." And I never did hear it.

Another woman in the "big deal" group said:

was not giving me the support I really needed. . . . Like, you know, it'll be okay no matter what happens kind of thing. . . . He just didn't express any concern. . . . It could be just his inability to express it. His, his own fear . . .

Another woman in the "big deal" group wondered what her husband would think or feel if she had breast cancer.

I think women begin to immediately go, because it, it will effect you sexually, it will affect how you look, it will affect what your husband thinks when he looks at you, or your partner; if you're not married. And I, I just really think that I would have liked to have heard from my husband, "If you have to lose your breast, it doesn't matter." Whether he thought it, he still never said it, so maybe, I'm sure to him it does

matter more so than. . . . And I can deal with that.

I can be, I can deal with, even if he had to look at me and say, "I really won't like it." But we could deal with that together. Rather than for him to say nothing, I'd rather really know what he thinks. . . .

I remember feeling the whole time that I, I don't think my husband will react well if I lose a breast.

A result of this perceived lack of support was that women felt hurt and there was conflict in the relationship. Several women expressed this idea: "It's, but I can't, I can't stop myself from being hurt by it. . . . It would have been nice to have not had that, that kind of a sharp conflict that I felt. Conflict of my needs versus not getting them from that particular person [male partner]."

I could have had something terrible. I could have been dying. I started to cry. I just cried. I mean I was into this crying. I mean I was like, uh, you know, how you just get really into it. And I thought, oh, don't do this, you know, just don't do this. So I went up and I took a shower and I just couldn't stop. I was just really upset with my family.

In summary, women who expected or desired emotional support, particularly from a significant male, but sensed they did not receive the amount or type of emotional support they desired from that person, were upset by that perceived

lack of support. Women who did not expect support from these sources were not upset.

Minimization is another aspect of women's descriptions of their breast biopsy experience. Minimization is defined as the perceived underestimation or understatement of importance of the experience. This may be done by either the woman on reflection or by others, including health care providers. Health care providers referred to were personnel in the health care system including physicians, nurses, and other personnel in the office, clinic, or hospital setting. The excerpt at the beginning of the "big deal" section clearly illustrates minimization,

not a big deal procedure . . . nothing more than having a tonsillectomy . . . so everybody on the other side; on the health care side know[s] that most of the people they see are not going to have cancer . . . You can't treat a lump in the breast like you do a lump some place else . . . and if a doctor doesn't realize that then they don't realize, you know, they don't know . . . but it's because it's too personal or too much tied up in what your self is.

This same woman continued,

Even, I mean some people that maybe this could have happened to; if you hadn't really thought it out, you don't, you would minimize this. You know, I would not

have, in my mind, realized how, what a big deal it was because after all it was day surgery.

Another woman, whose appraisal was "big deal," spoke of the breast biopsy as a "tiny little surgery." Despite her minimizing words, her activities and interactions with others reflected concerns appropriate to her "big deal" appraisal. For example, she described her feelings and activities after hearing of the need for a breast biopsy by saying,

It was just like, "Oh I have to go right home and do this and I have to get this done and I have to get ready, and, and uh, just get everything up-to-date so that . . " which is really silly for a little tiny surgery . . . I know the difference between major and minor surgery.

This excerpt infers that although the difference between major and minor surgery is appreciated intellectually, the prospect of the potential cancer diagnosis following breast biopsy was of sufficient threat that preparations needed to be made. While the surgery itself was still minimized by her words the prospects related to the threat of cancer were major. Another indication that behaviors did not match the "tiny little surgery" statement can be seen in the following description of her interaction with her mother (who had breast cancer).

Well, I went and of course told my mom and she was, she, I'm sure did the same thing that I did. "I'll put this face on for her like I'm not worried." But of course I knew she was [worried]. And she was real, having been through it herself, she of course put her arms around me and gave me a hug and a kiss and said, you know, she was sorry to hear it.

Perhaps another type of minimization was others' reaction of "don't worry." As one woman in the "big deal" group said:

He [her husband] doesn't worry until he really has something to worry about. And for me, that seems easier for men to be able to do than women to be able to do. And, but he just kept saying, you know, "let's not borrow trouble, let's just wait till we really have something," you know, "if there's something to talk about then there's something to talk about. If there's not, then there's not." So, not to be concerned. He keeps trying to tell me not to worry until I have something, the real word, you know. If there, if in fact it was, uh it would be malignant or not, he just didn't want to . . . I don't, I just don't think he wanted to think about it until he actually had to.

Her description seemed to include aspects of her perceived lack of support as well as the perceptions that the breast biopsy experience was minimized.

Another woman whose overall appraisal was "no big deal" reported, "I remember being uh, a little apprehensive [the night before the breast biopsy] and saying it to my husband and he again said, 'Oh don't worry about it.'" She also reported her daughter's response, "And my daughter said the same thing, she said, 'Oh, you'll be fine.' Everybody said, 'Oh that's alright, you'll be fine, you'll be fine.'" This woman had experienced serious complications following a previous major surgery, which may have influenced both her and her family members' appraisal of the breast biopsy procedure as "no big deal" in comparison to her previous experience. Perhaps the breast biopsy threat was minimal when compared to the former surgery.

While minimization seems to be a concept that is important, it is unclear exactly how, or whether, minimization contributed to "big deal" appraisal since women in both groups talked about encountering minimizing statements from family and friends. Perhaps, when conversing with women who describe the need for breast biopsy (and possibly other types of surgical or diagnostic procedures), people don't know what to say or how to express support and therefore try to offer reassurance by saying "everything will be okay," which may be perceived as minimization.

In summary, a woman's expectations may serve as a filter which determines the degree to which she is satisfied

with what happens. When experience matches expectation, the result is satisfaction. When experience falls short of expectation, dissatisfaction results. Unmet expectations appear to contribute to "big deal" appraisal.

## Summary and Comparison with the Literature

Women described their breast biopsy experience using a continuum of "big deal" to "no big deal." These terms reflected the degree to which their retrospective cognitive appraisal of the experience indicated threat of potential harm or loss. This finding is consistent with Lazarus and Folkman's (1984) primary type of cognitive appraisal, which answers the question, "Am I in trouble or being benefitted, now or in the future, and in what way?" (p. 31). (See Figure 1) The "big deal" appraisal inferred that the women perceived threat, while the "no big deal" appraisal inferred the women's appraisal was that there was no threat or that the potential threat was minimal.

Lazarus and Folkman (1984) reported that secondary appraisal also occurs. Secondary appraisal answers the question, "What can be done?" (p. 35). Secondary appraisal was only minimally evident in the data, with only one woman making comments reflective of secondary appraisal. While not stated, secondary appraisal may have been the driving force behind information seeking cognitive coping behaviors, which will be reported under the coping behaviors section about the first research question.

Unexpected difficulties reported by women appraising their experience as "big deal" included uncontrolled weeping and surges of anxiety. This finding is consistent with Lazarus and Folkman's (1984) statement that "the way a person appraises an encounter strongly influences . . . how the person reacts emotionally" (p. 45). This finding is also consistent with findings of Janis (1958) and Johnson, Dabbs, Jr., and Leventhal (1970) indicating that high preoperative fear is associated with high emotional disturbance postoperatively. Women who described their experience as "no big deal" did not report postoperative emotional discharge. Therefore, data from this study do not support part of Janis' (1958) findings that low preoperative fear was associated with a high incidence of postoperative emotional discharge.

### Coping Behaviors

Coping was a second major conceptual theme in the data related to the first research question, "What is the experience of having a breast biopsy procedure under general anesthesia on an outpatient basis like when the results are benign?" As previously stated, at least five of the eight women in this study seemed to appraise the breast biopsy experience as a threat. In response to the primary appraisal, all women reported using a variety of coping behaviors to manage the demands of the situation. Coping behaviors are defined as actions or cognitive activities

undertaken to help manage external or internal demands that are perceived as taxing or exceeding the individual's resources (Lazarus & Folkman, 1984). Coping behaviors reported will be described using the following categories: cognitive coping behaviors, social coping behaviors, practical coping behaviors of their social roles, and affective coping behaviors (Table 5). Behaviors grouped in any one category may serve the function of that category and also other categories. For example, "keeping busy" may serve the function of cognitive coping behavior by controlling thoughts through distracting activities, as well as the function of practical coping behavior by completing tasks required by social roles.

Table 5

Examples of Four Types of Coping Behaviors

Type of coping	Examples	
Cognitive	Information seeking	
	Self-talk	
	Controlling thoughts	
	Putting life on hold	
Social	Talking with other people	
	Tell/not tell	
Practical/"just in case"		
Preparation	Domestic	
	Gardening	
	Financial	
Distraction	Keeping busy	
Affective	Emotional release	
	Putting on this front/ purposeful denial of emotions	

## Cognitive Coping Behaviors

Cognitive coping behaviors refer to those mental activities reported by women that helped alter their thought processes about the breast biopsy experience. Examples of cognitive coping behaviors include information seeking, self-talk, controlling thoughts, and putting life on hold.

Information seeking. Information seeking is defined as a problem-focused coping behavior that provided a way to begin to deal with uncertainty and begin to help formulate answers to the secondary appraisal of "What can be done?" (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) indicate that problem-focused type of coping refers to doing something to relieve the problem. Women reported using information seeking as a coping behavior throughout the breast biopsy experience, beginning very early in the process. The following excerpt illustrates a typical information seeking coping behavior described by five women.

But from then [discovery of need for biopsy] until...
the appointment with the surgeon, was probably the
worst time. Because I didn't know, I mean, I was
frantically trying to find information about this. You
know, reading. That's my answer to everything. And
uh, ... I was looking about things about breast
cancer, you know, that kind of thing.

For this woman, reading was her usual coping behavior. She was unable to find the information she needed, however, so

her usual coping behavior did not work, possibly contributing to her appraisal of the experience as "big deal." Another woman, who also appraised the experience as "big deal," said "I think prior to the surgery was the most important thing. You know, the getting the information." Preoperatively women sought six types of information:

1. Information about family history of breast cancer. The following excerpt illustrated this type of information:

"There was none [history of breast cancer] in my family. I checked. To look and see if there was any in my family. I even called my aunt. I have no family living. I have no brothers and sisters and my mother and father have deceased, and so I called the aunts and uncles on only one side because there is none on the other side of my family . . . So that, that relieved me too. Just talking and delving into the subject really helped me, you know. And getting information."

- 2. Information about breast cancer, including: "the problem, and causes, and the prevention, and things like that."
- 3. Information about possible treatment options, for example:

"treatment options in case it was cancer."

4. Information about statistics.

"And that first appointment, you know, reading on them and the stats on mammograms, and you know, the chances are and all those kinds of reading."

- 5. Information about the incision. One woman said:
  But if you could, you know, they've got all the
  little diagrams with breasts. If the doctor could
  say, okay, draw a line, "this is where the surgery
  will be." You know, "I can't tell you exactly for
  sure, but you know it'll be about this size;
  what's in there is about this size" or something.
- 6. Information about an estimated time frame for recovery. Another woman said:

  They never really told me, gave me a time line.

  They never really said, you know, you will heal and it will start itching at so and so time.

  They, you will know that you are healing. But they never, they never said anything about how long it would take you to get well or heal.

A variety of information sources was utilized, including reading, listening to talk shows, and talking to people -- other than doctors and nurses.

. . . and so the kinds of things that I did to cope with it was find out. I think I, for one thing, had to find out as much as I could possibly know about it [breast cancer]. You know, I did all this reading and

stuff and so that was one thing; plus to talk to people.

#### One woman said:

I basically have to go on most of my information about what I've either read in the paper, or articles or talk shows or whatever you hear. I haven't really talked to any other woman, other than my mother, that's had breast cancer. So I can only go on, on the literature that I have had.

## Another woman continued the idea:

And so I began to talk to some other people, because I'm the kind of person that tries to get different opinions and I didn't want to go to other doctors. I didn't care to go to other doctors; but I just wanted to find out what had happened to friends and colleagues and so I talked to quite a few people and they just all seemed to help me, you know, make the decision that I'd never really know unless they went in and did a biopsy on it. And that would be the best way to know.

One woman reported her search for information from someone who had experienced a breast biopsy:

. . . that was my first thing was finding someone who it had happened to . . . . Not a nurse or doctor, they can't . . . . They can tell you but you don't really believe them because they haven't had it done to them or, you know. I was wondering before . . . . But I

didn't call and bug the nurses or the doctors and you know . . . . I just felt I would find out eventually. For this woman it was important to obtain information from a woman, not a health care professional. Another woman also expressed reluctance to talk to the health care professionals, saying, "I hate to take their [time], it seems trivial. . . ."

Reluctance to talk to medical professionals is quite evident in the previous excerpts. Women tended to rely on other women and written materials for their information sources. In fact, one woman quoted above expressed distrust in information provided by doctors and nurses!

On the other hand, some women expressed confidence that the information provided by the health care providers was right.

And they told me everything on the face of the earth that I asked them. I mean even things that I didn't. And I knew they weren't lying to me, because sometimes you can tell. People will say things, they're sure it's going to be okay and you don't, you kind of doubt that they're telling you the truth.

Another woman said, "I just felt that they were going to give me the right information early enough so I could make some choices. Which for me was important."

While the previous excerpts refer to getting enough of the right kind of information, some women felt the information did not meet their perceived needs; women also referred to their responsibility to seek the information, as in the following:

Other than for my own self of getting a little more information from [surgeon] before surgery. But I should have been responsible for that. That if I had, I, I think that I just was too scared to ask him the right questions and I wasn't thinking in the right. I mean, I did ask a lot of questions, but I don't think I got the kind of answers that I [needed].

As another woman said, "I mean they might have told me [about the changes noted on her mammogram] and I might not have been listening." These excerpts suggest that women's anxiety level may be too great in the preoperative period to be able to formulate and articulate questions at the time they have access to the physician during the preoperative appointment, and that they don't hear or remember the answers to questions they asked.

In the hospital, women wanted information about what was going to be happening to them and how it would feel. "I think the patient should know every step of the way what's going on. . . . " The following excerpt illustrates the importance of providing explanations prior to events:

I think you're, you and I end up having a lot of anxiety if I don't know what's going to happen, and that made it a lot more clear. It didn't make the

process any, any less comfortable or more, more uncomfortable or whatever. I just liked knowing. And uh, it just made it easier to deal with if you knew what was going to happen and why.

Postoperatively, women's need for information shifted to how to best care for themselves (what activities were permitted, whether to wear a bra or not, and whether to use heat or cold on the incision) as well as what the problem/diagnosis actually was. After hearing the diagnosis was benign, one woman explained how her need for information shifted.

And I began to immediately shift to "what was it?" and, I still don't know. I cannot remember what [the surgeon] told me. I, I'll tell you what I wanted him to do, and I wanted him to draw a diagram and exactly where it was and what it looked like, even though I had the scar there; I would have liked to have had or for him to put my x-ray up there and say, "Come over here now, I'm going to show you exactly what it was." He [the surgeon] really should have written it [the diagnosis] down so I could have said, "Okay, it's so and so and so." I would have liked that.

This statement suggests that having a specific diagnosis would decrease uncertainty and may help bring closure to the experience.

In summary, information seeking was a coping behavior frequently used by women in this study. This finding is consistent with other research investigating coping behaviors in surgical (Caldwell, 1991) and other situations (Lazarus & Folkman, 1984).

Self talk. A second kind of cognitive coping behavior, described by five of the eight women, was the use of "self talk." Self talk is defined as "intrapsychic processes" (Cohen & Lazarus, 1979, p. 221) used to help deal with uncertainty. Self talk is used to deal with emotions, plan actions, help intellectual detachment, and find something positive about the experience. The self talk statements that were described reflected efforts to (a) deal with their own emotional response to the situation ("And that's really what I told myself the whole time, you know, 'don't get upset before you have to.'"), (b) make a plan of action if the diagnosis was cancer, ("I was setting myself up to go 'All right, if it's that [cancer], these are the things that I'll begin to do.'"), (c) intellectually detach ("I guess I thought that whatever happens is going to happen."), and (d) find something positive about the experience ("I mean I, I just kept telling myself that . . . I kept doing things like,' well this time next week I'll be out of there and I'll know and you know, that'll be good.'").

Examples of the finding-something-positive as a type of self talk were provided by three women who used probability

to reduce their perceived odds of having a malignant diagnosis.

But the, one of the good things; I'm a mathematician so this is a crazy good thing. But, I talked to, the majority of people I talked to; well, I talked to a really good close friend of mine who's mother, sister and best friend had this [breast biopsy] done; and of the three of those people, two had had cancer. Well, see, I added myself to that list of four, and then the odds were in my favor.

Another woman cognitively dealt with hearing about other women's reports of cancer diagnosis following breast biopsy by thinking of probability and saying to herself, "And so I was reassured in the sense that I thought,' Well, this is going to be different and this will be okay.'" A third woman using the same strategy reported she and her family had had so many problems already that this diagnosis simply couldn't be bad also. "And, and how could one more thing happen? That's what everybody kept saying and I kept believing. How can one more thing happen?"

Controlling thoughts. A third cognitive coping behavior closely related to self talk was efforts to control thoughts. Controlling thoughts is defined as conscious efforts to direct thinking away from undesired thoughts or allowing these thoughts only at specified times. The

following excerpts provide examples of ways women described controlling thoughts as a coping strategy.

Why worry until it happens because all you're going to do is make yourself sick . . . and so just go along and try not to, you know, worry that much until it happens. When it happens then you have to deal with it . . . . I think I try to block a lot of, of unnecessary stress out.

Other women reported consciously deciding when to think about a subject or to be nervous.

I tend to give myself these little measures of time and say, "Okay, you can be nervous on Monday when you see the doctor; but don't be too nervous before then." I give myself permission to be nervous at certain times and for me that works real good.

Another woman went on a cruise between the time of discovery of the need for breast biopsy and the surgery. She said:

Well, I didn't think about it [the need for breast biopsy] . . . . Yeah, just thought I'd earned [the cruise], didn't talk about it, didn't anything. I thought, "I don't want to even think about this right now." So I didn't do that.

Other examples of controlling thoughts include "checking out" and ignoring, strategies for purposefully avoiding thinking about the breast biopsy and possible

diagnosis: "So, quite frankly, I kind of put things out of my mind and I just went along my way and did what I had to do . . . . But I don't really dwell on things too much." Another woman said she "checked out": "I had just like so checked out from it [the need for breast biopsy], you know. Like separating myself from the up and coming surgery."

Putting life on hold. A fourth type of cognitive coping behavior was "putting life on hold." Putting life on hold is defined as interrupting the planning for future activities until after the breast biopsy diagnosis was known. As one woman said, "I really felt like it was putting everything on hold. Waiting to see what this was going to, what this meant . . . We didn't make a lot of long range plans in case that this would be something, you know." This category is incomplete and warrants further investigation.

#### Social Coping Behaviors

A second category of coping behaviors was social coping, which included talking to other people for the purpose of psychological support and information. Social coping provided human emotional support and also served as a vehicle for some information gathering. Two women stated very clearly that they felt it was good to talk about their experiences, including their fears. "And it really helped me to verbalize it." ". . . and just the fact that I talked about it and didn't keep it inside myself was really good."

While all women reported talking with other people, some women reported being selective about whom they talked to, what they talked about, and when. For example, one woman said, "I know I worked the week before and I never said anything to anybody I worked with." She also reported not telling her friends. "I just didn't talk about it." She did, however, talk with her family -- other than her mother. In contrast, another woman told everyone, even the custodian at her place of work.

When asked who they did not tell about the need for breast biopsy, of the five women whose mothers were still living, three reported that they told their mother only when it was certain they would need the biopsy, i.e. after seeing the surgeon. Two of these three women referred to the experience as "big deal." Another woman told her mother-inlaw just prior to having surgery. Only one woman told her mother about the need for breast biopsy soon after discovering the need for biopsy. She reported receiving emotional support from her mother. Reasons for not telling included "She gets real uptight and nervous and we just thought it would be better if she knew not very far ahead," "I especially didn't tell my mother. I did not want her to begin to worry about what was going on with me until it was absolutely necessary," Even then, the mother was given only limited information.

I told her just before I went into the hospital so she'd know that I was not . . . I said, "I'm just going to go in, but it's a little test, and it's no, no big deal." It wouldn't do her any good to, to know anything about it. She gets confused sometimes, and she's a big complainer, and she would just drive you nuts about it really.

Not telling one's mother at times was a means to protect the mother; however, providing that protection resulted in not getting support from the mother. One woman said:

And it was real hard for me not to tell my mother. My mother and I are very close. And it was real hard for me to not, I, because I, I knew that I could get what I needed to hear back from her. But I didn't to do that until I had to, because it, if I didn't need surgery, I wasn't going to tell her . . . . Because I knew that she would really worry and worry.

These excerpts suggest that women were concerned about how the mother would respond and that their concern for protecting their mothers was greater than their need for emotional support.

One aspect of the decision of who and when to tell seemed to be the woman's uncertainty and anxiety level. "I was so scared I didn't really want to talk to anybody about it [the breast biopsy] . . . . Uh, it wasn't until I knew

all the facts that then I was, I could talk . . . . And once I knew stuff, it wasn't so scary."

While women talked a lot about social coping and information seeking, these areas may not be saturated and there may be additional facets and dimensions not yet fully identified or differentiated. A strategy needing further exploration is "tell" and "not tell." These may be different strategies with different motives and goals that perhaps conflict. "Tell" may provide support; while "not tell" protects the other person but prevents support.

#### Practical Coping Behaviors

Practical coping behaviors is a third category of coping behaviors. The category practical coping behaviors is defined as actions taken to prepare for surgery and/or recovery or to prepare one's household ahead "just in case" the diagnosis was cancer and further surgery and recovery would be required. An additional type of practical coping behavior was to just keep busy  $(\underline{n}=3)$  doing activities for the purpose of distraction, which may have been useful as an adjunct to the cognitive coping behavior of controlling thoughts. Examples of practical coping behaviors that were described by two or more women include cleaning  $(\underline{n}=4)$ , laundry and changed sheets  $(\underline{n}=4)$ , gardening  $(\underline{n}=3)$ , and paid bills/figured taxes  $(\underline{n}=2)$ . Practical coping behaviors were consistent with the women's social roles.

Four women used the term "just in case" when talking about the kinds of things they did to prepare for the breast biopsy. For example, one woman said,

I was planning, you know, I was, I'm a kind of "let's just be prepared, just in case." And I, I don't mean to say that I was worrying, worrying, worrying. Maybe I was more than I thought. But just, you know, just in case this is going to be out here in the future, let's just, you know. I wanted to get my house all cleaned. I wanted to take care of everything beforehand . . . . But if it did turn out to be anything, well, you know, then I'd have to . . . . Physically I wouldn't be able to do certain things, you know, weed, weeding in my yard.

This excerpt illustrates the very complicated lives women lead. These women worried not only about the potential problems related to treatment for cancer, but also about how to manage their household responsibilities. The two women who provided care for grown daughters with chronic illnesses did not report using any special practical coping behaviors; perhaps because they were already too busy.

Women used practical coping behaviors which reflected their social roles. Practical coping behaviors were multidimensional and overlapped with other coping strategies, depending on the woman's goal or motive. For example, cleaning activities may have served to prepare the

household as well as provided a distraction to help in controlling thoughts, a cognitive coping behavior.

Affective Coping Behaviors

A fourth category of coping behaviors is affective coping behaviors. Affective coping is defined as emotional release, such as episodes of uncontrollable weeping and surges of anger and anxiety. Examples of emotional release were discussed previously. Another aspect of affective coping is "putting on this front." "Putting on this front" is a purposeful denial or suppression of emotions to indicate to others that "everything is okay" even though the internal perception is that "everything is not okay." "Putting on this front" is illustrated in the following excerpt from a portion of an interview related to events in the hospital,

Sure, even though you're putting on this front like "Oh, I'm not scared and everything's okay." Of course inside I think you are more nervous than you're, or scared or I don't know what word's a good word. But, than you're letting on. And I just think some people need to focus on that, "Well, maybe I should just really give them a few minutes of my time here."

# Summary and Comparison with the Literature

Coping has many definitions in the literature.

According to Lazarus and Folkman (1984), "Coping is the process through which the individual manages the demands of

the person-environment relationship that are appraised as stressful and the emotions they generate" (p. 19). Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Cohen and Lazarus (1979) identified two functions of coping: (a) "attempts to alter the troubled person-environment relationship in a stressful transaction" and (b) "efforts to regulate the emotional responses themselves" (p. 220). further identify four main modes or forms of coping - information seeking, direct actions, and inhibition of action and intrapsychic (or cognitive) processes - - with a fifth mode, turning to others, added (p. 221). According to Lazarus and Folkman (1984), "Coping functions defined within specific contexts are less general and more situationspecific than those derived from larger theoretical perspectives" (p. 149).

In summary, the data indicated that women in this study used four categories of coping behaviors during the breast biopsy experience - cognitive, social, practical, and affective. Because there is no clearly accepted single organization of categories of coping behaviors in the literature, it is difficult to compare the findings from this study with the literature. Consistent with Lazarus and Folkman (1984), the coping described by these women appeared

to be situation-specific as well as general. While the findings do not disagree with the literature, the findings did not cluster in a way that supports any one theorist.

# Memorable Events

Another way women described the breast biopsy experience was by particularly memorable events that occurred as part of the experience. Two events that women spent a lot of time discussing were the mammogram experience and localization experience.

# Mammograms

Mammograms were a memorable event because of women's perceptions that something about the mammogram experience contributed to a sense of threat. All but one of the women had her breast biopsy based on mammography results. The other woman had a palpable lump which she and her physician had known about for at least six months prior to the decision to biopsy it. Women talked about three general topic areas when discussing their mammogram experience: clues, frustration with the system, and problems.

Clues were ways women (<u>n</u>=4) sensed that something was "not right" with the mammogram. Clues ranged from difference in the "patter" ("weren't giving me the same patter as that they were giving the other women. Or, it wasn't similar to what they had told me before.") to being told "I see something" by the technician performing the mammogram. Other clues included being called for a repeat

series of mammograms and multiple mammograms taken because "the picture was fuzzy -- you must be moving or something."

Two women expressed frustration with the system used to report the results of the mammogram. "I wanted someone to say, 'Oh there it is, Oh, that's what we're looking for.' But nobody ever did. At least not then." Another woman, who had multiple mammograms without any explanation about the reason, said:

Well, I thought a lot of it was unnecessary. I thought why are we doing things over and over again, if he sees something let's get on with this. And uh, I, it was so confusing that even the gal that was giving, doing the mammogram. She was beginning to get confused it seemed like. And I was really getting a little bit ticked about that. Because I didn't think, you know, and then when I went in, he and they don't tell you anything, which really aggravated me a great deal. And I think they would be better to tell you that they are suspicious of something, instead of waiting for another doctor to tell you. I think this is all unnecessary. I, truly I do. I think they uh, they should just focus in on it and do it and not mess around so much . . . I don't like this where you have to go to another doctor and blah, blah, blah, it's just a bunch of baloney. And it's just costing everybody a lot of money.

Problems women reported related to the mammogram experience included pain after mammogram, which went away a half hour after calling to make an appointment with the physician to investigate the cause of the pain, and having to put up with lost mammograms which were later found. Localization

# Seven women whose mammograms showed changes also had a localization procedure prior to the breast biopsy. The localization procedure involves inserting a needle into the breast, inserting a wire through the needle to the precise location of the suspicious tissue, and then injecting dye to mark the area visually for the surgeon. Mammography is used to verify that needle placement is at the exact location of the suspicious tissue. Women reported requiring 1 to 5 needle placements attempts (4 women each had two placements and 3 women each had five placements) before the exact location was found. One of the seven women had bilateral localizations (2 attempts on one side and 5 attempts on the other) and biopsies.

Women reported a variety of reactions to the localization procedure ranging from "I was almost at the edge, like let's forget the whole thing and I'm walking out of here . . . I was really upset" and "not a real pleasant experience" on the one hand to "really interesting" on the other. Throughout the localization experience health care providers were friendly, used "small talk" conversation

to distract, and explanation of what was happening and covering the breast to promote comfort. Coping strategies women used during the localization procedure varied including not watching what was going on and detachment. One woman stated she tried to "get out of myself and watch what's going on . . . be totally absorbed in the process."

# Experiences Women Did Not Talk About

Women did not say much about their experiences in the operating room or the postanesthesia recovery room. One reason for this omission may be that some medications used during anesthesia cause slight retrograde and antegrade amnesia. One woman did, however, report a frightening experience on emergence from anesthesia while still in the operating room. She said:

I just remember the struggle for trying to get air, and I couldn't get it, and it just seemed like it was taking way too long for whatever the process was going on. It was . . . I was really very, very scared and I, I couldn't communicate because I, I couldn't, it seemed like I couldn't talk, so, you know, it seemed like I couldn't tell whoever it was that was doing that, that I couldn't breathe. And I just, I still remember that. It was creepy.

Research Question 2: Actions By Others

The second research question was "What actions by
health care professionals and others do these women describe

as helpful and not helpful?" Women's comments focused on the personal characteristics and style of interaction of health care providers and on the interpersonal behaviors of family and friends. Table 6 summarizes clusters of characteristics, actions, and behaviors that two or more women described as helpful. Other actions or personal characteristics were also mentioned; however, because they were mentioned by only one woman, they could not be clustered and are not reported in the table.

Table 6

Characteristics, Actions, and Behaviors Two or More Women

Described as Helpful

Characteristic or behavior	Number	of	women	reporting
Characteristics of health care pro-	viders			300 from open traffel arisma.
Personal characteristics				
Friendly/nice			4	
Sense of humor			2	
Smiled			2	
Interactions				
Talked to me			3	
Was straightforward			3	
Gave information			3	
Various characteristics of job performance			4	
Interpersonal behaviors of family/f	riends			
Called me just to talk			3	
Listened to me			2	

Women described helpful health care providers' personal characteristics and interactions. As seen in Table 6, the personal characteristics category included being friendly, having a sense of humor, and smiling. The interactions category included talking to the woman, being straightforward, and giving information. One additional category of health care providers, job performance, was identified. Examples of characteristics in the job performance category include "being efficient and thorough," "cared about their job," and "not acting too busy." Each characteristic in this category was mentioned by only one woman. This category agrees with Caldwell (1991a) regarding quality and competence of professional care.

Women also described interpersonal behaviors of family and friends that were interpreted as helpful. Examples of behaviors in this category that were mentioned by more than one woman include "called just to talk to me" and "listened to me." Examples of other actions mentioned by only one woman each include "brought meals in," "took me places," "sent flowers/cards," and "prayed for me."

Women had little to say when asked the question "What actions by health care professionals or others were not helpful to you?" None of the answers were duplicated by another woman. Three women responded by describing ways they were glad they had not been treated. One woman, who

said she appreciated the way the surgeon interacted with her, nonetheless also stated,

Well, you know, I don't know if this is individual though. But for me, if somebody, the kind, I've been around medical people most of my adult life. An uh, there's a certain kind of, some physicians, who often are kind of popular physicians with patients, are just real glad handers and real, just totally nice to you, and they're going, "Everything's going to be fine" and all that kind of stuff. A lot of obstetricians are this way. And you, but I don't trust that. because I didn't want to be talked down to for sure, you know, I did want to know everything, that I could know. . . And I mean he didn't say, "Oh, this is big, but it's no big deal." He said, "Yeah, you know, this is kind of a large lump." But he said, "Some of them turn out to be such and such" and he said, he didn't sound like it was the end of the world, I guess. Another woman, who also expressed gratitude for the way her surgeon interacted with her, said,

There wasn't this kind of aloofness or false non-aloofness which sometimes, you know, uh, sort of denying, uh, aloofness or something that sometimes doctors have that, "Although you couldn't probably understand this, but you know, so don't worry about it" kind of attitude.

A woman, who had concerns about anesthesia, talked about previous experiences in which she felt health care professionals did not really listen to her. As she said,

You feel like you don't know anything technical, of course. So you feel like when you're trying to explain this [referring to a previous problem with anesthetic] to a physician or someone that they're going, "Well yeah, sure." I mean because I had gotten that feeling from doctors and from, not so much nurses but, but people in the medical profession. They really don't think you know what you're talking about. "Oh well, that probably really didn't happen."

In summary, women in this study described actions of health care providers, family, and friends that were helpful or not helpful to them during the breast biopsy experience. The characteristics and behaviors of health care providers that more than one woman reported were personal and interactive in nature, while job performance characteristics, for example, being efficient and thorough, were less frequently mentioned. This finding indicates that for these women, the psychological needs were important. Because information was of great importance to the women, it is not surprising that the interaction characteristics of "talked to me," "was straightforward," and "gave information" were mentioned by several women. These characteristics are consistent with the Smith et al. (1985)

finding that the most important type of support for oncology patients was having someone listen to and talk with the patient about their illness. Helpful behaviors by family and friends that were reported by more than one woman were also interpersonal in nature.

Research Question 3: Impact On Life

The third research question was, " What impact does the breast biopsy experience have on women's lives?" The responses to this research question indicated that the greatest impact occurred during the preoperative period between discovery of the need for breast biopsy and the biopsy itself. This finding is consistent with the Northouse (1989a) finding that women having mastectomy for cancer experienced the most stress during the preoperative period as compared to hospitalization or the time at home after discharge. The cognitive, social, practical, and affective coping behaviors described earlier were used to manage the intrapsychic and interpersonal strain experienced during the pre-biopsy phase. Once the surgery was over, some of the tension was relieved, with another increase in tension just prior to hearing the results. One woman described the time she spent waiting in the surgeon's office just prior to being told the diagnosis as a "a bit of a crap shoot." This woman experienced an episode of uncontrolled weeping upon leaving the surgeon's office after learning of the benign diagnosis.

Women had varied responses related to the question about whether the breast biopsy experience had a lasting impact on them or their relationships with family members and other women. While most (n=5) did not think there would be any lasting impact, one woman described her relationships with her mother and children as having been changed as a result of her breast biopsy experience. She and her mother now shared an experience. She said:

Two things. Um, not a radical change, for sure, but two things. I notice things about people that I hadn't noticed before, and one of the things that I still kind of puzzle about is my mom's reaction to the whole thing. She was convinced that it was malignant, and my mom's the most positive person I've ever known. [This mother had breast cancer.] . . And I think it was a good thing as far as my relationship with my kids.

Because uh, I think it's a good thing that you know, that they know what's going on with you. Uh, and that you're a person and that they know that I think that they are a person too.

Another woman reported, "it probably has [an impact] but it's nothing that I recognize. I mean, I'm, it's done, it's over with, it's gone, it's no longer there . . . it probably does have an effect in that I don't have that in the back of my mind to think about." However, another woman responded that the experience had changed her "tremendously."

I know that now when I come upon a woman who is going to have a biopsy, I want to talk to her and, you know, I mean if she's interested, and not do like a play-by-play deal, but just say, "I really appreciate what you're going through." I think I'd be, for anybody going through that I'd be a lot more, really almost with any biopsy . . . This has changed me, you know, just the whole, the whole thing.

Unlike Mock's (1990) finding that having a mastectomy for cancer changed women's perspectives on life, most of the women in this study did not think the breast biopsy experience would have long-lasting impact. Perhaps this discrepancy exists because once the benign diagnosis is learned, the threat aspect of the primary appraisal is removed.

# Summary of Results

The results of this study were presented as answers to the three research questions (see Table 7). The first research question was, "What is the experience of having a breast biopsy under general anesthesia on an outpatient basis like when the results are benign?" The major findings for the first research question related to "big deal" appraisal, coping behaviors, memorable events, and aspects of the experience women did not talk about. Women described their breast biopsy experience using terms along a continuum from "totally big deal" to "no big deal". Aspects of the

"big deal" appraisal included concerns related to possible diagnosis of cancer, concerns about surgery, and concerns about self-image. Factors contributing to the "big deal" appraisal were personal characteristics, personal knowledge of persons with cancer, and congruency between expectations and experience. Discrepancy between expectations and experience related to physical sensations, emotional response, perceived lack of support from the male partner and family members, and minimization also contributed to the "big deal" appraisal. Coping behaviors reported by women included behaviors in four categories: cognitive, social, practical, and affective (see Figure 2). Another way women described their experience was to talk about the particularly memorable events of mammogram and localization. Women did not talk much about their experiences in the operating room or PACU.

Table 7

Summary of Findings

1		
kesearcn Question	Findings	Sbi
- 1	Major Themes	Components of Themes
1. The Experience	"Big Deal"-"No Big Deal"	Aspects of Big Deal Appraisal Concerns re: Cancer Surgery Self Image
		Factors contributing to Big Deal Appraisal: Personal Characteristics Personal Knowledge of Other Women with Cancer Congruency Between Expectation and Experience
	Coping Behaviors	Cognitive Information Seeking Self-talk Controlling Thoughts Putting Life on Hold Social Practical Affective
	Memorable Events	Mammograms Localizations
2. Actions by Others	Characteristics Interpersonal Behaviors	
3. Impact on Life	Greatest impact was in prebiopsy period.	biopsy period.
		11

The second research question was, "What actions by health care professionals and others do these women describe as helpful/not helpful?" Helpful behaviors were personal and interactive in nature. Women's responses to the "not helpful" aspect of this question were limited to what they were glad their physicians did not do.

The third research question was, "What impact does the breast biopsy experience have on women's lives?" For these women, the greatest impact was intrapsychic and interpersonal strain experienced in the preoperative period. Most women reported that they did not feel that there would be long range impact from the breast biopsy experience.

#### CHAPTER V

IMPLICATIONS FOR THEORY, RESEARCH, AND PRACTICE

In this section, the results will be reported related
to the research subjects' experience, the limitations of the
study, similarities to other findings in the research and
theoretical literature, suggestions for research, and
implications for nursing practice.

The Research Subject Experience

At the end of the interview, women were asked to reflect on the interview process and explain what participating in the interview was like for them. Although two women requested to have the tape recorder turned off during the interview to allow them time to regain composure after becoming tearful, all the women indicated that it was a positive experience. They used descriptions such as "very nice, "fine," "good to re-talk it," "comfortable," "great," and "healthy." As one woman said, "you get some things out that you didn't think you were thinking about. It [the interview] reinforces the whole attitude that, 'Boy, you know, they're finally taking this serious. They're finally going to find out what women really need.' You know, the technology is there, but it's more that just that." The responses suggest that the women wanted to help other women by describing their concerns and issues. Responses also suggest that the interview process was helpful to the women.

Two women used the interview as an opportunity to get

some questions answered. One of these women stated that she was reluctant to "bug" the doctors. Her questions related to why the incision was so long, why her breast looked bruised, and what calcifications are. The second woman wanted to know where to find further information about breast cancer. She used the interview to express her belief in the need to have more information available to women very early in the breast biopsy experience. To meet these needs, information-seeking questions were answered by the investigator at the end of the interview. On the other hand, information may have been provided earlier but anxiety prevented these women from hearing or remembering what they heard.

# Limitations of the Study

There are several limitations to this research study about women's experience of having a breast biopsy under general anesthesia. Generalizability is not a goal of qualitative research, and it is recognized that the small number of subjects in this study may limit the transferability of the findings. Possibly because of the small number, many results that seem important were reported by only a few women. Whether the results would be important to a larger population is unclear.

Another limitation is that all women were recruited from practices of only two surgeons who worked at a single hospital. Although the investigator hoped to avoid biasing

the findings based on the training, practice, or surgical technique of any one physician, patients of only two consenting surgeons were included. However, the other 19 surgeons who perform breast biopsy procedures at the study hospital either did so infrequently ( $\underline{n}$ =11), used primarily local anesthesia ( $\underline{n}$ =4), or refused to allow their patients to be approached ( $\underline{n}$ =4). Another related limitation is that during the time period of the study, there was a significant shift in surgical practice from using general to local anesthesia for performing breast biopsy.

The study hospital serves primarily physicians in private practice and patients who have health insurance, and all women who participated in the study were Caucasian. Therefore, there may be cultural or other differences that could not be identified. A related limitation is that although data were not collected regarding financial status, all women seemed to have financial resources to meet more than minimal basic needs. There may be, therefore, concerns experienced by poor women that are not reflected in these findings.

While the study participants were very complimentary about their surgeons, they did report some things other physicians do that are not helpful. However, they did not mention things that nurses or other hospital employees do that are not helpful. Because the investigator is a nurse working at the study hospital, women may have been reluctant

to talk about nurses, hospital practices, or actions what were not helpful. Anesthesia caused retrograde and antegrade amnesia and may also have contributed to lack of remembrance about nurses.

An important limitation is that theoretical saturation of conceptual themes (Strauss & Corbin, 1990) may not have been achieved because of limited time and resources. Categories related to actions that are helpful and not helpful may not be saturated since few actions and characteristics were mentioned by more than two women. Also, the relationships between categories of factors (e.g. putting life on hold and physical sensations) that appear to contribute to the "big deal" appraisal are tentative. Additional data could be used to further develop unsaturated categories and confirm, refine, modify, or negate the relationships among categories.

Similarities To Other Findings in Research and Theoretical Literature

When planning the study, uncertainty in illness was identified as a potentially applicable concept which had not been applied by other researchers to women having breast biopsies with benign pathology results. Thus data were collected in such a way as to neither address uncertainty in the findings nor to rule out its emergence. Openness of data collection method and data analysis allowed the findings to represent the empirical phenomenon.

Hilton (1988), from a study of women with breast cancer, associated uncertainty with various emotions, including anxiety and anger. Some of the women in this study also reported experiences of anxiety and anger.

Northouse (1989a) looked at the uncertainty women experienced before having breast surgery for cancer, noting that uncertainty contributed to stress. While some of the findings of this study are supportive of those of Hilton and Northouse, other findings also suggested the need to look at stress, coping, and cognitive appraisal (Lazarus & Folkman, 1984). The finding that the most difficult part of the experience was prior to surgery and just before hearing the diagnosis strongly suggested threat appraisal as a relevant framework.

Lazarus and Folkman (1984) presented a theory of stress, appraisal, and coping (see Figure 1) which was useful when analyzing data and explaining the retrospectively-recalled experience of women. Women's descriptions of having a breast biopsy are consistent with and confirm the threat aspect of primary cognitive appraisal that Lazarus and Folkman (1984) described. Several new additions to the framework were identified and described. One new addition was the contributing factor, personal knowledge of other women having cancer. Another new finding was that degree of congruency between expectations and experience with the aspects of minimization, physical

sensations, perception of support, and emotional response appears to contribute cognitive appraisal of threat. While the exact relationship is unclear, it appears that congruency between expectation and experience serves as a cognitive filter used when interpreting experiences. Experiences congruent with expectations are not appraised to be as highly threatening as those which are incongruent. Further concept refinement is needed.

While literature on coping is inconsistent in definitions and classifications of coping behavior, the cognitive, social, and affective categories of coping behaviors discovered in this study seem to be consistent with other author's descriptions of coping. The category of practical coping behavior found in the present study seems to be an expansion of other classifications and thus is a new finding. Practical coping is possibly a category representative of the realities of everyday life for women.

# Suggestions for Research

Consistent with products of most research studies, more questions are raised than are answered. Because results of this study showed that having a breast biopsy is often a "big deal," it would be useful for nurses to study the needs of women who have had multiple biopsies and who may experience even greater needs for emotional support.

Conducting a similar study involving women who have breast biopsy under local anesthesia would provide useful answers

for what is becoming a more common surgical practice.

Including both women whose previous results were benign and those whose previous results were malignant would help refine the concepts of threat appraisal, "big deal," coping, congruency between expectations and experience, and their interrelationships. The factor of congruency between expectations and experience is one which is clearly present, but, as yet, insufficiently saturated. A study with subjects of different ages, ethnic groups, socioeconomic status, and from a variety of physicians and hospitals would be useful in determining consistency and generalizability of the results (Lincoln & Guba, 1985).

A longitudinal study of women's perceptions, with data collection occurring as they go through the breast biopsy process, would be useful in determining the degree of distress women experience at each phase and whether they are aware of their own distress as it happens. A study of this kind would also yield information related to when the "big deal" versus "no big deal" appraisal is realized and whether it changes over the period of time between realizing the need for a breast biopsy to hearing the biopsy results.

Further studies are needed to discover the types of specific information wanted by women who are facing breast biopsy. The most useful format for information and when they need that information could be discovered through a longitudinal study of the experience.

The lack of support from male partners was a significant problem for some women in this study. Therefore, an additional area for research is the reaction of husbands or families to women's breast biopsy. If nurses know what men understand, how they experience the needs of their partner, and what needs they may have, nurses may be in a position to arrange a counseling or informational intervention with the man and woman. Another potential study would be to investigate whether men who have a prostatic or testicular biopsy report threat appraisal similar to that of women undergoing breast biopsy.

A follow-up quantitative, descriptive study could be conducted to further investigate the aspects and factors of "big deal" appraisal discovered in this study. A Likert-type scale could be constructed using the aspects of "big deal" appraisal and the factors contributing to it. A larger sample could include women of many ages, having both initial and repeat breast biopsy in a variety of settings, and performed by numerous surgeons. Results of a study of this nature could provide information to test theoretical relationships and the applicability, consistency, and neutrality of this study's findings (Lincoln & Guba, 1985).

Implications for Nursing Practice

Several findings from this study have implications for nursing practice. All of the women who appraised the breast biopsy as "big deal," but none of the women who said the

experience was "no big deal," reported that they knew women with cancer. Therefore, it may be useful for clinic or office nurses to ask women who are being scheduled for breast biopsy if they know anyone with breast cancer and whether their own experience seems like a "big deal" to them. A positive answer to either question could alert nurses to be more aware of the woman's emotional status and needs. Nurses could then explore with the woman what makes the experience seem like a "big deal," identify and correct misconceptions, and provide teaching to create realistic expectations.

Women seemed to get emotional support from other women more than from their husband or male partner. Although their mothers might have been very supportive during this experience, many of the women in this study protected their mothers by not telling them until it was absolutely necessary. In these cases, the women perceived protection of their mothers as important. Because these women did not get the support they needed early in the prebiopsy experience from either their mothers or their male partners, there are issues related to where they can get the support they need. All but one of the women in this study seemed to rely on their friends more than their mothers for support. Nurses and other health care professionals may assist women in coping with uncommon experiences by encouraging woman-woman connections, such as encouraging discussions with

friends or establishing prebiopsy support and informational groups.

The need for information about breast cancer, diagnostic tests, and treatments options was expressed quite often by the women in this study. Perhaps nurses and other health care providers could be more aggressive in offering printed information to women early in the breast biopsy experience. Printed information is important because anxiety levels may be high enough that women either do not ask the questions they have or they do not hear or remember the answers to the questions they ask. Nurses could be supportive by encouraging women to write down questions as they occur. Nurses could also write answers to questions women ask.

Northouse (1987, 1989b), in her study of women who had mastectomy for breast cancer and their husbands, found that the husbands were not insulated from the effects of their spouse's illness. The husbands reported distress levels and information needs similar to those of their wives. Based on Northouse's findings and the finding of this study, an area where nurses could make a difference is providing prebiopsy information appropriate to assessed education and support needs for both the woman anticipating a breast biopsy and her partner.

Although only one woman talked about the need for information to both be given to men and presented by a man,

that idea seems important. Perhaps a male's empathetic behavior and attitudes could be modeled by such a male presenter. Because most breast biopsy procedures are preformed on an outpatient basis, an area of nursing intervention that needs to be developed is creating teaching opportunities to improve patient and family understanding of the procedures to be done and the preoperative and postoperative care needs. Teaching programs need to be developed where women and their families can come together to discuss the process, feelings, and potential problems related to the breast biopsy experience. A holistic approach, such as the teaching program just mentioned, would help encourage communication so support is given and received.

In conclusion, results of this study demonstrate that many women appraise the breast biopsy as a threat and that they do not always receive the information or support they desire or expect. Nurses who are aware of women's needs and who assess and appreciate women's appraisal can provide care with increased thoughtfulness, creative resourcefulness, and tact (van Manen, 1990).

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# APPENDIX A Breast Biopsy with Benign Results: The Lived Experience

# Subject Selection Form

Pt. Name:	Potential Subject #
Age:Dr	Subject #
Date of breast biopsy:	Phone #
Address:	
Pathology results: Malignant?	Vog
	Yes*No
History: Surgery in last 10 year	csYes*No
Previous breast biopsy - ever	Yes*No
Live within 20 miles of (study hosp (Gresham, Milwaukie, Portland)	oital) *YesNo
If only * responses are marked, pla	ease call the woman.
Does she have an accent? (If yes, I can't interview her transcribing the recorded inte	Yes *No erview.)
If no, please:	
Introduce the idea of the study. Some nursing student at Oregon Health Some part of her studies she would like and having a breast biopsy is like also like to learn what nurses and helpful and not helpful. Women who participate in one interview. The recorded and will take place in a malocation, perhaps your home. If you will not be paid. Some women have their experiences is helpful to the	ciences University. As to find out what needing for women. She would others did that was join the study will interview will be tape nutually acceptable ou join the study, you found that talking about em.
Your relationship with your doctor will not be affected whether you journey leave the study at an arm of the study at an arm of the study at an arm of the study at a	oin the study or not.
Would you be willing to participate If No, please write her reason, if	? *YesNo

If Yes, please thank her and tell her that she will receive a letter giving further information. If, after reading the letter she is still interested, she should write her name, telephone number, and the best time to reach her on the enclosed card and return the card to Sue in the enclosed stamped, self-addressed envelope.

PLEASE RETURN THIS PAPER TO Sue Yount, PMC ext. 5317. THANK YOU!!!!

# APPENDIX B

#### INTRODUCTORY LETTER

(Study hospital letterhead) (Date)

Dear (patient name),

You recently had a breast biopsy procedure at (study hospital). As part of my graduate studies at Oregon Health Sciences University School of Nursing, I am interested in finding out what needing and having a breast biopsy was like for you. I would also like to learn what health care providers and others did that was helpful and not helpful to you. This information may help health care providers give better care to other women having breast biopsies in the future. The interview will take between one and two hours and will be in a mutually acceptable location, such as your home. Although you will not be paid for participating, some women have found that talking about their experiences is helpful to them. Information will be reported in such a way that you will not be identified.

Your relationship with (study hospital) or your surgeon will not be affected whether you join this study or not. Also, you are free to leave the study at any time.

If you agree to join this study or are interested in learning more about the interview, please write your name and telephone number on the enclosed card and return it to me using the self-addressed, stamped envelope. I will call you within one week of receiving your card.

Thank you for your help.

Sincerely,

Sue T. Yount, RN, BSN, CNOR

# APPENDIX C

# Telephone Interview Guide

Patient Initials	Study ID#
Address	
Date called	Participant?
Age	Date of interview
Accent?	Interview time
Date of breast biopsy surgery	
Surgeon	Interview Place
Date of previous surgery	Instructions to location
History of breast cancer?	40.4
Educational background	
Occupation	
Procedure explained: Interview of	
Permission to tape record?	
Perception of general health	
Reason for deferral, if given	
I would like to ask you a question	similar in nature to the
kind of questions you will be asked	d in the interview. This
will give you an opportunity to see	e what the interview will
be like. What has happened to a p	person in the past can
make a difference in how they react	to events related to
illness. Will you please tell me a	about a time when you went
to the doctor or dentist and you we	ere afraid?

#### APPENDIX D

# OREGON HEALTH SCIENCES UNIVERSITY

# Consent Form

TITLE: Breast Biopsy with Benign Results: The Lived Experience

# PRINCIPAL INVESTIGATOR:

Sue T. Yount, RN, BSN (Phone: 503-230-1111, ext. 5317), Master's Student, Oregon Health Sciences University School of Nursing.
Faculty Advisor: Margaret Imle, RN, PhD. (Phone: 494-8382).

<u>PURPOSE</u>: The purpose of this study is to describe women's experience of having a breast biopsy under general anesthesia on an outpatient basis when the results are benign. An additional purpose is to describe actions by health care provider and others that were helpful and not helpful.

PROCEDURES: You are being asked to participate in one interview with the investigator that is estimated to take from one to two hours. This interview will be tape recorded and the investigator will take notes during the interview. You will be asked to describe in detail what happened to you from the time you first became aware of breast changes or made the doctor's appointment until the present time. Your thoughts, feelings, concerns, and the meanings you attach to the experience are important and will help health care providers understand what the experience was like for you. You will also be asked to describe the actions people took that were helpful and not helpful to you. An additional brief interview may be requested with some participants.

RISKS, DISCOMFORTS AND BENEFITS: There is little risk to joining the study. The personal nature of the questions and the breast biopsy experience may cause some mild emotional discomfort. Participation is voluntary. You may choose to not answer any question and if you wish, you may end the interview at any time without penalty, or jeopardizing future care. Whether or not you choose to join this study your relationship with the hospital and your physician will not be affected. While you may not receive any direct benefit from joining the study, the information you provide may help health care providers improve the care given to other women having breast biopsy procedures in the future.

There is no cost to you to be in the study. Also, you will not be paid for participating in the study.

CONFIDENTIALITY: Your identity will be kept confidential. Neither your name nor your identity will be used for publication or publicity purposes. Your study records will be identified by a code number rather than by name. The transcript of your interview will be kept indefinitely and may be used for further analysis about women's experiences with breast biopsy surgery. Information will be reported in a way that you will not be able to be identified.

LIABILITY: The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please call Dr. Michael Baird at (503) 494-8014.

(STUDY HOSPITAL) STATEMENT: Should you suffer any injury as a result of participation in this research activity, all of the necessary medical facilities are available for treatment, insofar as is reasonably possible. (Study hospital) is not the sponsoring agency of this research project and will not assume financial responsibility for such treatment, or provide financial compensation for such injury.

# SUBJECT'S STATEMENT:

I have had an opportunity to ask questions about the study, and they have been answered to my satisfaction. I understand that any future questions I may have will be answered by the investigator. I understand that I may refuse to participate or withdraw from the study at any time without affecting my relationship with my physician or treatment at (study hospital).

I have read the preceding information and voluntarily agree to participate in the study.

Subject:		Date:	
Investig	ator:	Date:	
copies:	Subject Investigator's file		

# APPENDIX E INITIAL INTERVIEW GUIDE

Introduction:

Greetings:

Thank you for agreeing to talk with me. You have valuable insights about having a breast biopsy which will assist nurses and other health care providers understand what the experience is like. I want to understand this experience from your point of view. There are no right or wrong answers. I'll be writing up the information from you and other participants in a way that no one will be identified. This information may help us provide better care to women during breast biopsy procedures. I would like you to share what happened to you; your thoughts, feelings, and concerns during this time; and the actions that you thought were both helpful and not helpful to you. Everything you say is important, so as we talked about before, I need your permission to proceed with the interview and to tape record our conversation. I'll ask you to sign two consent forms. I'll give one to you and I'll keep the other one.

<u>Event</u> <u>Ouestion</u>

Previous experience with breast cancer:

Do you know anyone who has breast cancer? (relationship?)
What was their experience like?

Discovering the need for breast biopsy:

Going to the doctor:

What prompted you to make an appointment with your doctor? (routine/special?)

Did you discover a change in your breast on your own?

Describe your feelings/concerns.

Did you suspect anything was wrong?

Describe what happened the day you

called to make the appointment.

Describe your feelings/ concerns.

Did you suspect anything was wrong?

Describe what happened (i.e. events related to the breast changes --e.g. mammogram) between the time you make the first appointment and the time you were told you would need a breast biopsy.

Describe your feeling/concerns.

# Being told:

How were you told you needed a breast
biopsy? (in person/phone)

Did you suspect anything was wrong?

What did the doctor say?

What did you feel like physically?

emotionally?

What went through your mind then?

# After being told:

What did you do?

Who did you tell? Who did you intentionally not tell? Why?

What did you say?

What did they say that was helpful? not helpful?

How did you feel - physically/
emotionally?

What did you think about?

# Waiting for the breast biopsy:

How long did you wait between being told and having the breast biopsy?

What happened to make it that length of time?

What did you do during that time?
What did you think about? How was it
different than before "being told"?
What were your concerns/ worries/ fears?

What preparation explanations or information were you given regarding the breast biopsy?

Who told you this information?

Did the information turn out to be true in your experience?

What preparation was helpful?

not helpful?

Day of the breast biopsy:

Preparing at home:

How did you sleep the night before?
What was waking up like?

Did you wake up at a different time than usual?

How was that day different from other days? What did you think about?

How did you feel physically/ emotionally? What kinds of things did you talk about that day?

Was it what you wanted to talk about?
Were there other things you wanted to
talk about?

Who went with you to the hospital?

Arriving at the hospital/ being admitted:

How did you feel driving up to the hospital?

How did you locate the admitting area?

What happened when you got to the admitting area?

What was being admitted like for you?

What did you think about?

How did you feel physically/emotionally?

What kinds of things did you talk about?

Preparation and waiting in Short Stay: People have to wait varying amounts of time between arriving in the Short Stay area and going to the operating room.

How long did you have to wait between arrival to the unit and transport to surgery?
What was the waiting period like for you?
Who was with you?

What did he/she/they do that was helpful? not helpful?

What happened to you?

What did you feel like - physically/ emotionally?

talk about? Who did you talk to? do?

see/smell/hear?

Who did you see?

What health care provider actions were helpful?

not helpful?

Localization: Did you go to x-ray for a localization procedure?

What was that like for you?

Transport to the operating room:

How did you feel when the transporter came? What did you say?

think about?

do?

What was it like to be transported through the halls?

What did you see, smell, hear, talk about?

What health care provider actions were helpful/not helpful?

What did people say to you?

What was the waiting area like?

Entering the operating room:

What did you see, smell, hear?

Who was there?

What did they say to you?

What happened to you?

How did you feel --physically, emotionally?

What did you think about?

What actions were helpful, not helpful?

Going to sleep - anesthesia induction:

What was it like for you to go to sleep?

What did you think about?

What did you feel?

Waking up in recovery room:

What is the first thing you remember?
What was the waking up experience like for you?

What did you think about?

What did you feel physically, emotionally?

What did you hear, see, smell?

What did the people caring for you do that was helpful?

not helpful?

Being transported back to the room:

What did you hear, see, feel, smell?

What was it like for you?

Recovery in the short stay unit:

Who was there?

What happened?

How did you feel physically, emotionally?

What did you think about?

What did you talk about?

What health care provider actions were

helpful, not helpful?

What kind of information did you learn about

your surgery while you were in the hospital?

Preparation to go home:

Who helped you get ready to leave?

Did you feel ready to leave?

What were you told about how you might feel at home?

Did it turn out to be true in your experience?

Did you feel differently than you had anticipated you would?

# The trip home:

Who drove you home?

What did you do on the way home?

How did you feel physically, emotionally?

What were you concerned about?

Rest of the day and the next day:

What did you do for the rest of the day? ...the next day?

How did you feel physically, emotionally? Who stayed with you?

What did they do that was helpful/ not helpful?

Who did you talk to?

What were you concerned about?

Waiting for the pathology results:

How long did you wait before you got the results?

What did you think about during the waiting time?

How did you feel physically, emotionally during that time?

What were you concerned about?

What actions were helpful/not helpful to you? Hearing the results:

Where were you when you heard the results?
Who was with you?
How were you told? (phone/in person)
How did you feel just before you heard the results ...physically, emotionally?
What did the doctor say?
How did you feel right after you were told?... physically, emotionally?
What did you do right after hearing the results?

Describe the rest of that day.

# Life since:

What has your life been like since your breast biopsy?

What about relationships with your family and friends been different?

What surprised you about your experience?
What do you wish had been different about your experience?
What advice would you give nurses and others to make the
breast biopsy experience easier for other women?

Suppose I was your best friend and I told you I need a breast biopsy. What would you tell me? What would you not tell me?

What has this interview experience been like for you?

May I call you if I have further questions?

THANK-YOU!! - This interview will be typed. After it has been checked for accuracy, I will no longer need the tape.

Would you like it? If you do not want to have it, I will destroy it. If you would like the tape, I will mail it to you. Thank you again for taking time to share your experiences with me.