

THE UNIVERSITY OF CALGARY

EFFECT OF THE THREAT, DIAGNOSIS AND TREATMENT OF BREAST DISEASE  
ON PSYCHOLOGICAL DISTRESS, MARITAL INTIMACY AND SOCIAL SUPPORT

by

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The undersigned do certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, the thesis entitled "The Effect of the Threat, Diagnosis and Treatment of Breast Disease on Psychological Distress, Marital Intimacy and Social Support" submitted by Janice M. Bell in partial fulfillment of the requirements for the degree of Doctor of Philosophy.



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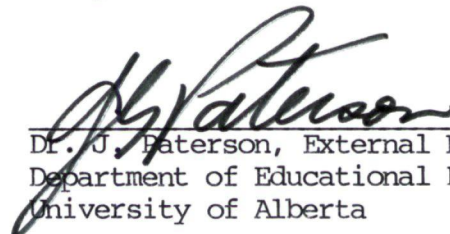
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## ABSTRACT

The discovery of a breast lump or other abnormality is a prevalent female experience. Concern about the possibility of breast cancer and its effect on body image, quality of life, and personal relationships often exists. To examine the ripple effect of the biopsy, diagnosis and treatment of breast disease on psychological distress, marital intimacy and social support, 56 married women who were scheduled for a breast biopsy and their spouses were interviewed conjointly three times over a six-month period using standardized instruments and a semi-structured interview.

The highest levels of distress for both husbands and wives were reported at the pre-biopsy time period. Fear of breast cancer and its consequences was rated as a primary concern by 71% of the wives and 91% of the husbands. At six to eight weeks post-biopsy, the level of distress dropped significantly for both husbands and wives, regardless of the diagnosis, and remained at the lower levels five to six months later.

No significant changes in marital intimacy occurred over time for either the benign or malignant couples. Information obtained from the semi-structured interview found that positive changes, such as greater appreciation for the spouse, were noted by couples following the diagnosis. These changes were reported more frequently by the malignant couples. Coping strategies such as obtaining support within the marital relationship and receiving information about the biopsy procedure and cancer treatment alternatives were commonly reported as helpful by

all couples.

Women reported having more supportive relationships than men. Statistical differences related to time and diagnosis could not be examined because of insufficient data..

The results suggest that the ripple effect of the biopsy, diagnosis and treatment of breast disease may have a profound influence, not only on the woman, but on her spouse as well. Implications for health care services which provide information and enhance marital communication are proposed.

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Finally, I acknowledge the paramount contribution of the couples who participated in the study. They provided unselfishly of their time and experiences so that others might benefit.

To the memory of  
Doris Luchak Mathews (1913 - 1968)  
and Vivian Horne Bell (1920-1975)  
whose experiences with breast cancer  
profoundly influenced many.

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## CHAPTER 1

### INTRODUCTION

#### Statement of the Problem

"I have not been sleeping well. In the middle of the night I keep thinking, 'what if' and I just go crazy. During the day I can say I am not going to think about it and I don't. But at night it's harder not to think about it because you are just lying there". (Woman, age 48, pre-biopsy)

A woman's discovery of a lump or other abnormality in her breast often triggers thoughts of breast cancer and raises a multitude of concerns ranging from fear of dying to disfigurement and abandonment by her partner. Numerous accounts in the popular literature describe this intensely emotional response to potential signs of breast cancer. An interesting study about perceptions of breast cancer found that 59% of healthy men and 26% of healthy women thought that losing a breast was the "worst thing that could happen to a woman" (Peters-Golden, 1982). For some women, the fear of the diagnosis of cancer or of breast loss may result in waiting weeks, even months before consulting a physician (Worden & Weisman, 1975).

Breast cancer affects 1 in 11 Canadian women and is the leading cause of death of women ages 40-59 (Statistics Canada, 1981). However, 80% of abnormal breast conditions, including tumors, are not malignant (National Institutes of Health [NIH], (1982). Surgical removal of breast tissue by excisional biopsy is frequently used to make an accurate diagnosis. Anxiety levels of women scheduled for a breast biopsy have been documented as being extremely high (Scott, 1983a).

Given the results of the biopsy, the woman either escapes the threat of breast cancer with benign results or has to deal with the confirmation of malignant findings. With the diagnosis of cancer, surgical removal of some or all of the breast tissue is initiated at the time of the biopsy or shortly thereafter, requiring the woman to deal with issues ranging from fear of her own death to concerns about disfigurement and sexual functioning. The critical time periods appear to be after a lump is detected (Jamison, Wellisch, & Pasnau, 1978); the first two months after cancer surgery (Worden & Weisman, 1977); and for some women, an extended period of time after treatment is initiated (Morris, Greer, & White, 1977).

Just as a stone thrown into a quiet pond creates concentric circles of response, the psychological impact of the biopsy and diagnosis experience is likely to have a ripple effect on the woman, her spouse, and even on the larger family and social relationship systems (Wellisch, 1985). There is a growing body of literature which suggests that these interdependent systems (i.e., individual, marital, family, and social) are inevitably affected by illness of any kind (Grolnick, 1972; Klein, Dean, & Bogdonoff, 1967; Olsen, 1970; Wright & Bell, 1981).

However, no study has adequately addressed the nature of the reciprocal relationship between the individual woman's psychological response to the threat, diagnosis, and treatment of breast disease and the concomitant response of her spouse or her larger support system.

The importance of examining illness-in-context, which this study addresses, reflects current excitement about the union of previously separate areas of research and theory. The newly developing interest in families and illness led to the creation of a new journal in 1983 called "Family Systems Medicine". As well, the area of "psychosocial oncology" has emerged with emphasis on identifying psychological and social factors for individuals with cancer, their families and involved health professionals. The "Journal of Psychosocial Oncology", established in 1983, is an outcome of this new direction.

The empirical studies and clinical observations related to female breast cancer which have been reported in the literature have been limited almost exclusively to an individual focus on the post-diagnosis and treatment phases or the terminal phase. The individual woman's physical and psychological adjustment to the diagnosis of breast cancer and surgical removal of the breast (mastectomy) has received wide attention in the literature (Ervin, 1973; Lewis & Bloom, 1978-79; Meyerowitz, 1980; Morris, 1983; Morris, Greer, & White, 1977; Scott, 1983b). Except for the literature referring to the clinical indications for breast biopsy, little is known about the experience of the individual during the critical pre-diagnostic time period when the possibility of breast cancer is a major concern. Variables which mediate this pre-diagnosis experience have not been identified. Furthermore,



nothing appears to be known empirically about the husband's psychological response to the biopsy experience or his need for information and support.

From the perspective of a health care provider, it would be important to determine what impact the possibility of breast cancer has on the marital subsystem. In most settings where women receive breast care, the husband is typically involved only peripherally, if at all. There is little provision for spouse involvement in the information conveyed to the woman or in the decision-making process around treatment alternatives. A comprehensive listing of breast cancer services identified only one program which provided women and their families pre-biopsy education sessions (NIH, 1982). Describing the effect of the threat of breast cancer on the marital couple would assist identification of marital dyads at risk and suggest intervention strategies which might be useful during the pre-biopsy and diagnosis phases. Early assessment of the couple at the pre-biopsy stage may have the potential of reducing distress and family disruption.

Generally there is a dearth of literature available on the impact of the diagnosis of breast disease on the spouse or family. The dynamics of the marital relationship may be influenced by and in turn influence each of the spouse's individual responses to the diagnosis and treatment of breast disease. Several reports in the literature suggest that the experience of breast disease carries significant risk of marital disruption (Grandstaff, 1976; Taylor et al., 1985; Wellisch, 1981) but few studies have examined the variable of marital intimacy longitudinally over the pre- and post-cancer diagnosis phases. Empirical

validation of areas within the marital relationship which are reported by spouses as problematic during the diagnosis and early treatment phase of breast disease would provide direction for future program development and clinical intervention.

Lastly, the variable of social support has been shown to be a powerful factor in maintenance of health and adjustment to illness (Berkman & Syme, 1979; Cobb, 1976; Dean & Lin, 1977). Research has documented negative changes in social support as a consequence of the diagnosis of cancer (Hinton, 1975; Peters-Golden, 1982). Poor adjustment to breast cancer has been associated with anticipated or actual lack of support (Bloom, 1982; Funch & Mettlin, 1982). However, a review of the literature by Lindsey, Norbeck, Carrieri, and Perry (1981) which examined social support and mastectomy concluded studies were weak in the conceptualization and measurement of social support. It would be important to document the availability of social support during the threat, diagnosis and early treatment phases of breast disease using a standardized instrument. This contribution to knowledge about social support as a moderator variable would assist in the development of interventions which might be useful in helping the woman and her spouse maximize their personal and social system resources.

#### Purpose of the Study

The purpose of this study was to describe the ripple effect that the biopsy, diagnosis and treatment of benign and malignant breast disease has on the woman, her spouse, and the larger support system (see Figure 1). Several self-report instruments along with a semi-struct-

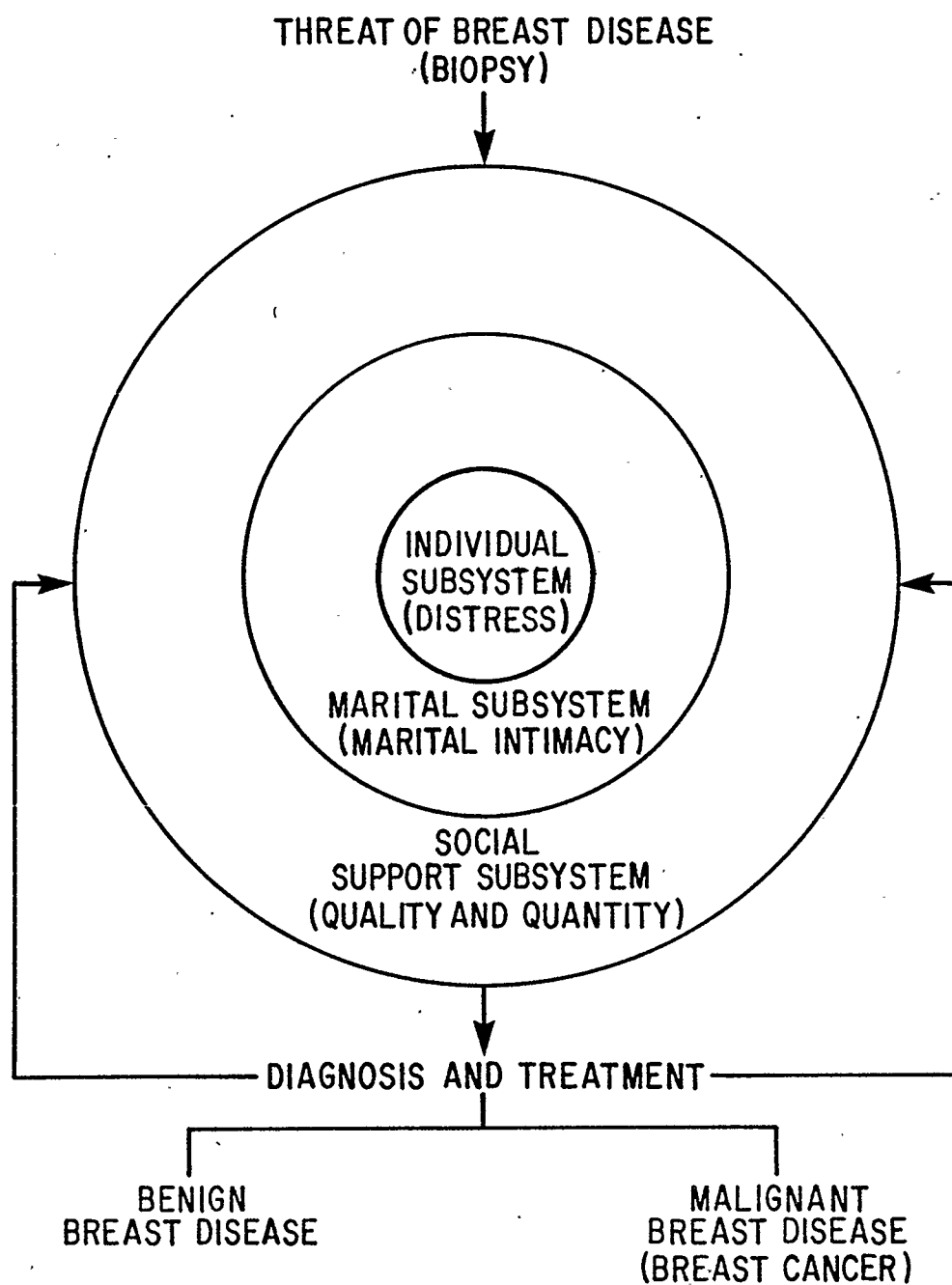


Figure 1. Ripple effect of the biopsy, diagnosis and treatment of benign and malignant breast disease on the individual subsystem, marital subsystem, and social support subsystem.

tured interview were used to generate a description of the impact of the biopsy, diagnosis and treatment phases using a longitudinal, repeated measures design. The study attempted to determine if changes occurred over time from the biopsy to the treatment phase on the dependent measures of psychological distress, marital intimacy and social support. As well, the study attempted to assess whether changes were different for husbands and for wives and different depending on whether the biopsy revealed benign or malignant breast disease. The study extends knowledge regarding the impact of the threat of breast disease as well as the diagnosis and treatment of breast disease on the individual subsystem, the marital subsystem, and the social support subsystem.

#### Research Questions

1. What is the effect of the biopsy, diagnosis and treatment of breast disease on the level of psychological distress experienced by both the woman and her spouse?
2. What is the effect of the biopsy, diagnosis and treatment of breast disease on marital intimacy?
3. What is the effect of the biopsy, diagnosis and treatment of breast disease on the quantity and quality of social support reported by the woman and her spouse?
4. What is the relationship between psychological distress, marital intimacy and social support?

#### Definition of Terms

Breast Biopsy: refers to surgical excision of breast tissue for the

purposes of making a diagnosis of either benign or malignant breast disease. Surgery is performed under a local or general anesthetic.

Breast Disease: refers to the presence of non-malignant breast tissue (e.g., cyst, fibroadenoma, lipoma, etc.) or malignancy (breast cancer). If malignant breast disease is diagnosed, subsequent treatment generally includes surgical removal of some or all breast tissue (segmental resection, modified radical mastectomy, etc.) and axillary node dissection for staging purposes. Post-surgical treatment for breast cancer (referred to as adjuvant therapy) may involve chemotherapy and/or radiotherapy. Only Stage I and Stage II breast cancer were considered in this study. (Staging is the process for determining the type and extent of cancer at a particular time to determine treatment options and predict and compare outcomes. Stage I refers to a tumor less than 2 inches with no lymph node involvement and no evidence of metastasis. Stage II refers to a tumor less than 2 inches with nodal involvement but no evidence of metastasis [Knobf, 1984]).

Psychological Distress: for the purposes of this study, refers to the presence of selected negative affective states reported by each subject on the Profile of Mood States.

Marital Intimacy: refers to the degree of closeness between marital partners on a variety of issues within their relationship (Schaefer & Olson, 1981). Marital intimacy was measured by the Personal Assessment of Intimacy in Relationships (PAIR) Inventory.

Quality and Quantity of Social Support: refers to the number and quality of interpersonal relationships which provide affection, affirmation, and aid (Kahn & Antonucci, 1980). Social support was measured by the Norbeck Social Support Questionnaire.

### Limitations

In designing the study, the investigator recognizes and acknowledges the limitations of the study which are discussed in the following paragraphs.

The size of the sample, the sampling procedure, and the number of interviews during the biopsy, diagnosis and treatment phases impose limits on the generalizability of the results.

The population for the study was confined to women who were seen by nine Calgary surgeons, who spoke and understood English, who were married, who were scheduled for a breast biopsy, and who consented to being involved in conjoint interviews with their husbands. This convenience sample was used because of limitations imposed by time, expense, and the notion of informed consent. Thus, the representativeness of the sample is questionable.

The time involved in data collection permitted sampling at only three time periods in this longitudinal design: pre-biopsy; 6-8 weeks post-biopsy (benign group) or post-surgical treatment (malignant group); and again at 5 to 6 months. Given that the adjuvant treatment of breast cancer can continue for as long as four years, an accurate description of the impact of treatment for breast disease, specifically malignant breast disease, is incomplete.

### Organization of the Thesis

This introductory chapter has presented the nature of the problem and the significance of this study in advancing knowledge about selected variables related to the biopsy, diagnosis and early treatment phases of benign and malignant breast disease. It has also explained the purpose of the study, identified the research questions, defined the terms used in this study, and acknowledged limitations to generalizability of the results. The next chapter provides a review of the relevant literature and identification of the conceptual framework for the study. Chapter three outlines the methodology used in conducting the study. Chapter four presents a quantitative analysis of the variables and a qualitative analysis of the semi-structured interview. In chapter five, a discussion of the study's findings is presented. In addition, implications for future research and for the practice of counselling psychology are identified.

## CHAPTER 2

### REVIEW OF THE LITERATURE

The purpose of the literature review was to provide a context for the present study in relation to prior research and theories. This chapter is broadly organized in the following manner: conceptual framework of the study; overview of the health problem of breast disease, and review of the psychosocial aspects of the threat, diagnosis and treatment phases of breast disease.

The conceptual framework for this study was based on systems theory. This theory was described and connected to the research questions of the study. A brief overview of the epidemiology and current treatment of breast disease was included to provide an orientation to the medical background of this topic.

The major focus of the literature chosen for inclusion in this chapter was confined to the psychosocial aspects of cancer, and more specifically to the threat, diagnosis, and treatment of benign and malignant breast disease. The selection of literature was guided by the



following question: "What psychosocial variables influence the experience of breast disease for the individual subsystem, the marital subsystem, and the larger social support subsystem?" A review of what is known about the specific variables of psychological distress, marital intimacy and social support at the biopsy, diagnosis and treatment phases was addressed. Both empirical studies and reflections of authors on their own clinical experience or observations were included. Figure 2 illustrates the organization of the topics and their subdivisions within the psychosocial focus of this review of literature.

#### Conceptual Framework

The assumed reciprocal relationship between physical illness and psychological processes upon which this study is based seems contrary to our cultural norms about disease. Lewis, Beavers, Gossett, and Phillips (1976) state:

In this culture, the magnificent discoveries of the biological sciences are basic to the development of a model of disease that is characterized by a focus on the individual patient, a dualism in which the physical processes are considered separate from and more 'real' than psychological processes, a search for a single, specific cause for each disease and, all too frequently, an episode-oriented system for provision of health care. (p. 182)

This dualistic model is comprised of mind vs. body components, and individual vs. contextual components with no relationship between the

<u>TOPICS</u>		
SUBTOPICS	Threat of Breast Cancer (Pre-Biopsy)	Diagnosis and Treatment of Breast Disease
<b>Individual Subsystem</b>		
<u>Variables:</u>		
- Psychological Distress of the Woman	X	X
- Psychological Distress of the Spouse	X	X
<b>Marital Subsystem</b>		
<u>Variable:</u>		
- Marital Intimacy	X	X
<b>Social Support Subsystem</b>		
<u>Variable:</u>		
- Quality and Quantity of Social Support	X	X

Figure 2. The organization of topics and their subtopics in the review of the psychosocial literature.

parts. A systems perspective clearly points to the fallacy of such dualism.

The conceptual framework for this study was based on the "systems view of man" (Brody, 1973). General systems theory postulates that the world is comprised of component parts with complementary, hierarchical relationships between the parts (von Bertalanffy, 1950). Living systems are arranged from biological to societal levels (see Figure 3). In this paradigm, a person is seen as a part of a hierarchy of natural systems.

General systems theory postulates that each level of the system is organizationally distinct, but there is communication between all levels. Therefore, change at one level of the hierarchy affects change in other levels of the system (referred to as upward or downward causation). This modifies our conventional views of illness in several ways. It is generally accepted that dysfunction in one organ system within the body affects other organ systems as well, e.g., respiratory distress signals compensatory effects of the circulatory system. However, this concept helps bridge the traditional dualism between physical and psychological processes as change in one level is now seen to affect change in other levels. This contextual paradigm suggests that illness affects both psychological and organic functions of the individual. Moreover, it suggests that the impact of illness occurs at several levels and that there is interaction between levels (Beavers, 1983).

Viewed from this multilevel systems view, disruption in individual functioning will also have an impact on the larger social systems. Central to the thesis of this study is the notion that the disruption inherent in the threat and diagnosis of breast disease probably began at

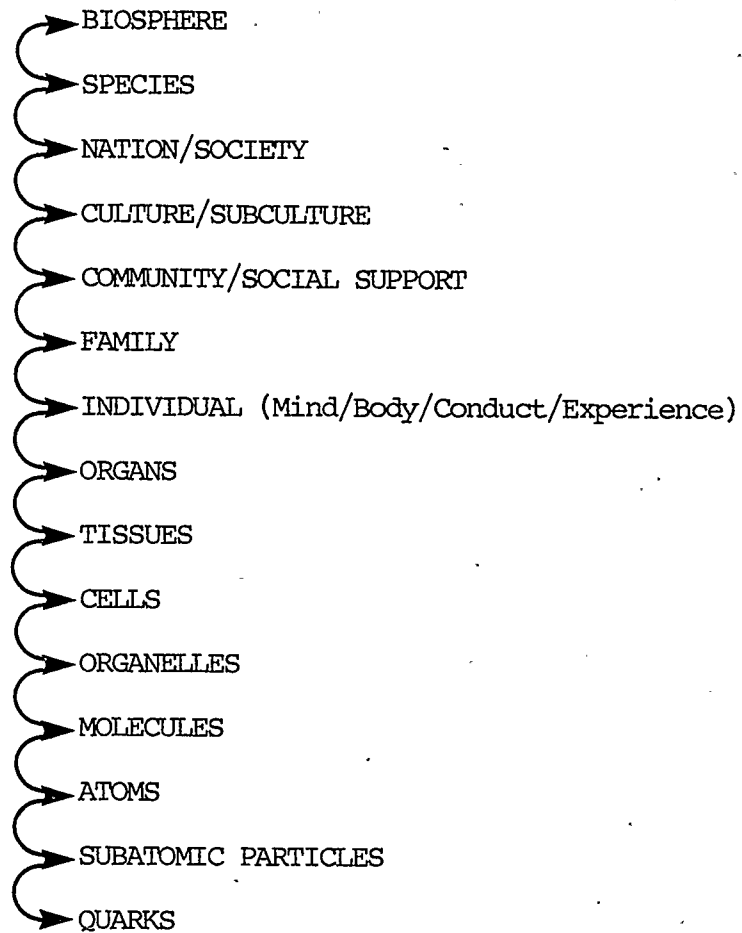


Figure 3. The hierarchy of natural systems shown is adapted from Brody (1973) and Engel (1977).

the gene level of the system and crept upward, through, and beyond the individual and soon involved the higher social levels of the system. However, to view this effect as unidirectional would be to deny that downward causation within systems also exists. It is speculated that processes within the higher social system levels may contribute to the predisposition and susceptibility of disruption (e.g., breast disease) at the tissue and cellular levels.

In conclusion, systems theory challenges research to examine illness in context and to describe variables which may reciprocally influence the predisposition, maintenance and adaptation to illness at several levels of the hierarchy. This research study sought to describe the experience of the threat, diagnosis and treatment of benign and malignant breast disease. The context of this illness was three levels of the systems hierarchy including the individual, marital, and social subsystems using a selected variable at each of these subsystem levels. The interaction effect between system levels was examined by determining if a relationship exists between the selected subsystem variables of individual distress, marital intimacy and social support.

#### The Health Problem: Breast Disease

Approximately 25% of women who seek advice from a primary care physician do so because of a breast-related complaint (Townsend, 1980). Once the abnormal breast condition is detected, a biopsy is often performed to provide a definitive diagnosis. The method of breast biopsy is a current topic of debate; however, there seems to be a trend towards increasing use of needle biopsy and excisional biopsy using local anes-

thetia (Scanlon, 1984). Excisional biopsy (surgical removal of the suspicious tissue for evaluation) was the only mode of biopsy considered by this study.

A surgical biopsy can be performed under a local anesthetic or under general anesthetic on either an inpatient or outpatient basis. The excised tissue specimen can be examined two ways - either quickly by a frozen section while the patient is still anesthetized or by permanent section. A frozen section permits the biopsy and surgical treatment for breast cancer to be combined in one treatment (one-stage procedure). This eliminates the need for a biopsy as a separate operation and is more acceptable to some women who do not wish to worry during the waiting interval between the two stages. Permanent section provides the opportunity for more definitive analysis and time for the patient and her surgeon to consider alternative treatment methods (two-stage procedure) if malignant cells are reported. No studies have examined the psychological impact of a one-stage vs. two-stage procedure.

If the biopsy reveals benign breast disease in the form of fibrocystic disease, fibroadenoma, or other benign tissue, the woman is usually examined regularly by her family physician and is encouraged to practice routine self breast examination. She may also be advised to avoid foods containing caffeine which have been implicated in the aggravation of benign fibrocystic disease. Women with a history of fibrocystic disease have a two- to four-fold increased risk of developing breast cancer (Hutchinson et al., 1980; Lubin et al., 1983).

Recent Canadian statistics indicate that the incidence of breast cancer in females is 142.5 per 100,000 population (Statistics Canada,

1981). Breast cancer kills more women aged 35-54 than any other disease and it is the single largest cause of cancer deaths among women in the United States (NIH, 1982). Silverberg (1985) estimates that in the U.S. in 1985, 119,000 new cases of breast cancer will be diagnosed and 38,400 women will die of the disease. There is growing concern about the alarming increase in the incidence of this disease.

The specific cause or causes of breast cancer are not known but there appears to be several factors that increase the risk of developing the disease. Increasing age, previous history of breast cancer, and positive family history (women whose mothers or sisters have had breast cancer are twice as likely to develop it) are associated with a relatively high risk for breast cancer (Helmrich et al., 1983). Early detection through breast self-examination, mass screening, and use of mammography (x-ray of breast tissue) is emphasized and is the subject of much research.

If the biopsy has confirmed the presence of malignant cells, treatment for breast cancer is initiated. The surgical treatment options used for the treatment of primary breast cancer range from removal of the tumor only (lumpectomy or segmental resection) to removal of all the breast (mastectomy) and some axillary lymph nodes (modified radical mastectomy) which aid in the staging of the disease. Controversy surrounds the choice of surgical treatment, particularly for early stage (Stage I and II) breast cancer. The debate centers around the amount of breast tissue which must be surgically removed in order to control the disease and yet maintain quality of life. Mastectomy is no longer synonymous with breast cancer surgery. Steinberg, Juliano, and Wise (1985) found

women who had only part of the breast removed (lumpectomy) showed better overall adaptation of their surgery and less functional change than women who underwent a modified radical mastectomy. The lumpectomy patients reported feeling less self-conscious about their appearance, received more emotional support from friends and were more open about their surgery and sexual feelings after surgery than the comparison group.

Breast reconstruction is also becoming an option for women who face breast cancer surgery. One study found that breast reconstruction at the time of mastectomy or within one year had a positive impact on psychological adjustment and social adaptation (Schain, Wellisch, Pasnau, & Landsverk, 1985).

Schain (1985, p. 201) sums up the treatment of breast cancer by saying, "Today's breast cancer patient is not without choices. She is faced with multiple options and often is ill-equipped to make measured and informed decisions regarding the most effective and psychologically safe-guarding treatment". This concern about participation in decision-making about treatment has led several U.S. states to legislate that women be informed about alternate therapies.

A staging classification is used to describe the extent and prognosis of the breast cancer. Such classification aids in selecting the surgical treatment used as well as the adjuvant therapy (radiation therapy, chemotherapy, and endocrine manipulation) which is recommended. It also provides a standard for researchers to compare and evaluate rates of treatment and survival rates in patients with similar disease characteristics.



At the present time, there are still no definitive answers about breast cancer treatment because funding for intensive, comparative research only began in the mid-seventies. Surgical and adjuvant interventions are useful in "curing" breast cancer in the short-term; however, because breast cancer is a systemic disease and influenced by a number of factors (e.g., number of affected lymph nodes, hormone receptor status, etc.), cancer professionals are impotent to guarantee outcome for the long-term. Yet among the solid tumors, cancer of the breast is one of the most responsive to a wide variety of treatment modalities. The latest data on survival by stage indicates the five year survival rate for Stage I (localized) breast cancer is 96%. For combined Stage II, III and Stage IV (spread) breast cancer, the rate is 71% (Silverberg, 1985).

### Impact of the Threat of Breast Disease

#### Individual Subsystem

Upon discovery of a breast lump, the immediate concern of the individual as well as the attending health professionals is whether the lump is a symptom of cancer. There are few studies which have examined the impact of the threat of breast cancer on the individual during the pre-biopsy phase. In fact, there appears to be little interest in the experience of this pre-diagnosis time period except where it has been included in prospective studies as the potential breast cancer subject enters the health care system. The pre-biopsy period has also been included in studies which used a control group to study the effects of breast cancer. The control group became those subjects who escaped the

breast cancer diagnosis by receiving benign results from the breast biopsy.

A clinical description by Thomas (1978) suggests that the woman responds to the discovery of a lump with shock and disbelief. "A generalized behavioural disorganization may ensue until either additional information is obtained or some form of active coping is established" (p. 58). The woman is often fearful of the outcome and anxious about techniques and procedures which may be recommended.

No empirical evidence could be found which described the psychological response of the husband to the threat of breast disease during the pre-biopsy time period before the diagnosis was known. Thomas (1978) suggests from clinical observation that the husband's response is not dissimilar to his wife's reaction. He reacts with shock and disbelief and feels excluded during the pre-diagnostic period. He too is fearful of the results.

While 4 out of every 5 biopsies are benign, there is a feeling that life is in limbo until the results are known. Often the pre-diagnosis phase consists of waiting for an appointment with a specialist surgeon, waiting for the results of a mammogram, and waiting to be booked for the biopsy procedure. While this phase may take only a few days, for others it can take several weeks, creating what Welch (1981) calls the "worry and waiting syndrome". Schain (1976) identifies the detection of a lump and the period of delay as one of eleven psychosocial crises in the breast cancer experience.

Variables have been identified from clinical experience that mediate the psychological response to the threat of breast cancer. These

include personality, coping patterns, affective state, health beliefs and practices, intellectual and cognitive abilities, attitude towards breast cancer, and self-concept (Thomas, 1978). The degree of threat which is perceived may also be influenced by a number of other factors such as age, amount of support available, and previous experience with illness or surgery. Kelley (1980) reported that women who had a maternal history of breast cancer experienced extreme and long-term anxiety about cancer.

Of related interest to the concept of "threat of breast cancer" is the finding that 25% of women with a breast problem delayed presentation to a physician by more than three months. Many reasons have been advanced: fear of breast loss; fatalism concerning the outcome; ignorance; prior history of benign breast problems lulling the patient into indifference; and embarrassment, false modesty and shyness. These women tended to be older and of lower socioeconomic status. There appeared to be no difference between delayers and non-delayers with respect to marital status, attitude towards doctors, experience of breast cancer among family and friends, previous history of physical or psychiatric illness, life crisis in the preceeding five years, interpersonal relations, and work record (Magery, Todd, & Blizard, 1977; Worden & Weisman, 1975).

The theoretical work of Lazarus, Averill, and Opton (1974) has emphasized the mediating cognitive process of appraisal in determining what is perceived as threat. Three aspects of appraisal may be distinguished. Primary appraisal concerns the judgement that some situational outcome will either be harmful, beneficial or irrelevant. Secondary appraisal refers to the perception of the range of coping resources

possessed by which the harm can be mastered or beneficial results achieved. Reappraisal, the third aspect, refers to a change in the original perception, say, from benign to threatening or vice versa. Such reappraisal is a response to changing external or internal conditions.

This framework helps explain why women who find a lump in their breast and are scheduled for biopsy may experience a significant amount of anxiety and other negative affects. Two studies examined the presence of distress at the pre-biopsy time period. Scott (1983a) interviewed 85 women with benign results at the pre-biopsy phase and at six to eight weeks post-biopsy to determine the level of anxiety and critical thinking ability. Anxiety levels of patients prior to knowledge of diagnostic results were extremely high. Group average was above the norms for acutely ill psychiatric patients and one-third of the group scored one standard deviation or more above the norms for medical-surgical patient populations. Six weeks later, state anxiety levels were found to be significantly reduced.

Maguire (1976) included pre-biopsy measures in his study of 94 mastectomy and 65 benign breast disease patients. On admission to the hospital for biopsy, 40% of the women rated themselves as very anxious or depressed. More research is needed to describe the response of the individual at the pre-diagnostic stage and identify the variables which mediate perception of the threat of breast cancer and enhance coping resources to minimize that threat.

### Marital Subsystem

No empirical evidence could be found which described the impact of the pre-biopsy phase on the marital relationship.

Only one study by Morris, Greer, & White (1977) asked women for pre-biopsy self-report measures of marital and sexual satisfaction to provide a base-line measure for comparison at later time intervals post-surgery. The findings and limitations of this study will be discussed in a later section of this review.

In an interesting description of Israeli women's concerns which emerged in a post-mastectomy therapy group, Baider, Amikam, and De-Nour (1984) reported that only 6 out of 24 married women talked with their husbands about the breast lump before seeing a physician. The reasons cited for not involving the husband were that he was too busy to be alarmed and that he would probably react as if it were unimportant, thus diminishing any sense of urgency about or preoccupation with the breast lump. Cultural norms may have significantly influenced the experience reported by this sample. Other themes which also emerged over the group sessions led the researchers to conclude that the subjects' picture of their husbands was one of weakness, vulnerability and inability to assume a protective role.

### Social Support Subsystem

While there are several studies which document the relationship between social support and response to the diagnosis and treatment of breast cancer, parallel literature which specifically focuses on the pre-biopsy phase appears non-existent. There is a need to document

longitudinal measures of social support over the illness experience.

### Impact of the Diagnosis and Treatment of Breast Disease

#### Individual Subsystem

Little has been written about the consequence of hearing good news about benign biopsy results, however, the individual woman's psychological adjustment to the diagnosis of malignant breast disease (breast cancer) has received wide attention in the literature (Ervin, 1973; Hughes, 1982; Morris, 1983; Scott, 1983b). However, Meyerowitz's (1980) review concludes that the enormous body of literature is "disorganized, disjointed, confusing, and inconclusive" (p. 126) and is based primarily on clinical experience, small samples and anecdotal material.

Herz (1980) suggests that one of the factors that affects response to illness is the nature of the illness itself. This is especially significant for breast disease because the breast is associated with nurturing, femininity and sexuality (Goin, 1982). Margaret Mead (1976) has noted, "the American culture...is so obsessed with the female breast that it has become the primary focus of a woman's total feminine identification" (p. 360). As well, cancer is often perceived to cause pain, suffering and death. A study by Levin, Cleeland, and Dar (1985) found that cancer was perceived as an extremely painful disease relative to other illnesses. It is no wonder then that a woman facing breast surgery may feel vulnerable, angry or depressed.

Beginning in the early 1950's, several studies reported radical mastectomy patients experienced anxiety, depression and feelings of shame and worthlessness (Bard & Sutherland, 1955; Renneker & Cutler,

1952). This led researchers to document the incidence and severity of mood disturbance following mastectomy and correlate this to breast loss.

Morris, Greer, & White (1977) found that of 63 cancer subjects, 46% reported psychological stress at three months post-surgery. Twenty-four percent of the subjects related the stress to loss/disfigurement while 16% related the stress to the diagnosis of cancer. Gottesman and Lewis (1982) compared breast cancer patients to surgery patients and healthy female controls. The cancer group reported the highest degree of subjective distress when compared to the other groups and significantly high levels of helplessness.

Contradictory findings have been reported on measures of depression. Krouse and Krouse (1981) found no significant depression among mastectomy patients at one and two month intervals prior to and following surgery. Worden and Weisman (1977) compared breast cancer patients to other cancer patients and found little difference between the groups on measures of depression and self-esteem. Only 20% of the mastectomy patients experienced depression after a period of six months. They argued that breast loss be conceptualized away from the narrow focus on "femininity" towards the larger context of altered body image.

Support for the concept of body image came from Polivy's (1977) study which compared mastectomy patients to a benign breast disease control group and a general surgical control group on self-concept measures. Results substantiated a decline in body image and total self-image in the mastectomy group which did not occur until several months post-mastectomy. Rosser (1981) suggests that the literature to date has been based more on clinical assumptions of women's reactions to breast

loss than on the subjective meaning of the experience reported by women themselves.

Other studies related to the impact of breast cancer have examined changes in sexual functioning (Jamison, Wellisch, & Pasnau, 1978; Lief, 1978; Maguire et al., 1978) and fears about the recurrence of cancer (Northouse, 1981).

Several factors such as age, marital status, and stage of disease have been associated with adjustment to breast cancer. Younger women seem to report more adjustment difficulties than do older women (Jamison, Wellisch, & Pasnau, 1978). Metzger, Rogers, and Bauman (1983) found that younger women are more likely than older ones to fear recurrence and are more troubled by disfiguring surgery. They also found that although married women were less depressed than widows or divorced women, they still experienced similar mastectomy-related concerns of disease recurrence and disfigurement. Silberfarb, Maurer, and Crouthamel (1980) found that serious emotional disturbance varied depending on whether the disease was in a primary, recurrent or final stage. A higher percentage of women (78%) reported emotional disturbance at the recurrent stage, followed by the final stage (54%) and the primary stage (46%) respectively.

Only one study was found which included the spouse in a description of the impact of breast cancer. The concerns of marital partners were identified by Gotay (1984) who examined the problems expressed by female cancer patients and their mates (husbands, common-law partners, or close male friends). The marital pair was interviewed individually. Of the 112 subjects, 24 were females diagnosed with Stage III and IV breast



cancer; the rest of the patient group had some form of gynecological cancer. The top ranked concern for both mates and patients was the fear of cancer itself which included fear of the diagnosis and concerns about disease spread and recurrence. The second and third ranked concern of the men in the early stage cancer group was dealing with their wives' emotional reactions to cancer and fear of the death of their wives. This was similar for men of the advanced stage cancer group who cited fear of wife's death as the second most important concern.

While evidence from published clinical experiences, anecdotal materials and scientific investigations supports that the illness experience of breast cancer is stressful and requires numerous physical, social, and psychological adjustments (Lewis & Bloom, 1978-79; Thomas, 1978), more rigorous research is needed. Most empirical studies used convenience samples, retrospective designs and lacked comparison groups. Furthermore, with the variety of breast cancer treatment alternatives now available, investigators need to address the homogeneity of the sample depending on the research question asked. For example, modified radical mastectomy patients need to be separated from segmental resection patients in studies which examine negative affect or adjustment attributed to the issue of breast loss. As well, characteristics of the sample such as diagnosis, stage and duration of illness, and prognosis must also be considered. Many studies fail to account for these variables, collapsing the sample together regardless of the time since surgery or stage of the disease. Wellisch (1984) suggests that the most optimal research strategy is the prospective design where the same group of subjects is interviewed sequentially.

In the classic control group design, differences between pre-diagnosis and post-diagnosis measures are attributed to changes due to the illness experience. The failure to control for psychosocial influences attributable to relevant demographic, medical or response-style variables is a serious methodologic flaw in the breast cancer literature. For example, treatment of breast cancer with adjuvant therapies (chemotherapy, radiation therapy, etc.) has been associated with alterations in emotional distress and lifestyle (Meyerowitz, Watkins, & Sparks, 1983; Silberfarb, Philibert, & Levine, 1980) which may be attributed to the illness itself. Likewise, changes in sexual functioning may be related to factors such as premature menopausal state caused by chemotherapy rather than the diagnosis of cancer itself. Bloom's (1984) response to Ware's (1984) paper on conceptualizing disease impact and treatment outcomes points to the utility of including the patient's subjective perspective. By including the patient's interpretation of what a change means, less misinterpretation about the cancer experience may occur.

#### Marital Subsystem

What effect does the diagnosis and treatment of breast disease have on the marital system? A review of the literature exposes meagre and inconclusive findings characterized by an over-reliance on non-objective and idiosyncratic measures with data collected from the female partner only. This is particularly disappointing since the tools and methodologies for assessing marriage have been developed (Filsinger & Lewis, 1981). Again, the literature virtually ignores the impact of benign

breast disease and focuses almost exclusively on breast cancer. The marital relationship has been examined by using self-report measures of marital adjustment and sexual satisfaction.

A longitudinal study of mastectomy adjustment using a benign comparison group asked women to rate their marital relationship and sexual adjustment on a four-point rating from good to very unsatisfactory before the biopsy and at 3, 12, and 24 months following the surgery (Morris, Greer, & White, 1977). At two years post-surgery, 76% of the benign group reported the same rating of marital adjustment as at the pre-biopsy interview. Only 6% reported their marriages had worsened. Statistical differences were not found between the benign vs. malignant women on the marital relationship measure. In the area of sexual adjustment, 27% of the benign group and 32% of the malignant group reported their sexual relationships had become worse over the 2-year follow-up time. This study did not use measures with established reliability or validity for examining marital or sexual adjustment and did not include the spouse in the sample. Statistical correlations were not reported between sexual adjustment and psychological distress.

These findings have been substantiated by Maguire et al. (1978) who also included measures of sexual satisfaction in a longitudinal study of mastectomy patients and benign controls. At one year, the mastectomy group reported significantly higher levels of stressed sexual functioning.

Contradictory findings were reported by Gerard (1982) who explored the effect of mastectomy on sexual functioning using a laboratory experiment. The results on physiological and subjective measures showed

no significant differences between the mastectomy subjects and matched controls on variables such as sexual arousal and satisfaction. These findings were limited by the small, non-random sample ( $n=13$ ) and the varying length of time which had elapsed since the mastectomy. As well, five of the mastectomy subjects had undergone breast reconstruction.

A recent study by Taylor et al. (1985) reported that the more disfiguring the breast cancer surgery, the more likely the woman reported a decline in affectionate and sexual behaviour in her marital relationship.

Limiting a description of the impact of breast disease on the marital subsystem to the woman's sexual functioning only is a major weakness of the studies reviewed. Bransfield (1982-83) summarized the problem by stating:

"Overall, the importance of assessing the marital relationship, both in terms of quality and satisfaction, has been given marginal attention. The result of this neglect is reflected in the research methodology and the subsequent discussions of the research findings which create the impression that sexual functioning is an adequate measure of relationship stability and communication or a distinct entity untouched by other relationship complements." (p. 206)

While anecdotal reports in the literature have emphasized that husbands are affected by the diagnosis and treatment of breast cancer (Gates, 1980; Grandstaff, 1976; Metze, 1978; Thomas, 1978), only two studies were found which examined the husband's response. Wellisch, Jamison, and Pasnau (1978) retrospectively studied 31 male partners or

husbands of mastectomy patients using a mailed questionnaire. The response rate was 15%. The average amount of time since mastectomy was 22 months. Those husbands who were involved in presurgical decision-making reported greater sexual satisfaction post-surgery than those men who were less involved. A significant number of men reported psychosomatic and psychological reactions of sleep and appetite disorders and work disruption during their partners' diagnosis and surgery.

A recent report of preliminary findings by Lewis, Ellison, and Woods (1985) documented that husbands of breast cancer patients reported fewer illness demands than their wives as measured by a Demands of Illness Inventory. The greater the extent the couple attributed the demands to the woman's illness, the higher family coping was rated by the husband and the higher the quality of marital relationship was rated by the wife.

Wellisch (1985, p. 196) has proposed that several important variables affect the impact of breast cancer on the marital relationship. These include:

"(1) the status of the relationship before the cancer developed; (2) the longevity of the marriage; (3) the stage of the breast cancer, especially as this influences the treatment required; (4) the point in the course of the illness, i.e., primary treatment, recurrent or progressive disease; and (5) the interpersonal skills available to the partners, especially their ability to empathize and communicate".

In the particular area of marital communication and breast cancer,

two findings are noteworthy. Jamison, Wellisch, & Pasnau (1978) found that 89% of their sample of 41 women reported spending little or no time talking about the emotional aspects of the biopsy and possible cancer diagnosis with either the spouse or significant other prior to the surgery. This occurred despite the fact that the women retrospectively rated the time around the discovery of the lump as most stressful. Eighty-seven percent of the women indicated that they did not talk about emotional aspects while in the hospital either. Finally, in examining the effects of chemotherapy on breast cancer patients, Meyerowitz, Watkins, and Sparks (1983) found that 42% of their sample chose to "be strong" and did not discuss their reactions to their disease in the hope of protecting their husbands or family members.

Literature which examined the impact of physical illness, including other types of cancer, on the marital relationship was also reviewed. Marital satisfaction was examined in a review by Peterson (1979) who concluded that the presence of a physical handicap in the marital relationship increased marital stress. Higher marital satisfaction was associated with clear and appropriate role expectations with regard to the ability of the handicapped spouse. Mayou, Foster, and Williamson (1978) found 24.1% of their sample reported improvement in their marriage in the one year period following myocardial infarction; 55.7% reported no change; while 20.3% reported a decrease in marital satisfaction.

Abrams (1981) reviewed three decades of literature on the marital impact of adult-onset paraplegia. Examination of research on marital stability, sexual interaction and marital satisfaction found no consistent evidence of significant negative changes in these areas following

the onset of the disability. Another study on the impact of home dialysis on the marital dyad found marital satisfaction related to the spouse's attitude and adjustment to the treatment program (Brackney, 1979).

The importance of marital communication in negotiating the challenges of chronic illness such as cancer was emphasized by Corbin and Strauss (1984). Cooper (1984) found that the diagnosis of lung cancer had an effect on the openness of communication between the marital couple. Most spouses reported not sharing their fears and concerns with the patients; and more spouses than patients reported signs of stress and feeling alone. Baider and Sarell (1984) examined patient-spouse communication about the illness of cancer and found no differences between agreeing and disagreeing couples on variables such as gender, age or diagnosis. Spouses tended to view the illness more pessimistically than the patient.

In a similar study, Checkryn (1984) interviewed women with cancer recurrence and their spouses to assess the communication exchanged between the marital dyad about the recurrence. No significant difference on a marital adjustment scale was found between couples who talked about the recurrence and those who said they did not. Small sample size (n=12 couples) was a major limitation of this study. As well, sample characteristics such as various types of cancer, and number of the recurrences (e.g., first vs. third cancer recurrence) were not controlled for.

The needs of the marital partner during the illness experience have not been sufficiently examined. Oberst and James (1985) followed forty bowel or genitourinary cancer patients (who were mostly male) and their

spouses post-discharge and found that the spouses focused on the patients' needs and lacked support themselves. Increasingly, the spouse reported fatigue, somatic complaints and lessened ability to cope which peaked at 60 days post-discharge and continued for up to six months.

This review substantiates the need for more information about marital subsystem response to the diagnosis and treatment of benign as well as malignant breast disease. The variable of marital intimacy was chosen for this study to describe the marital subsystem response. A growing body of literature has described the concept of intimacy as a distinctive feature of relationships reflecting the depth and breadth of personal information exchanged between a dyad which leads to the emergence of higher order relational qualities such as interdependence, commitment and caring (Chelune, Robison, & Kommer, 1984; Chelune & Waring, 1984).

Dictionary definitions of intimacy suggest closeness, familiarity and affection. Dahms (1972) asserts that intimacy in a relationship is an evolving process where how the individuals relate to one another is more important than what they relate. From a systems perspective, Perlmutter and Hatfield (1980) suggest that intimacy can be operationalized as "intentional metacommunication and the possibility of second-order change" (p. 19). Chelune and Waring (1984, p. 284) state, "classifying a relationship as intimate or nonintimate involves not only an examination of the interactive behaviours that occur within it but, more important, a consideration of the interactants' cognitive/affective expectations about these interactive behaviours".

Sullivan (1953) was the first to describe intimacy as an important dimension of interpersonal relationships. Since then, several studies



have documented the role of intimacy in physical health of the elderly (Lowenthal & Haven, 1968), and males with angina (Medalie & Goldbourt, 1976).

The link between intimacy and mental well-being has also been studied. Brown and Harris (1978) found the lack of an intimate relationship with a significant other was related to the development of depression among women. Women experiencing severe life stress were 10 times more likely to become depressed if they lacked an intimate confidant. This was supported by Costello's (1982) study which demonstrated that the risk of depression was related to a specific lack of intimacy in the marital relationship. Waring and Patton (1984) found clinically depressed patients reported deficits in intimate communication with spouses. Lower levels of intimacy have been related to negative mood states in nonclinical couples as well (Waring, Reddon, Corvinelli, Chalmers, & Vander Laan, 1983). Positive correlations have been found between marital satisfaction and intimacy (Schaefer & Olson, 1981; Waring, McElrath, Mitchell, & Derry, 1981).

#### Social Support Subsystem

During the mid-1970's, research documented the role of supportive relationships in buffering the impact of stressful experiences on physical and mental health (Cassel, 1974; Cobb, 1976; Dohrenwend & Dohrenwend, 1974). A comprehensive review of the social support literature by Broadhead et al. (1983) indicates that the concept of social support has become a central focus of health research and has been examined in three ways: as an effect modifier against the stress of life events, as a

direct determinant of health or illness (independent variable), and as a dependent variable with its own causes and determinants.

A major weakness of the studies to date has been the lack of consensus about how social support should be defined and operationalized. Wood (1984) suggests the term "social support" appears to be a multidimensional construct in need of further conceptualization and measurement to establish the dimensions accurately. Definitions of support frequently include emotional as well as instrumental aspects (Caplan, 1974; Cobb, 1976; Kahn, 1979). A comprehensive definition by Kahn and Antonucci (1980) refers to interpersonal transactions that include one or more of the following: expression of positive affect, affirmation or endorsement of the person's beliefs and values, and provision of aid, i.e., things, money, information, advice and time.

Measures of social support also address the quality (content of interpersonal relationships) and quantity (size, duration and frequency of contacts). Blazer (1982) found that quality was a stronger predictor of health outcomes than quantity.

Specific types or sources of social support appear to be more effective in certain kinds of situations. A study by Morrow, Hoagland, and Carnrike (1981) found that for parents of children with cancer, the sources of social support which were beneficial varied with the stage of the child's illness. Woods and Earp (1978) retrospectively studied 49 mastectomy patients and included measures which examined the amount of help available through the patients' social network and the willingness of the social network to listen to the patient's concerns. The "helping" support was more influential than the "listening" variety with

social support surprisingly correlated with the level of family income.

Besides being situation specific, social support may also be influenced by characteristics such as age, sex and marital status. A landmark Canadian study by McFarlane, Neale, Norman, Roy, and Streiner (1981) described the distribution of social support by demographic characteristics. The mean network size was found to be 9 or 10 persons. Several categories of relationships were identified including close friends, work-related relationships, professionals, spouse, other family, neighbors, and others. Age caused a decrease in both network size and the amount of support received by persons over age 55. Women's networks were slightly larger and had a higher proportion of family and friends, while men reported more work-related relationships. Married individuals received the most amount of informal support as compared to the nevermarried, widowed and divorced. Berkman and Syme (1979) in a nine-year follow-up study found that marital status and contacts with friends predicted lower mortality rates for both men and women across all age groups.

What effect does the illness of breast disease have on social support? Only one study could be found which included women diagnosed with benign breast disease in a description of the social network's response to illness (Morris, Greer, & White, 1977). Cancer in general, and more specifically, breast cancer, has been examined in several studies of social support (Lindsey, Norbeck, Carrieri, & Perry, 1981). The husband has been identified as one of the important people in the breast cancer patient's social network (Ervin, 1973); however, no study was found which examined the impact of breast cancer on the husband's social net-

work.

A review of social support and the cancer patient by Wortman (1984) suggests that social support affects and is affected by the cancer experience. Unfortunately, it appears that "the social relationships of the cancer patients may not only fail to buffer them against the stress of cancer, but may be an additional source of distress (p. 2341). Whether this is because access to social support is limited by the illness as suggested by Bloom and Spiegel (1984) or because the individual perceives supportive relationships to be less effective remains unclear.

An early, descriptive study of 21 post-mastectomy women over one year found that the subjects felt alienated because they had few family members and friends who were willing to discuss problems related to breast cancer (Quint, 1963). A study of breast, lung and sarcoma cancers by Peters-Golden (1982) found that 72% of the patients reported they were treated differently after people knew they had cancer. Of these, 72% said they were "misunderstood" by others, 50% said they were "avoided" or "feared", and 14% said they were pitied.

In a theoretical analysis of the interpersonal relationships of cancer patients, Wortman and Dunkel-Schetter (1979) describe a negative circular communication pattern which may occur. They propose that the social network (including health care professionals) may feel apprehensive or uncomfortable about the disease of cancer but believe that they should be optimistic and cheerful in their interactions with the patient. This conflict results in behaviours such as physical avoidance and strained, uncomfortable and closed communication. The cancer patient interprets these behaviours as rejection and the negative pattern

creates a climate of communication problems and "conspiracies of silence".

Research has suggested that this negative communication pattern need not always occur. Morris, Greer, and White (1977) asked benign and malignant breast disease patients about frequency of contact with family and friends on a four-point rating scale. A significantly higher number of the malignant women (17%) reported an improvement in their interpersonal relationships at three months post-surgery than did the benign comparison group (4%). However, at two years, the benign group also reported improvement with 16% of the sample reporting an increase in interpersonal relationships. Silberfarb, Maurer and Crouthamel (1980) found that 69% of the breast cancer patients in their study reported positive feelings about the emotional support received from family members and friends.

Social support may also have an effect on the outcome of breast cancer. Marshall and Funch (1983) found that social stress decreased the length of time breast cancer patients survived, whereas social involvement increased survival. Poor adjustment to mastectomy was found to be related to an anticipated or actual lack of support (Bloom, 1982). Funch and Mettlin (1982) reported that social involvement had a significant independent effect on survival from breast cancer. Northouse (1981) found those mastectomy patients who reported having fewer supportive relationships had a higher fear of cancer recurrence.

In conclusion, social support appears to be an appropriate and important focus of inquiry. Most of the research reviewed for this section suffers from a lack of standardized measures. Frequently, the

assessment of social support was limited to frequency of contact (quantity) or evidence of relationship disturbance. Sample characteristics of women with breast cancer were often a heterogeneous mix of age, marital status and stage of illness. If social support is situation and demographic specific, more control needs to be made to ensure homogeneity of the sample.

While a specific instrument to measure social support in cancer patients is not available, Wortman (1984) advises that ideally, measurement should include distinct types of support by distinct providers, quality as well as quantity of support, positive as well as negative support, the perspective of the provider as well as the recipient, and the aspect of utilization in addition to availability of social support. Comprehensive measurement would enable a better understanding of the complex, reciprocal relationship between social support and health outcomes.

#### Summary of the Literature Review

While the preceding literature review indicates that a variety of studies have examined aspects of the impact of the threat, diagnosis and treatment of breast disease, a number of questions remain unanswered.

The pre-biopsy "threat of breast cancer" time period has infrequently been assessed using self-report measures of psychological distress. As well, no study appears to have asked about the effect on the marital partner by including the partner in data collection using quantitative and/or qualitative methods. What is the effect of having to deal with the possibility of breast cancer on the marital relationship

and on the social support system? The present study assesses responses of both marital partners on reliable and valid measures of psychological distress, marital intimacy and quality and quantity of social support. Qualitative methods of data collection are also proposed.

Another question is once the diagnosis is known, what effect does this have on each spouse, on their relationship, and on their larger social support systems? Again, studies have primarily been retrospective and have only examined the impact of malignant breast disease on the woman with few reports of the husband's experience. Do differences exist between husbands and wives in their reports of psychological distress, marital intimacy and social support? Do differences exist between the diagnostic categories of malignant vs. benign couples on these measures? And do differences exist over time on these measures from just learning the diagnosis to living with breast disease? A prospective longitudinal design with repeated measures is proposed for this study as a method to answer these questions.

## CHAPTER 3

### METHODOLOGY

The content of this chapter is divided into two sections: the research design and the method used to conduct this study.

#### Research Design

##### Statement of the Problem

The problem addressed in this study was to obtain a description of the ripple effect of the threat of breast cancer on the woman and her spouse. The description was aimed at indicating the level of individual distress, degree of marital intimacy, and quality as well as quantity of social support experienced by the marital couple during the pre-diagnosis phase. As well, a parallel description of the effect of the diagnosis and treatment phases of both benign and malignant breast disease on the marital couple was addressed.



### Design of the Study

This study was undertaken using a non-experimental descriptive design. In descriptive research there is no possibility for control over the independent variable (the experience of breast disease) or for random assignment to groups (Polit & Hungler, 1983). The phenomena are described as they exist in their natural social condition. The relationship among variables is described in a descriptive correlational design.

The limitation of this type of research is that while it describes the qualities or characteristics of the phenomenon of interest, it leaves cause-and-effect relationships ambiguous. This inability to reveal causal relationships is a major weakness of descriptive design and carries with it greater risk of faulty interpretation of study results than experimental research. However, Schmale (1980, p. 44) notes that psychosocial oncology research is not looking for cause-and-effect relationships but at "covariate, facilitating and inhibiting interreactions".

While experimental studies are frequently considered more scientifically rigorous, Siegel (1983) comments about the importance of descriptive design in the progression of research studies from descriptive to explanatory where the goal is an integrated body of knowledge and theory:

Finally it must be acknowledged that descriptive studies are often regarded as less significant and therefore less prestigious, which has often made researchers reluctant to undertake them. This is an unfortunate and mistaken perception. Des-

criptive research usually becomes the critical foundation for later more complex studies. If that foundation is weak or full of gaps, subsequent research is likely to be seriously flawed. Investigators undertaking the more complex studies at later stages will be prone to fill in gaps in understanding with numerous inferences, which, while often plausible, might prove unsubstantiated if data were unavailable [sic]. In addition, the statistical analysis applied to the more advanced design studies are often predicated on certain assumptions about the parameters of the population or phenomenon under study which can only be determined through careful descriptive research. (p. 104)

Spinetta (1984) supports this view and asserts that, "In a field of research as relatively new as that of the rigorous application of the scientific method to the psychosocial aspects of cancer, there is a need to establish base rates for the frequency of psychological and social reactions associated with various types of cancer" (p. 2224). Descriptive research is essential and legitimate.

Quantitative and qualitative data were collected longitudinally from subjects about their experience at three time periods over six months using repeated measures.

### Method

#### Subjects

A convenience sample of fifty-six women who were scheduled for a breast biopsy consented to participate in the study. They were required

to meet the following criteria: married, with husband consenting to participate in the study; able to speak and read English; live in Calgary or the surrounding area; and if malignancy was diagnosed, the disease limited to Stage I or Stage II breast cancer.

A total of 112 subjects or 56 couples comprised the sample. Of the initial 56 couples, 45 were diagnosed as having benign breast disease. Thirty-six couples completed all three test sessions. Nine couples were dropped by the investigator for various reasons. One couple did not have the breast biopsy as scheduled, one moved to another province, two were dropped because the husband's cooperation was suspect, and five were unable to be contacted within the necessary time frame for the follow-up interviews. It is interesting to note that no couples requested to withdraw from the study.

Eleven couples were diagnosed as having breast cancer. Eight completed all three test sessions. Three couples completed only the pre-biopsy interview and were subsequently dropped from the study by the investigator. One was dropped because the diagnosis revealed Stage IV breast cancer; one had complications related to the breast cancer surgery which necessitated a long and unusual hospitalization; and one was initially given benign results only to be told later that an independent lab investigation had revealed a small foci of malignant cells which necessitated removal.

Medical and demographic information on the characteristics of the research subjects was obtained from the surgeon's records and through the inclusion of a personal information sheet and family genogram with the research instruments.

Of the 112 subjects, the mean age was 44.1 years, with the range in age being 21-76 years. Eighty-three (74.1%) subjects were employed, five (4.5%) were unemployed, four (3.6%) were retired and 20 (17.9%) were homemakers. The length of marriage for the 56 couples ranged from 1-51 years with a mean of 19 years.

Table 1 presents the demographic information on the subjects (and couples) who were diagnosed as benign and malignant. Male and female categories within each diagnosis are included. Pronounced age differences between the benign and malignant groups were reported. The mean age of benign females was 40.3 years as compared to the mean age of malignant females which was 52.5 years. Similar differences were reported for the male benign group with a mean age of 43.4 years vs. the male malignant group with a mean age of 54.09 years. Other demographic information reported in Table 1, such as employment, race, religious preference, and participation in religious activities, appears consistent between the benign males and females as compared to the malignant males and females. The benign couples (n=45) were married an average of 16.55 years, while the malignant couples (n=11) reported being married an average of 29.36 years. Sixty-two percent of the benign couples and 72.7% of the malignant couples reported a net family income of over \$40,000.00.

In Table 2, the surgical procedure performed on the female subjects is shown. Forty-one percent (n=23) of the female subjects had a biopsy only with local anesthesia; 37.5% (n=21) had a biopsy only with general anesthesia. These comprised the benign group. Of the malignant females (N=11), 3 subjects had a one-stage modified radical mastectomy; 3 had a

TABLE 1

Demographic Characteristics of Subjects

		<u>Benign (n=90)</u>		<u>Malignant (n=22)</u>	
		Female	Male	Female	Male
<b>Age:</b>		40.33	43.42	52.5	54.09
<b>Education:</b>	8-12 Years	57.8%	42.2%	45.5%	45.5%
	13-16 Years	28.9%	33.3%	36.4%	18.2%
	17-20 Years	11.1%	22.2%	18.2%	18.2%
	More than 20 Years	2.2%	2.2%	0%	18.2%
<b>Employment:</b>	Employed	60.0%	88.9%	63.6%	81.8%
	Unemployed	2.2%	8.9%	0%	0%
	Retired	0%	2.2%	9.1%	18.2%
	Homemaker	37.8%	0%	27.3%	0%
<b>Race:</b>	White	95.6%	95.6%	100%	100%
	Asian	4.4%	4.4%	0%	0%
<b>Religious Preference:</b>	Protestant	60.0%	62.2%	54.5%	63.6%
	Catholic	24.4%	15.6%	36.4%	27.3%
	Jewish	0%	0%	0%	0%
	Other	4.4%	2.2%	0%	0%
	None	11.1%	20.0%	9.1%	9.1%
<b>Participation in Religious Activities:</b>	Inactive	40.0%	48.9%	27.3%	27.3%
	1-2 times/year	22.2%	22.2%	27.3%	27.3%
	About Monthly	11.1%	8.9%	9.1%	9.1%
	Weekly	26.7%	20.0%	36.4%	36.4%

		<u>Couples (n=45)</u>	<u>Couples (n=11)</u>
<b>Length of Marriage:</b>		16.55 Years	29.36 Years
<b>Total Family Net Income:</b>	\$15,999 and below	0%	9.1%
	\$16,000 - \$24,999	17.7%	0%
	\$25,000 - \$39,999	17.7%	18.2%
	\$40,000 and above	62.2%	72.7%

TABLE 2

Type of Surgical Procedure Performed on Female Subjects

Surgical Procedure	Frequency	Percent of Total Sample*
Biopsy only, local anesthetic	23	41.1
Biopsy only, general anesthetic	21	37.5
Modified Radical Mastectomy, 1-Step Procedure	3	5.4
Modified Radical Mastectomy, 2-Step Procedure	3	5.4
Bilateral Modified Radical Mastectomy, 1-Step Procedure	1	1.8
Segmental Resection, 1-Step Procedure	1	1.8
Segmental Resection, 2-Step Procedure	2	3.6
Bilateral Segmental Resection, 2-Step Procedure	1	1.8
No Surgery	1	1.8

\*n=56 females.

two-stage modified radical mastectomy, meaning they had a biopsy first and then several days later had the mastectomy performed. One subject had a one-stage bilateral modified radical mastectomy as malignancy was found in both breasts. One breast was removed immediately following the biopsy under general anesthetic which diagnosed the malignancy. The other breast was removed one week later. One subject had a segmental resection (lumpectomy) done in a one-stage procedure. Two subjects had a segmental resection done in a two-stage procedure. One subject was required to have a bilateral segmental (two-stage) resection when malignancy was confirmed in both breasts. One subject was scheduled for but did not receive a biopsy.

One last description of the females who participated in the study is that three women (two benign, one malignant) were pregnant at the time of the biopsy and three other women (two benign, one malignant) were required to stop breastfeeding prior to the biopsy procedure.

### Instruments

Data were gathered through the use of three questionnaires and a semi-structured interview which were administered at various times over the test period. The Profile of Mood States (POMS) provided a quantitative measure of the level of psychosocial distress experienced by each spouse. The Personal Assessment of Intimacy in Relationship (PAIR) served as a self-report measure of the degree of relationship intimacy experienced in the marital relationship. The quality and quantity of social support reported by each spouse was measured by the Norbeck Social Support Questionnaire (NSSQ). Finally, a semi-structured con-

joint interview provided qualitative information about family structure; understanding and concerns about the illness; coping response to the threat, diagnosis and treatment of benign and malignant breast disease; and involvement of the social support system. A detailed description of each instrument is presented below.

Profile of Mood States (POMS). The POMS, developed by McNair, Lorr and Droppleman (1981), is a 65-item, 5-point adjective rating scale which measures six identifiable mood states: tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment. A sum of the six factors gives a Total Mood Disturbance Score (weighting vigor negatively). The adjectives chosen for the instrument are meant to be easily understood by subjects having a grade seven education. Extensive factor analytic studies have established the independence of the six mood states. Analysis for internal consistency resulted in coefficient alphas of .84 to .95 for all items within each mood state. Test-retest reliability has ranged from .65 to .74.

The POMS has proven to be sensitive to change in mood states in a variety of clinical contexts, ranging from short-term psychotherapy (Haskell, Pugatch, & McNair, 1969), controlled clinical drug trials (McNair, Fisher, Kahn, & Droppleman, 1970), dental patients (Pillard & Fisher, 1970), marijuana users (Mirin, Shapiro, Meyer, Pillard, & Fisher, 1971), and alcoholics (Nathan, Titler, Lowenstein, Solomon, & Rossi, 1970). Results were congruent for different patient and normal samples and for different rating time periods. Concurrent validity was established through significant correlations with three clinically de-



rived scores from the Hopkins Symptom Distress Scales (Parloff, Kelman, & Frank, 1954). Normative data from either college student or psychiatric outpatient samples are available. The instructions with regard to time set can be altered and for the purposes of this research the "past week" format was used. The one-week rating period was chosen to depict the typical and persistent mood reactions to the subject's present life experience.

The POMS has been used with a breast cancer sample by Bloom, Ross and Burnell (1978). In their experimental design they found post-mastectomy women in the intervention group were significantly more tense, depressed, less vigorous and more confused than women in the comparison group at 4-7 days after surgery. The experimental group reported less negative affect two months later.

In summary, the POMS was chosen because it appeared to be a reliable and valid instrument for measuring mood states and mood changes over time and was therefore included in this study as a measure of psychological distress at each of the three test periods.

Personal Assessment of Intimacy in Relationships (PAIR). The PAIR Inventory (Schaefer & Olson, 1981) is a 36-item self-report instrument designed to assess five types of intimacy derived from the conceptual dimensions proposed by Dahms (1972) and Clinebell and Clinebell (1971). The five scales include: (1) emotional intimacy - the ease with which moods and feelings are communicated and mutually experienced; (2) social intimacy - the importance and role of friends in the relationship; (3) sexual intimacy - the degree to which sexual needs are communicated and fulfilled in the relationship; (4) intellectual intimacy - the degree to

which ideas and beliefs are discussed; and (5) recreational intimacy - the degree to which interest in various leisure time pursuits is compatible. A Conventionality scale used to detect a social desirability response set is also included. Internal consistency of items within each factor ranged from .70 to .82. Test-retest reliability has not been documented.

The PAIR is administered individually and consists of two phases. The subject is asked to provide a five-point (agree-disagree) rating of the relationship describing "how it is" and "how I would like it to be". Differences can be used to assess each partner's concerns about the relationship as well as differences in expectations between the couple.

In terms of concurrent validity, positive correlations were found with the Locke-Wallace Marital Adjustment Scale (Locke & Wallace, 1959) and the Family Environment Scale (Moos, 1974). Further support for the PAIR was provided by a study which examined the role of marital intimacy among psychiatric inpatients (Hames & Waring, 1980). Perceived intimacy on the PAIR was found to be negatively correlated with a measure of non-psychotic emotional illness.

The strengths of this instrument appear to be the identification of various areas of relationship intimacy and the assessment of each spouse's unique perceptions of an ideal relationship as opposed to an absolute standard of what "ideal" should be. Furthermore, the instrument appears to measure the degree to which each spouse presently feels intimate in the relationship and the degree to which each spouse would like the relationship to be intimate. Thus scores are not of themselves indicators of good relationship or poor relationship but are relative,

depending on the perceived versus expected scores reported by each spouse and between each couple. This emphasis on perception of intimacy was chosen for use in this study over other marital relationship characteristics such as adjustment, satisfaction or happiness.

Norbeck Social Support Questionnaire (NSSQ). The NSSQ, developed by Norbeck, Lindsey and Carrieri (1981, 1983), is a self-report instrument which measures multiple dimensions of social support. The subject is first asked to identify up to twenty-four "significant persons" in nine categories of relationships (e.g., spouse, relatives, friends, co-workers). Eight questions are then asked about each person listed such as, "How much does this person make you feel liked or loved?" and "If you were confined to bed for several weeks, how much could this person help you?"

The instrument has three main variables: (1) total functional (affect, affirmation and aid dimensions); (2) total network (number in network, duration of relationships, frequency of contacts); and (3) total loss (number of categories of persons lost and amount of support lost during the past year). Test-retest reliability ranged from .85 to .92. High levels of internal consistency within items have been shown: total functional items .72 to .97; and total network items .88 to .97. Total loss items have shown acceptable coefficients of .54 to .68. Intercorrelations among all items were .88 to .96. The instrument has been documented to be free from response bias using the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960). Concurrent validity was obtained through moderately high correlations between another social support questionnaire on selected items. A small normative data base

and construct validity have been established.

This instrument was considered to be a useful measure of social support for this study because it is short, easy to administer and includes multiple dimensions which focus on the quality as well as the quantity of supportive relationships in the individual's social system. As well, it has been shown to be sensitive to predicted changes in network composition over time.

Semi-Structured Interview. The semi-structured conjoint interview was designed by the investigator as a means to engage the couple in the research project and to supplement the information from the quantitative instruments. Based on the skills of family interviewing identified by Wright and Leahey (1984), the questions have been developed to obtain information about family structure, the couple's understanding and concerns about the illness, individual and marital coping response to the threat and diagnosis of breast disease, and involvement of the social support system. A decision to interview the couple conjointly was based on the rationale of wanting to observe the marital subsystem interaction and communication and provide the opportunity for the spouses to hear each other's concerns. The risk of conducting the conjoint vs. separate interview was that all concerns may not have been articulated with both spouses present. Each interview question will be discussed separately in the next section.

1. Family Structure. A genogram or diagram of the family constellation was a useful way to begin the first interview and engage the couple in the research project. Besides obtaining information about the family structure, specific questions used to generate the genogram also

provided information about several other important issues such as: previous experience with illness; family history of breast cancer; the number of family relationships available for support; and even self-fulfilling prophecies about health. The question began with the investigator saying, "It would help me get to know you by having an idea about who is part of your family". Typical questions posed to couples included: How old are you? What do you do for a living? How long have you been married? How many children do you have? How old are they? Do either of you have children from a previous relationship? Are you presently being treated for any illness? Tell me about your family origin. How many brothers or sisters do you have? Where do they live? Are your parents alive? Where do they live? How often does your family get together? Who do you see most often? Are there any illnesses which tend to run in your family such as cancer, heart disease, high blood pressure, diabetes?

In order to enhance engagement efforts, the investigator began the questions with the husband and then asked the parallel genogram questions of the wife. Research which compared various methods of obtaining family information by physicians found that the semi-structured genogram interview was a useful and efficient way to obtain family information. The genogram interview resulted in four times as much family information as compared to the informal health interview with 96% of the subjects responding favourably to its use (Rogers & Durkin, 1984).

2. What do you folks understand about the diagnosis and treatment at this time? This question was asked at each of the three interviews and set the stage for exploring what the couple understood about the

health problem. Moos (1982) identified seeking information about the illness, treatment procedures, and probable outcomes as one of the coping skills used to deal with an acute health crisis. This question allowed for an assessment of information deficits.

3. "Who have you told about the biopsy?" This question was designed to be supplementary to the social support questions of the NSSQ and was asked at the pre-biopsy interview.

4. "What is your greatest concern at this time?" This question was asked at each interview to assess differences between husbands and wives and differences over time.

5. "What changes have you noticed in your spouse?" The answer to this question reveals the coping response of each spouse to the potential and actual diagnosis.

6. A related question posed to each couple was, "What has been helpful for you as a couple in dealing with this situation?" This question required the couple to consider problem-solving approaches used by them to deal with the threat or reality of breast disease. This question was asked at each of the three interviews.

7. "In giving advice to health care professionals, what do you need most at this pre-biopsy time?" This question was designed to elicit suggestions as to how health care services for this unique health problem could be improved.

8. "What changes have you noticed in your relationship?" Relationship changes over time following the biopsy were assessed as a supplementary question to the PAIR Inventory. Another way of asking for the same information was to ask the couple to rate their satisfaction with

their relationship compared to most marriages they knew. It was suggested that the rating be made on a hypothetical scale of 1 to 10 where 1 was least satisfied with the relationship and 10 was most satisfied.

### Procedure

Women who met the previously described criteria and who were scheduled for a breast biopsy were recruited through surgeons' offices. It is standard practice to be referred to a surgeon by a family physician upon discovery of a breast lump which looks suspicious. In September, 1983, nine surgeons with admitting privileges to two general hospitals in Calgary agreed to participate in the study.

Subject accrual proved to be a major problem in this study. Data collection began in September 1983 and was terminated in October, 1985. In the initial plan, a standardized patient information sheet (see Appendix A) was given to each surgeon as a way to introduce the study to the patient and obtain the patient's permission to reveal her name to the investigator. Weekly phone contact with each surgeon's office revealed that surgeons "forgot" or were "too busy" to give the patient the information sheet. Another reason given for not using the patient information sheet was that the patient, upon hearing that a breast biopsy was indicated, was "too distraught" or "too emotional" and therefore deemed inappropriate to be given the information sheet.

In January, 1984, the first subject was recruited. This subject had many questions about the biopsy procedure and about alternative cancer treatments and was unable to be seen numerous times by the surgeon in order to discuss these concerns. The surgeon's receptionist remem-

bered the study and essentially referred the patient to the investigator without the surgeon's knowledge as a way of assisting the patient with her questions.

In March, 1984, the surgeons were asked if the investigator could ensure subject accrual by being informed about appointments that were scheduled to be seen for a breast problem. Permission was obtained and, when possible, the investigator or a research assistant came to the surgeon's office at the time of the appointment and waited for the patient to be seen by the surgeon. This change in procedure made it possible to engage subjects and surgeons more readily through personal face-to-face contact.

Confidentiality of the patient was maintained by withholding the patient's name from the investigator until such time as it was determined that the patient fit the study criteria, required a biopsy for her presenting breast problem, and upon discussion with the surgeon, agreed to meet the investigator to learn more about the study. The woman was then introduced to the waiting investigator by the surgeon, and the investigator proceeded to carefully tell the potential subject about the nature, purpose and requirements of the study. Opportunity was provided for the subject to ask questions about the research or ventilate concerns about just learning that she required a breast biopsy. Because a conjoint interview with the woman and her spouse was an integral part of this study, a discussion of how to obtain her husband's participation ensued. Often the subject would offer to speak to the husband herself; however, the investigator would occasionally request to contact the husband by phone to personally explain the study and enlist his participa-



tion.

Women who refused to participate or who suggested their husbands would be unwilling to participate were thanked for their time and were assured that their refusal to participate would in no way influence the care they received from the surgeon.

It is estimated that, for each subject who fit the criteria and agreed to participate in the study, 4.5 hours of waiting time was spent in surgeons' offices.

When consent to participate was obtained from the couple, an interview was scheduled. The investigator met with the couple in their home or, if the couple preferred, at the Family Nursing Unit at the University of Calgary. Home visits were made to the majority of couples and included visits within the City of Calgary as well as the surrounding area.

Following a verbal review about the nature of the project, a consent form was read and signed by each spouse at the beginning of the interview. Consent was also obtained to audiotape each interview.

Data were collected from each couple at three time periods over 6 months; pre-biopsy, within 2 weeks of the biopsy procedure; diagnosis, 6-8 weeks post-biopsy for the benign breast disease group, and 6-8 weeks post-surgery for the breast cancer group; and follow-up, 5-6 months post-biopsy or post-cancer surgery.

The couple was interviewed at each of the three time periods. Each interview took 1 to 2 hours and consisted of a semi-structured conjoint interview with the couple which was taped. The interview was followed by a request for each spouse to complete the written questionnaires

independently, without sharing answers. This ensured that the marital partners could not influence each other's response. The investigator was available to answer any questions the individuals raised about the instruments or the instructions related to them. The instruments were administered at the following times (see Table 3):

1. The pre-biopsy interview occurred within two weeks prior to the biopsy. The timing of this interview was difficult to standardize between couples, as the hospital was responsible for scheduling the surgery time which was dependent upon many factors outside the surgeon's or patient's control. The instruments administered at this time were the POMS, PAIR, and the NSSQ. Each subject required approximately 45 to 60 minutes to complete the three written questionnaires. Rationale for administering all three instruments was to provide a base-line measure at the onset of the illness experience when the threat of breast cancer at the pre-diagnosis phase was a predominant issue. Jamison, Wellisch, and Pasnau (1978), in a retrospective study of women post-mastectomy, reported the most stressful time period claimed by the women was immediately after the lump was discovered.

2. The second interview occurred at 6-8 weeks post-biopsy or post-cancer surgery when the diagnosis of benign or malignant was known. Worden and Weisman (1977) did a six-month follow-up study of newly diagnosed breast cancer patients and found that the women experienced most distress approximately two months after learning the diagnosis. The POMS was the only instrument administered at this time.

3. The last interview occurred at 5-6 months post-biopsy or post-cancer surgery. Adjuvant treatment (chemotherapy, radiation, etc.) had

TABLE 3

Schedule of Administration of Instruments at Each Time Period

INSTRUMENTS	TIME PERIODS		
	<u>Pre-Biopsy</u>	<u>Diagnosis</u>	<u>Follow-Up</u>
	Within 2 Weeks of Biopsy	6-8 Weeks Post-Diagnosis	5-6 Months Post-Diagnosis
	Semi-Structured, Interview	Semi-Structured Interview	Semi-Structured Interview
	POMS	POMS	POMS
	PAIR		PAIR
	NSSQ		NSSQ

usually begun for most breast cancer patients by this time. For subjects who received a benign diagnosis, a retrospective review of the experience provided an opportunity to discuss any enduring change that they attributed to the biopsy experience. All three instruments were administered at this time period to complete the repeated measures design and to compare the responses on the POMS, PAIR and NSSQ with those obtained at the pre-diagnosis time period. The same presentation of the instruments used at the first interview was also used at the last interview. With a repeated measures design, extraneous variables such as history, maturation and testing may threaten the internal validity of the study (Campbell & Stanley, 1963) and need to be considered when results are interpreted.

The investigator, who was a registered nurse with a master's degree in mental health nursing, conducted all the conjoint interviews. Research assistants were employed to assist with subject recruitment. These were registered nurses or undergraduate nursing students enrolled in a research course.

#### Ethical Considerations

Subject consent was sought after a brief explanation of the purposes, risks and benefits of the study. A consent form was signed by both the woman and her spouse (see Appendix B). Opportunity was provided for the couple to indicate their desire to receive a summary of the results. No remuneration was provided to any subject.

The anonymity and confidentiality of information was respected by assigning each couple a code number. The information sheet which con-

tained the subject's name and address and the consent form were kept separate from the instruments and transcripts of the interviews. No identifiable subject information will be used in publications or research reports. Ethical approval was received from the University of Calgary Ethics Committee on September 12, 1983 (see Appendix C).

#### Treatment of the Data

1. Quantitative Analysis. Descriptive and correlational procedures of the Statistical Package for Social Sciences (SPSS) were used in the analysis of the instruments. After preliminary examination of frequency distributions, Pearson correlations were used to determine the significance of the relationships between selected variables. Univariate and multivariate analyses of variance for repeated measures were used to assess the significance of changes on the instrument scores over the three time periods and the significance of differences reported by sex and diagnosis on the variables psychological distress and marital intimacy.

2. Qualitative Analysis. The information obtained from the transcripts of the conjoint interviews conducted at each time period was categorized according to the questions of the semi-structured interview. These responses were coded and tabulated. Frequencies of responses to selected questions were primarily used to further describe and enrich the meaning of the subjects' scores on the instruments.

## CHAPTER 4

### RESULTS

The results obtained from the quantitative and qualitative analysis of the data are presented and summarized in this chapter. Only the data obtained from the 112 subjects (N=56 couples) who completed the pre-biopsy interview and the 88 subjects (N=44 couples) who completed the diagnosis and follow-up interviews are included in the analysis.

#### Part I: Quantitative Analysis

The categories of time period (pre-biopsy, diagnosis, follow-up), diagnosis (benign, malignant), and sex (female, male) were used to describe subject scores on the three variables of psychological distress, marital intimacy and social support. A descriptive analysis including means and standard deviations and correlations is reported first. This is followed by a reporting of the statistical procedures of univariate and multivariate analysis which were used to describe the changes on the variables. Interaction effects were examined first and if

they were found to be significant, simple main effects were subsequently examined.

#### Sample Means and Standard Deviations

Psychological Distress. Tables 4 and 5 present the means and standard deviations for the benign and malignant male and female groups on the variable of psychological distress (POMS) at the pre-biopsy, diagnosis and follow-up time periods. The POMS includes six mood states and a total mood disturbance score (TMD).

Published normative data for a college student sample of 340 men and 516 women are available and the authors advise the norms be used with caution (McNair, Lorr, & Droppleman, 1981). The subjects' scores on POMS were compared with the normative sample by converting raw means to standard scores. McNair, Lorr, and Droppleman (1981) found no differences between males and females in their normative sample so one normative standard score was reported ( $M=50$ ,  $S.D.=10$ ). Figure 4 presents a profile of all subjects' standard scores on the POMS over the three time periods as compared to the normative standard score.

The means for the six mood states at the pre-biopsy time period were found to be within one standard deviation of the normative sample mean suggesting an absence of psychopathology. Similarly for the diagnosis and follow-up periods, all standard scores, with the exception of confusion, remained within one standard deviation of the normative sample mean. The standard score for confusion dropped to below one standard deviation for the treatment and follow-up time periods. The amount of psychological distress at the diagnosis and follow-up times

TABLE 4

Means and Standard Deviations Obtained on the 7 Subscales of POMS by Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy, Diagnosis and Follow-up Time Periods

		Benign				Malignant			
		Female		Male		Female		Male	
		Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
<b>Total Mood Disturbance:</b>	Pre-Biopsy	31.02	39.82	19.04	25.74	23.27	31.46	31.81	44.15
	Diagnosis	12.19	24.39	12.08	26.95	9.87	28.96	4.25	22.76
	Follow-Up	12.86	28.27	9.50	24.95	13.25	32.09	1.00	20.19
<b>Tension:</b>	Pre-Biopsy	13.11	9.48	9.73	5.82	13.18	7.22	11.45	8.94
	Diagnosis	7.63	5.09	7.66	5.51	6.37	5.42	7.00	7.34
	Follow-Up	7.55	5.37	6.88	5.04	7.87	7.23	5.75	4.20
<b>Depression:</b>	Pre-Biopsy	9.75	11.07	6.77	6.93	7.81	7.63	10.54	11.11
	Diagnosis	5.52	6.69	5.44	7.05	3.50	5.04	5.12	5.08
	Follow-Up	5.58	6.97	4.69	6.86	5.50	8.12	4.12	5.41
<b>Anger:</b>	Pre-Biopsy	7.53	9.25	6.11	5.74	3.81	3.28	7.90	10.68
	Diagnosis	4.63	5.85	6.00	6.68	4.00	4.78	2.62	4.53
	Follow-Up	4.80	5.41	4.47	6.04	5.25	6.84	2.87	2.99

**NOTE:**Pre-Biopsy:

Benign Female  $\bar{n} = 45$   
 Male  $\bar{n} = 45$   
 Malignant Female  $\bar{n} = 11$   
 Male  $\bar{n} = 11$

Diagnosis:

Benign Female  $\bar{n} = 36$   
 Male  $\bar{n} = 36$   
 Malignant Female  $\bar{n} = 8$   
 Male  $\bar{n} = 8$

Follow-Up:

Benign Female  $\bar{n} = 36$   
 Male  $\bar{n} = 36$   
 Malignant Female  $\bar{n} = 8$   
 Male  $\bar{n} = 8$



TABLE 5

Means and Standard Deviations Obtained on the 7 Subscales of POMS by Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy, Diagnosis and Follow-up Time Periods (continued)

		Benign				Malignant			
		Female		Male		Female		Male	
		Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
<b>Vigor:</b>	Pre-Biopsy	15.66	6.47	16.84	5.41	15.81	7.79	14.54	5.66
	Diagnosis	17.69	5.47	17.72	5.19	16.62	7.17	19.87	3.83
	Follow-Up	17.30	6.19	17.69	4.59	15.12	8.27	19.87	5.13
<b>Fatigue:</b>	Pre-Biopsy	8.95	6.78	6.95	5.48	6.09	6.28	7.63	5.51
	Diagnosis	5.86	5.02	5.55	5.75	7.37	6.06	4.25	3.45
	Follow-Up	7.27	6.46	6.05	4.47	4.00	3.96	4.00	4.14
<b>Confusion:</b>	Pre-Biopsy	7.64	6.00	6.33	3.92	8.18	4.91	8.81	6.46
	Diagnosis	5.19	3.79	4.94	3.48	5.25	4.92	5.12	3.79
	Follow-Up	4.94	4.26	4.77	3.20	6.12	4.67	4.12	2.41

**NOTE:**Pre-Biopsy:

Benign Female  $\bar{n} = 45$   
 Male  $\bar{n} = 45$   
 Malignant Female  $\bar{n} = 11$   
 Male  $\bar{n} = 11$

Diagnosis:

Benign Female  $\bar{n} = 36$   
 Male  $\bar{n} = 36$   
 Malignant Female  $\bar{n} = 8$   
 Male  $\bar{n} = 8$

Follow-Up:

Benign Female  $\bar{n} = 36$   
 Male  $\bar{n} = 36$   
 Malignant Female  $\bar{n} = 8$   
 Male  $\bar{n} = 8$

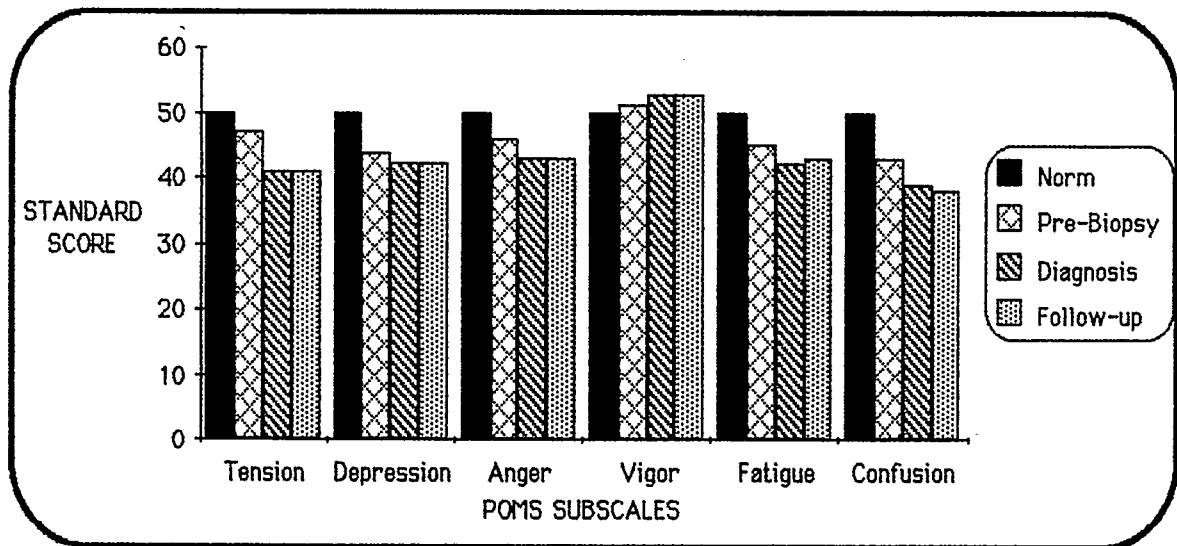


Figure 4. Comparison of standard scores of all subjects on POMS subscales at three time periods with the normative standard score.

appears to be considerably lower than that reported by the normative group.

Marital Intimacy. The scores on the variable of marital intimacy (PAIR) at the pre-biopsy and follow-up time periods for the benign and malignant male and female groups are presented in Tables 6 and 7. Five subscales each of perceived intimacy and expected intimacy are reported including a discrepancy score which describes the difference between perceived and expected intimacy on each of the five subscales. The mean score on the conventionality scale is also reported. Comparison of mean scores on perceived intimacy at the pre-biopsy and follow-up times with normative data obtained from 192 couples (Schaefer & Olson, 1981) is presented in Figure 5. The column chart shows the couples in this study rated their perceived intimacy higher in all subscales at both time periods than the normative couples. The conventionality score is also much higher for couples in this study at both time periods, suggesting a socially desirable response set.

Social Support. Tables 8 and 9 present the means and standard deviations for the benign and malignant, male and female scores on the variable of social support (NSSQ) at the pre-biopsy and follow-up time periods. The specific subscales which account for the total functional, total network and total loss scores are included. The means obtained on the NSSQ by males and females at the pre-biopsy time period were compared with available normative data derived from staff employees at a university medical center (Norbeck, Lindsey, & Carrieri, 1983).

The initial question on the NSSQ asked the subjects to identify all the significant persons in their lives who provided social support or

TABLE 6

Means and Standard Deviations Obtained on the 6 Subscales of PAIR by Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy and Follow-up Time Periods

			Benign				Malignant			
			Female		Male		Female		Male	
			Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
Pre-Biopsy:	Emotional:	P	69.51	19.96	74.04	15.15	78.54	14.99	68.72	18.66
		E	83.73	12.57	80.08	13.84	83.63	14.13	82.54	11.90
		E-P	13.72	17.58	6.09	13.86	5.09	11.18	17.60	18.78
Follow-Up:	Emotional:	P	68.45	18.19	72.77	17.54	79.00	18.23	79.50	16.62
		E	82.44	13.59	79.54	15.11	87.00	8.75	88.50	8.46
		E-P	14.66	20.16	7.64	12.23	10.66	10.63	9.00	14.02
Pre-Biopsy:	Social:	P	68.26	20.18	63.73	18.01	74.54	16.22	66.90	14.86
		E	76.53	15.71	70.53	14.29	82.00	12.80	74.54	12.55
		E-P	8.45	16.90	6.42	15.48	7.45	14.91	6.80	6.26
Follow-Up:	Social:	P	66.97	15.28	66.81	13.40	75.50	16.62	65.11	12.81
		E	73.77	13.57	69.71	12.43	80.50	12.72	81.00	12.78
		E-P	6.06	15.97	4.70	12.93	7.33	11.43	6.50	9.05
Pre-Biopsy:	Sexual:	P	72.66	17.27	70.93	16.95	70.18	17.00	62.90	16.59
		E	82.13	13.55	79.91	13.60	82.90	16.20	78.54	10.62
		E-P	9.31	16.32	8.47	15.40	12.72	14.51	17.20	19.04
Follow-Up:	Sexual:	P	72.00	15.46	69.77	17.48	74.00	15.85	64.50	17.02
		E	82.66	12.97	79.08	15.15	80.00	14.18	79.50	18.19
		E-P	10.90	12.09	10.70	14.32	9.33	8.64	15.00	19.56

## NOTE:

P = Perceived  
E = Expected  
E-P = Discrepancy

Pre-Biopsy:

Benign Female  $\bar{n} = 45$   
Male  $\bar{n} = 45$   
Malignant Female  $\bar{n} = 11$   
Male  $\bar{n} = 11$

Follow-Up:

Benign Female  $\bar{n} = 35-36$   
Male  $\bar{n} = 35-36$   
Malignant Female  $\bar{n} = 8$   
Male  $\bar{n} = 8$

TABLE 7

Means and Standard Deviations Obtained on the 6 Subscales of PAIR by Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy and Follow-up Time Periods (continued)

		Benign				Malignant			
		Female		Male		Female		Male	
		Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
Pre-Biopsy:	Intellectual: P	67.46	18.48	66.40	16.36	71.63	21.72	67.09	16.57
	E	78.71	13.62	75.82	14.74	86.54	17.73	73.81	14.23
	E-P	11.04	18.92	8.47	14.94	14.90	15.08	8.20	23.44
Follow-Up:	Intellectual: P	69.37	15.30	67.00	17.79	77.50	17.88	75.50	8.66
	E	81.50	11.55	77.48	13.01	84.50	11.60	82.50	9.05
	E-P	12.42	13.96	11.64	13.97	9.33	14.67	7.00	12.42
Pre-Biopsy:	Recreational: P	71.33	14.88	67.60	14.70	79.27	13.36	68.72	15.47
	E	78.88	12.76	76.31	11.92	86.54	11.21	81.45	12.42
	E-P	7.72	15.06	7.61	14.43	7.27	14.40	14.40	21.92
Follow-Up:	Recreational: P	69.71	16.72	68.00	12.17	79.50	11.98	70.50	14.95
	E	77.11	14.45	77.88	10.76	82.00	11.51	82.50	7.38
	E-P	7.87	15.46	10.76	12.06	4.00	10.43	12.00	14.50
Pre-Biopsy:	Conventionality:	65.91	21.12	67.82	18.23	72.36	19.55	67.63	12.95
Follow-Up:	Conventionality:	61.02	23.79	67.83	17.78	70.50	22.72	77.00	10.41

## NOTE:

P = Perceived  
E = Expected  
E-P = Discrepancy

Pre-Biopsy:

Benign Female n = 45  
Male n = 45  
Malignant Female n = 11  
Male n = 11

Follow-Up:

Benign Female n = 35-36  
Male n = 35-36  
Malignant Female n = 8  
Male n = 8

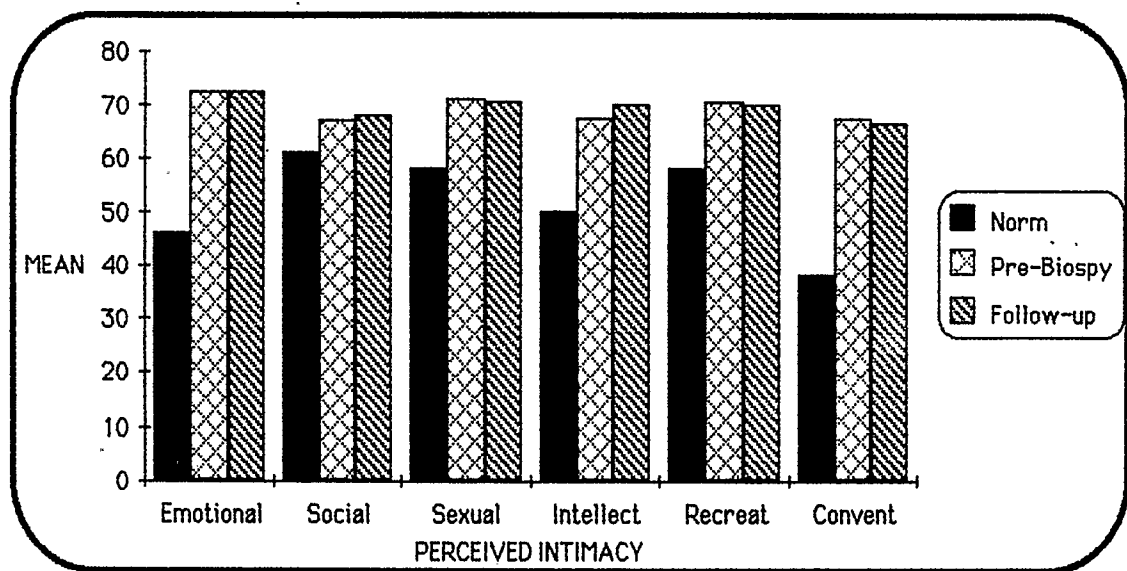


Figure 5. Comparison of means of perceived intimacy subscales (PAIR) of all subjects at the pre-biopsy and follow-up time periods with normative means.

TABLE 8

Means and Standard Deviations Obtained on Total Functional Subscale of NSSQ by the Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy and Follow-up Time Periods

		Benign				Malignant			
		Female		Male		Female		Male	
		Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
<b>Pre-Biopsy:</b>									
Total Functional A		233.81	105.77	219.76	105.27	243.81	50.15	213.20	120.13
Affect 1		43.66	20.86	37.39	18.45	44.54	10.47	36.18	19.31
Affect 2		41.36	19.75	37.13	18.18	43.72	11.63	36.54	19.76
Affirm 1		39.48	18.35	34.69	18.03	40.90	8.30	34.60	19.83
Affirm 2		39.77	18.94	34.69	17.50	40.00	8.63	34.60	19.83
Aid 1		40.60	21.37	39.79	20.59	41.18	10.89	41.30	23.73
Aid 2		34.20	17.50	33.13	17.06	33.45	9.22	29.60	16.52
<b>Follow-Up:</b>									
Total Functional B		222.08	111.13	215.57	101.67	286.66	72.97	274.25	58.58
Affect 1		41.14	20.69	36.94	16.72	57.15	19.32	47.00	10.47
Affect 2		39.91	20.22	37.82	18.07	54.71	17.58	47.12	10.76
Affirm 1		35.05	17.87	34.88	16.79	49.83	10.68	43.50	7.80
Affirm 2		36.70	18.60	34.40	17.67	46.50	11.11	45.37	9.31
Aid 1		37.35	23.53	38.51	19.51	49.83	17.74	53.50	16.00
Aid 2		31.44	16.24	33.00	15.57	38.83	19.50	37.75	12.06

**NOTE:**Pre-Biopsy:

Benign Female  $\bar{n} = 45$   
 Male  $\bar{n} = 43$   
 Malignant Female  $\bar{n} = 11$   
 Male  $\bar{n} = 10$

Follow-Up:

Benign Female  $\bar{n} = 34-36$   
 Male  $\bar{n} = 35-36$   
 Malignant Female  $\bar{n} = 6-8$   
 Male  $\bar{n} = 8$

TABLE 9

Means and Standard Deviations Obtained on Total Network and Total Loss Subscales of NSSQ by the Male and Female Subjects of the Benign and Malignant Groups at the Pre-Biopsy and Follow-up Time Periods

	Benign				Malignant			
	Female		Male		Female		Male	
	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
<b>Pre-Biopsy:</b>								
Total Network A	97.91	46.01	88.13	39.76	97.54	26.06	85.90	49.74
# in Network	10.33	4.96	9.32	4.39	10.18	2.67	9.18	5.01
Duration of Relationship	48.75	23.19	44.41	21.32	48.00	13.68	44.30	25.95
Frequency of Contact	38.82	18.57	34.39	14.81	36.36	10.80	32.40	18.76
<b>Total Loss A</b>								
# Lost	1.73	2.96	1.09	2.51	0.36	1.20	2.00	2.82
Amount of Support Lost	0.84	1.67	0.48	1.42	0.09	0.30	0.80	1.31
	0.57	1.05	0.41	0.95	0.18	0.60	0.80	1.13
<b>Follow-Up:</b>								
Total Network B	93.38	47.43	88.48	40.68	122.83	40.72	115.25	30.02
# in Network	10.05	5.41	9.27	4.42	14.25	4.83	12.00	3.11
Duration of Relationship	46.91	25.16	44.68	20.51	61.00	19.32	58.12	15.67
Frequency of Contact	36.44	17.49	34.42	16.40	49.00	17.94	45.12	12.17
<b>Total Loss B</b>								
# Lost	1.60	2.35	1.63	2.45	1.62	2.38	1.62	2.26
Amount of Support Lost	0.54	0.88	0.72	1.20	1.00	1.60	0.75	1.16
	0.68	1.10	0.05	0.99	0.37	0.51	0.50	0.75

**NOTE:**Pre-Biopsy:

Benign Female  $\bar{n} = 45$   
 Male  $\bar{n} = 43$   
 Malignant Female  $\bar{n} = 11$   
 Male  $\bar{n} = 10$

Follow-Up:

Benign Female  $\bar{n} = 34-36$   
 Male  $\bar{n} = 35-36$   
 Malignant Female  $\bar{n} = 6-8$   
 Male  $\bar{n} = 8$



who were important to them currently. In response to this question at the pre-biopsy time period, the mean number of persons listed in the network for the female group was 10.30 (S.D.=4.58)—less than the normative mean of 12.39 (S.D.=5.09) for females. Males reported 9.29 (S.D.=4.47) persons, again less than the normative mean of 11.85 (S.D.=6.24). Women reported more people in their networks.

Functional properties of social support were assessed by asking the subjects to rate each individual listed in their network according to the amount of support provided on three dimensions: affect, affirmation and short- and long-term aid. The mean scores of females ( $M=235.81$ ,  $S.D.=96.91$ ) and males ( $M=218.50$ ,  $S.D.=107.06$ ) in this sample for total functional (quality of social support) were slightly less than those reported for the norms of females ( $M=281.18$ ,  $S.D.=121.53$ ) and males ( $M=263.26$ ,  $S.D.=135.47$ ). The number of persons listed in the network plus the duration of the relationship and frequency of contact were combined to give a total network score (quantity of social support). The mean total network score for the females ( $M=97.25$ ,  $S.D.=42.65$ ) and males ( $M=87.71$ ,  $S.D.=41.30$ ) was also less than the mean reported for the norms of females ( $M=111.93$ ,  $S.D.=44.71$ ) and males ( $M=107.68$ ,  $S.D.=57.63$ ).

Of the total number of persons in the social support network list at the pre-biopsy time period ( $N=1070$ ), 57.66% were family or relatives, 32.42% were friends, 4.39% were work or school associates, 2.42% were neighbours, 1.68% were health care providers, and 1.21% were clergy.

Scores at the follow-up time period were similar to the pre-biopsy reports of social support for the benign group. Examination of the means seemed to indicate that the malignant males and females reported

an increase in the number of people in their social networks. This also had the effect of increasing their total functional and total network scores, making them more similar to the normative means.

A visual inspection of the means and standard deviations for the variables of psychological distress, marital intimacy and social support showed high variation within group scores. Univariate and multivariate analyses were used to test the significance of difference between group means.

#### Pearson Correlations

Pearson correlations between the variables of psychological distress, marital intimacy and social support were examined. The variables included in the correlation matrix were: the total mood disturbance score (POMS); the perceived intimacy score for each of the five subscales (PAIR); and the total functional, total network and total loss scores (NSSQ).

Table 10 presents the correlations between the identified variables at the pre-biopsy time period. Table 11 presents the correlations between the variables at the follow-up time period. An inspection of the correlations indicates that the pattern of correlation between the variables is similar for the pre-biopsy and follow-up time periods. Psychological distress appears to be significantly negatively correlated with perceived emotional, social and intellectual intimacy. Distress does not appear to be correlated with social support. Significant correlations are seen within the intimacy and social support subscales as would be expected. There is a significant positive correlation between per-

TABLE 10

Pearson Correlations of Psychological Distress, Marital Intimacy and Social Support at the Pre-Biopsy Time Period

		<u>Variables</u>								
<u>Variables</u>		1	2	3	4	5	6	7	8	9
<u>Psychological Distress:</u>	1. Mood Disturbance Score	100								
<u>Marital Intimacy:</u>	2. Perceived Emotional	-44***	100							
	3. Perceived Social	-29**	37***	100						
	4. Perceived Sexual	-12	60***	16	100					
	5. Perceived Intellectual	-34***	63***	42***	50***	100				
	6. Perceived Recreational	-17	41***	24**	33***	50***	100			
<u>Social Support:</u>	7. Total Functional	-07	07	31***	00	03	06	100		
	8. Total Network	00	-06	28**	-07	-01	07	95***	100	
	9. Total Loss	13	-17	-13	-01	-01	02	-19*	-19*	100

NOTE: Decimals have been omitted.

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$

TABLE 11

Pearson Correlations of Psychological Distress, Marital Intimacy and Social Support at the Follow-Up Time Period

		<u>Variables</u>								
<u>Variables</u>		1	2	3	4	5	6	7	8	9
<u>Psychological Distress:</u>	1. Mood Disturbance Score	100								
<u>Marital Intimacy:</u>	2. Perceived Emotional	-36***	100							
	3. Perceived Social	-29**	38***	100						
	4. Perceived Sexual	-10	61***	24*	100					
	5. Perceived Intellectual	-33**	67***	38***	61***	100				
	6. Perceived Recreational	-13	45***	39***	41***	50***	100			
<u>Social Support:</u>	7. Total Functional	-07	-07	25*	-09	-00	15	100		
	8. Total Network	00	-14	23*	-09	-02	09	95***	100	
	9. Total Loss	-05	15	-12	13	-06	01	-26*	-25*	100

NOTE: Decimals have been omitted.

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$

ceived social intimacy and the total functional (quality) and total network properties (quantity) of social support.

### Univariate and Multivariate Analyses

Univariate and multivariate analyses of variance were performed to obtain a global picture of change in subject scores on the variables of psychological distress and marital intimacy when the interaction of sex, diagnosis and time was considered. The significance level of  $p .05$  was chosen to answer the research questions. Because of the limited malignant sample size ( $n=8$  females;  $n=8$  males) at the follow-up time period and the missing data on two subjects' reports of social support for the follow-up time period, the social support subscales were not included in the multivariate analysis.

The BMDP computer program 4V statistical package was used to perform the univariate and multivariate analyses of variance because of its ability to deal with an unequal  $n$ .

The variable of psychological distress (POMS) was measured at three time periods. A three-way Anova ( $2 \times 2 \times 3$ ) with one repeated measure was used to analyze the main and interaction effects of Diagnosis (Benign versus Malignant), Sex (Male versus Female), and Time (Pre-Biopsy versus Diagnosis versus Follow-Up) on the total mood disturbance score of POMS. Analysis of variance is the statistical tool that provides a single composite test to compare all sample means simultaneously to determine the presence of statistically significant differences in the data.

Results of the univariate analysis displayed in Table 12 revealed a

TABLE 12

Univariate Analysis of Variance with Repeated Measure of the Effects of Sex (Male Versus Female), Diagnosis (Benign Versus Malignant) and Time (Pre-Biopsy Versus Diagnosis Versus Follow-Up) on Total Mood Disturbance Score (POMS)

Source of Variation	MS	Approximate F Ratio	df	Significance of F Ratio
Sex	479.184	.29	1,84	.5922
Diagnosis	24.75	.01	1,84	.9030
Sex X Diagnosis	323.047	.19	1,84	.6600
<u>WCPMS</u> <sup>1</sup>				
Time	9029.55	20.16	2,168	.0000****
Time X Sex	213.29	.48	2,168	.6219
Time X Diagnosis	1131.68	2.53	2,168	.0829
Time X Sex X Diagnosis	1652.68	3.69	2,168	.0270*

\*\*\*\*  $p < .001$

\*  $p < .05$

<sup>1</sup> WCPMS - Within contrast pooled mean squares.

significant univariate interaction effect of Time by Sex by Diagnosis on psychological distress ( $F=3.69$ ,  $df=2,168$ ,  $p=.0270$ ). Figures 6 and 7 illustrate the changes on psychological distress over time by presenting the difference in slopes between the mean scores of the benign and malignant males and females. The means reported in these figures were obtained from the univariate analysis and are different from the raw means because of data loss from the pre-biopsy to the diagnosis time period.

Differences between the groups over time indicated that benign females ( $M=34.17$ ) reported more distress than benign males ( $M=18.56$ ) at the pre-biopsy time; however, malignant males ( $M=45.88$ ) were more distressed than the malignant females ( $M=29.88$ ) at the same time period. While the mean scores decreased over time for all groups as reported below, the malignant females ( $M=13.25$ ) and benign females ( $M=12.86$ ) reported higher distress scores at the follow-up time than the malignant males ( $M=1.00$ ) and benign males ( $M=9.50$ ).

In addition to the three-way interaction, there was a significant main effect for Time ( $F=20.16$ ,  $df=2,168$ ,  $p=.0000$ ) indicating that the group as a whole rated their level of psychological distress as being significantly different over time. The total group means for the mood disturbance score over the three time periods were 28.45, 11.22 and 10.44 respectively. This indicates the pre-biopsy scores on POMS were significantly higher than the diagnosis and follow-up scores on this measure.

For the variable of marital intimacy, a three-way Manova ( $2 \times 2 \times 2$ ) with one repeated measure was used to analyze the main and interac-

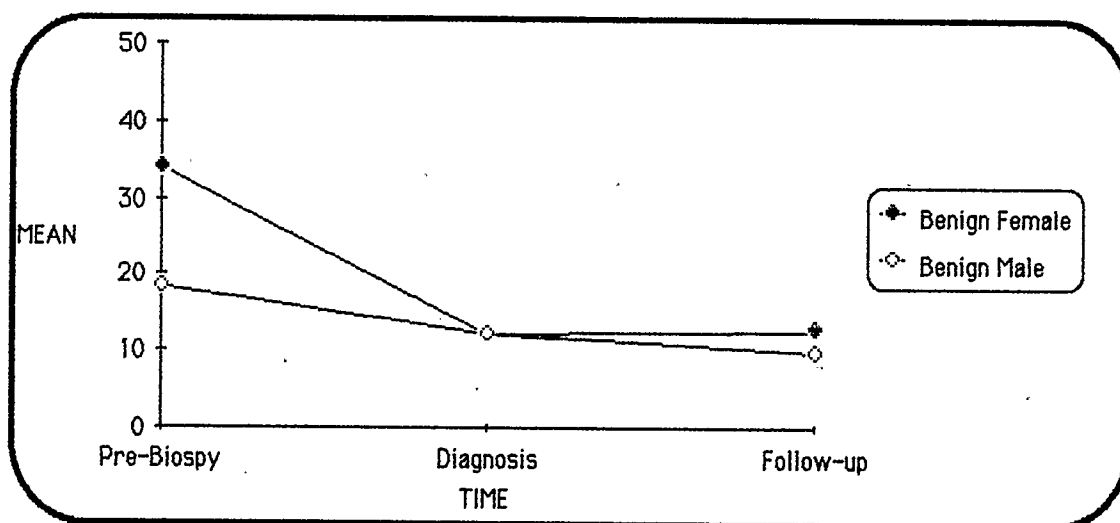


Figure 6. Mean scores of benign subjects on total mood disturbance (POMS) over three time periods.



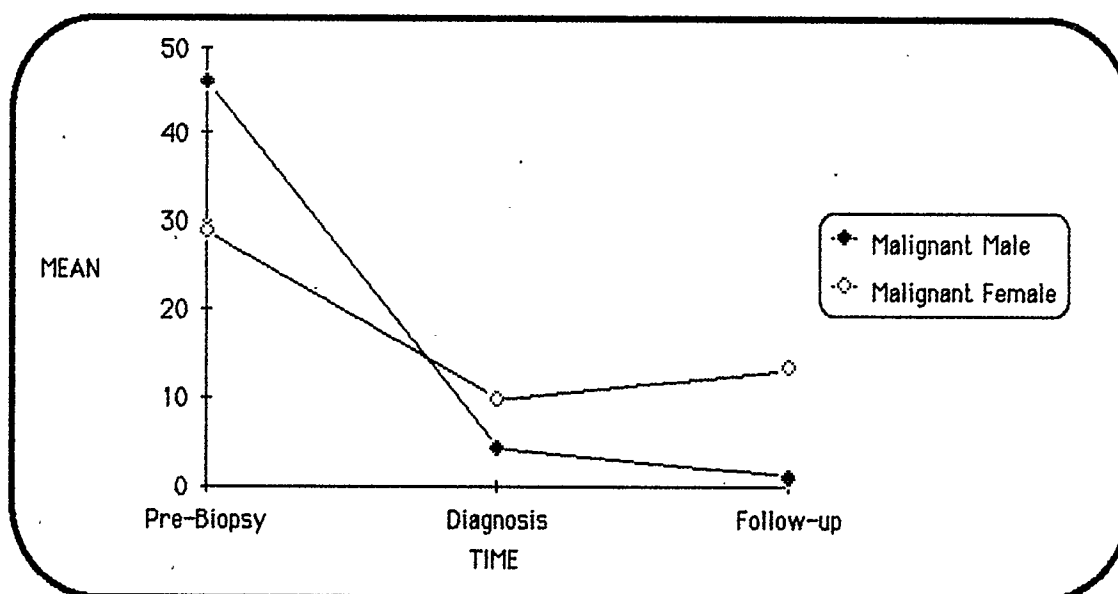


Figure 7. Mean scores of malignant subjects on total mood disturbance (POMS) over three time periods.

tion effects of Sex, Diagnosis and Time on the five intimacy subscales of PAIR using the perceived intimacy scores reported at the pre-biopsy and follow-up time periods.

The results of the three-way Manova with one repeated measure for PAIR are displayed in Table 13. All multivariate main and interaction effects are shown. The results showed that the multivariate interaction effect of Time by Sex by Diagnosis was not significant ( $F=1.30$ ,  $df=6,78$ ,  $p=.2679$ ) and there were no significant main effects.

An examination of the univariate effects presented in Table 14 showed a significant interaction effect of Time by Sex by Diagnosis on perceived emotional intimacy ( $F=4.36$ ,  $df=1,83$ ,  $p=.0398$ ). This needs to be interpreted cautiously in light of the lack of significance found for the multivariate interaction effect. Figures 8 and 9 plot the emotional intimacy scores of malignant males/females and benign males/ females at the pre-biopsy and follow-up time periods. Differences over time on perceived emotional intimacy were not observed for the benign males, benign females or the malignant females. However, the means indicate that the malignant males reported an increase in emotional intimacy from the pre-biopsy ( $M=68.00$ ) to the follow-up ( $M=79.50$ ) time period.

It was also interesting to note that for the univariate main effects there was a trend towards differentiating Diagnosis by perceived social intimacy ( $F=4.16$ ,  $df=1,83$ ,  $p=.0446$ ), and Time by perceived intellectual intimacy ( $F=4.63$ ,  $df=1,83$ ,  $p=.0343$ ). Again, these need to be interpreted very cautiously in light of the lack of significance found with the multivariate main effects for Diagnosis and Time.

TABLE 13

Multivariate Analysis with Repeated Measure of the Main & Interaction Effects  
of Sex (Male Versus Female), Diagnosis (Benign Versus Malignant) and Time (Pre-  
Biopsy Versus Follow-Up) on Perceived Marital Intimacy (PAIR)

Source of Variation	df	Approximate F Ratio	Significance of F Ratio
S: Sex	6,78	1.35	.2459
D: Diagnosis	6,78	1.77	.1169
S X D	6,78	.64	.6995
T: Time	6,78	1.35	.2474
T X S	6,78	1.53	.1837
T X D	6,78	.77	.5926
T X S X D	6,78	1.30	.2679

\*p < .05

TABLE 14

Univariate Analysis of Variance, F Ratio Results of Effects of Sex, Diagnosis and Time on Perceived Marital Intimacy (PAIR) Subscales (Degrees of Freedom Equal 1,83)

Significance of F Ratio	Source of Variation	Emotional	Social	Sexual	Intellectual	Recreational	Conventionality
NS	S: Sex	.01	.52	1.50	.07	3.34	.28
NS	D: Diagnosis	1.61	4.16*	.85	1.45	1.13	1.20
NS	S X D	1.54	.02	.67	.00	.82	.34
NS	T: Time	1.46	.01	.02	4.63*	.51	.00
NS	T X S	2.34	.70	.19	.27	.35	3.92
NS	T X D	2.48	.14	.97	2.38	1.44	.06
NS	T X S X D	4.36*	.30	.02	.01	.04	2.11

NOTE: \* $p < .05$

NS = Not Significant

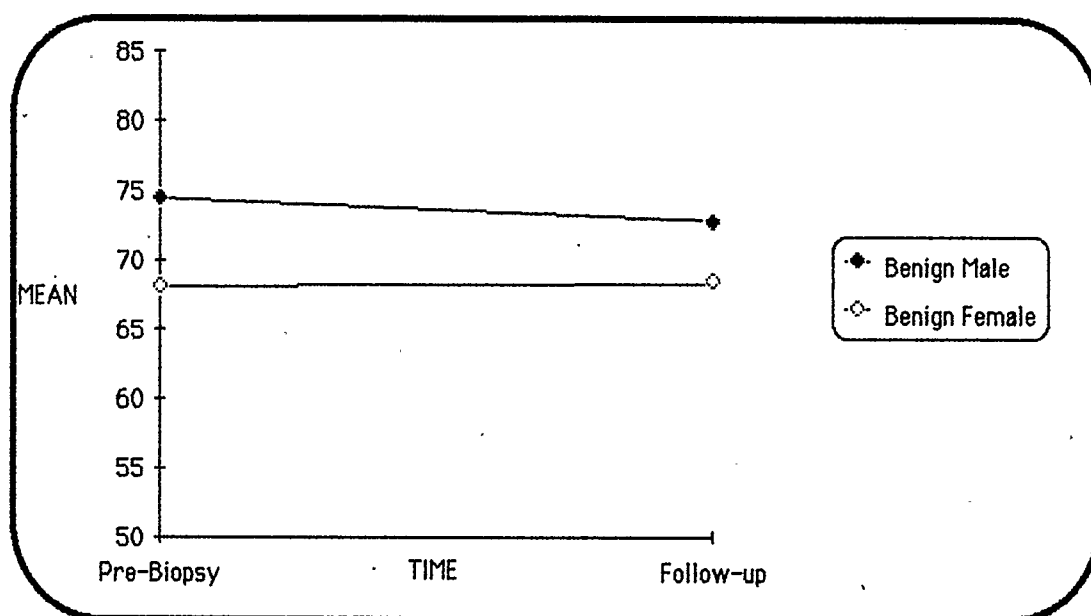


Figure 8. Mean scores of benign couples on perceived emotional intimacy (PAIR) for time, sex and diagnosis.

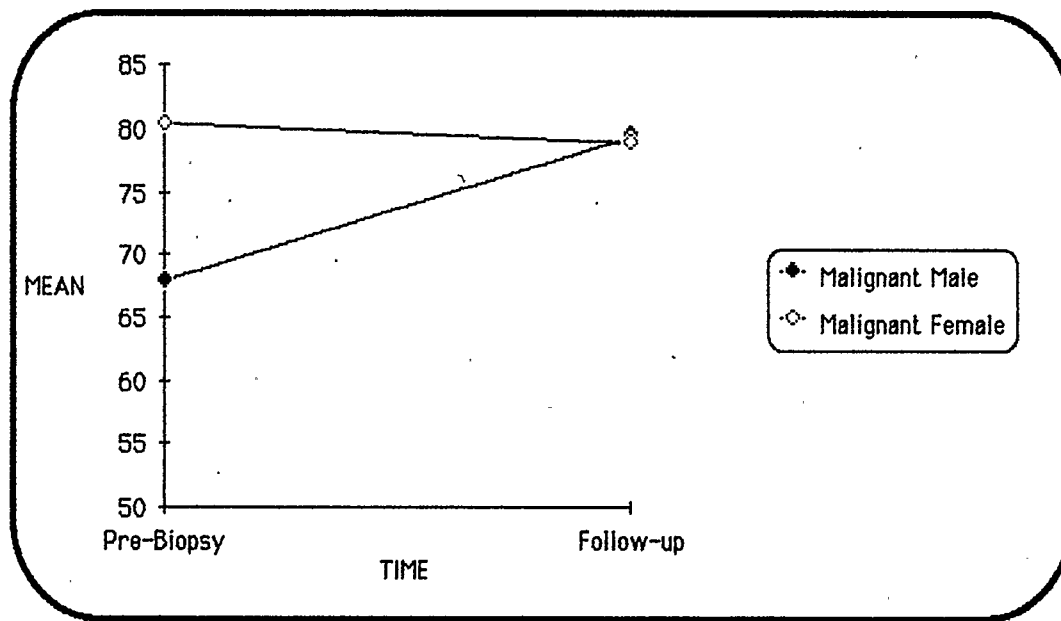


Figure 9. Mean scores of malignant couples on perceived emotional intimacy (PAIR) for time, sex and diagnosis.

## Part II: Qualitative Analysis

Subjects' responses to the questions of the semi-structured conjoint interviews were a rich source of data. There was a diversity of responses with multiple themes. The wording of categories came from the responses to each question which were included at the three interviews. The pre-biopsy period before the diagnosis was known, allowed the responses of all 56 couples to be pooled together. Subsequent interviews were organized by time period (diagnosis or follow-up) and by diagnosis (benign or malignant). The subjects' responses are discussed in the following sections.

### Pre-Biopsy Time Period

Fifty-six couples were interviewed within two weeks prior to the breast biopsy. None knew their diagnosis although they may have been told that the breast abnormality looked "suspicious" or "was nothing to worry about". Coding categories were developed from the questions asked during the pre-biopsy interview. Responses to each category were recorded and frequencies for each type of response were obtained. Each husband-wife dyad may have responded with more than one answer to a particular question. The percentages reported for the frequencies either represent the percentage of the total couples (N=56) who answered the question or the percentage of the total responses to the question when more than one response per couple was given. This distinction will be noted as each question is discussed. Percentages were rounded off to the nearest whole number for convenience in reporting.

The breast lump or other abnormality was found by the woman herself

in 54% of the female subjects (n=30). Sixteen (29%) of the subjects had volunteered for the National Breast Screening Study and had their breast lumps detected by the professionals associated with the research program. A physician detected the breast abnormality in eight (14%) of the subjects. Lastly, two husbands were responsible for detecting the breast lump. The breast abnormality had been discovered anywhere from a few days to eight years prior to consultation with the surgeon who recommended the breast biopsy.

"Who have you told about needing the biopsy?" was asked to assess the involvement of the social support system during the pre-biopsy period. Table 15 presents the categories of relationships of the people who were told about the anticipated biopsy. The responses ranged from telling the spouse only to "telling everybody!" As one husband said, "It's all but been in the newspaper!". The nuclear family of spouse and children were most frequently told (30%) followed by the extended family (27%) which included sisters and brothers, parents, and in-laws.

In addition to people who were told, some couples also identified people they wished not to know about the impending biopsy. Eight couples said they did not want their children to know. A couple with older, married children said, "They can have a good summer until we know for sure". Six couples said they did not want the extended family to know, such as aging parents. Two wives indicated they wished they had protected their husbands from knowing as it caused too much worry. In several cases, there was disagreement between the spouses as to who should be told. "He tells everyone", said one woman who did not like others, "talking about my problems". Misinterpretation was cited as a



TABLE 15

Who Was Told About the Biopsy

Relationship	Frequency	Percent of Total Responses*
Spouse Only	3	3
Nuclear Family - Spouse - Children	30	30
Extended Family	27	27
Friends	23	23
Co-Workers	15	15
Priest	2	2

\* Responses to this question total 100.

reason for not telling some people. One husband said he had told no one because, "they go away with a different opinion of what you've said and next thing they have you dead in six months."

The primary concerns of both husband and wife at the pre-biopsy time are presented and comparatively ranked in Table 16. Only the top 5 categories were ranked. It can be seen that the most common concern is the diagnosis of cancer. The particular fears varied from concern about having a breast removed to fear of death. More men than women were concerned about the quality of health and life expectancy issue. Comments like, "I hope she is going to be OK" and "I couldn't live without her" were offered by 16 (29%) husbands.

Four women (7%) as compared to no men specifically identified loss of breast as a concern. As one woman remarked, "In my mind, I have cut it off 50 thousand times". Not being as concerned about breast loss as some other issue was included in the responses of six women and six men. Comments like, "Actually the possibility of mastectomy doesn't even concern me as much as the big 'C'", speak to the priority of concerns. As well, some macabre humour was noted when one husband said to his wife, "If you have to have it off, we'll mount it on the wall".

More wives than husbands identified the breast biopsy itself as a major concern. Waiting for the biopsy date or not knowing what to expect during and after the procedure itself were the primary concerns of 20% (13) of the women. Three husbands were concerned about the surgery from the standpoint of loss of blood and discomfort with having "my wife cut into". Only 2 out of the 56 husbands (3.5%) and 3 of the wives (5%) had no concerns.

TABLE 16

Description and Comparative Ranking of Primary Concern of Husbands and Wives at Pre-Biopsy Time Period

Primary Concern	Wife*		Husband**	
	Frequency	Rank	Frequency	Rank
<b><u>Fear of Cancer:</u></b>				
Diagnosis of Cancer Itself	14	1	17	1
Concern About Removal/Spread	2	NR	3	4
Concern About Quality of Health/Life Expectancy	10	2	16	2
Concern About Breast Loss	4	5	0	NR
Concern About Chemotherapy	1	NR	0	NR
Concern About Children	3	NR	0	NR
Results/Knowing What "It" Is	6	4	15	3
<b><u>Fear of Biopsy:</u></b>				
Surgery/General Anesthetic	2	NR	3	4
Biopsy Procedure Itself	4	5	0	NR
Waiting for Biopsy Date	7	3	0	NR
<b><u>No Concern:</u></b>	3	NR	2	5

**NOTE:** NR = No Rank

\*Wife - n=56

\*\*Husband - n=56

Each spouse was asked to describe changes observed in the other spouse as a way of identifying individual coping responses to the threat of biopsy. Changes noted in husband by wife are summarized in Table 17. Percentages are reported for the total number of responses to this question (n=56). Twenty-four wives (43%) reported no observed change in the husband. Thirty percent (n=17) of these responses reported positive changes in the husbands' behaviour such as being more supportive, considerate and affectionate. When one husband was described as being understanding, he replied, "Well, there is no point in falling apart! I feel if I worry about it, it will affect her too. So I'm not worrying about it. She is going to be alright!". A similar theme was voiced by a wife who said, "He doesn't show his inner feelings. He tries to be strong for me all the time no matter what. I wish he would let his guard down once in a while." Fifteen (27%) of the responses noted that the husband was worried and preoccupied with symptoms such as irritability, tension, and inability to sleep.

Changes noted in wife by husband are presented in Table 18. Percentages are reported for the total number of responses to this question (n=65). Thirty-four percent (n=22) of the responses reported no change was observed in the wife. This observation was accompanied by comments such as, "She's tough!", or "She's really holding up well". Only two husbands noted positive changes such as being more affectionate. The majority of the husbands' responses (63%) indicated signs of distress in their spouse such as tension, cries easily, being on edge, short-tempered and pre-occupied. These may be the behavioural outcomes of what several women described as the "emotional rollercoaster" experience of

TABLE 17

Changes Noted in Husband By Wife During Pre-Biopsy Period

Changes in Husband	Frequency	Percent of Total Responses*
No Change	24	43
More Considerate/Attentive e.g. "Phones more frequently" "Asks me how I am doing" "Helps without being encouraged"	12	21
Very Optimistic/Reassuring	2	4
More Affectionate	3	5
Preoccupied	5	9
Unable to Sleep	2	4
Very Worried	5	9
Started Smoking Again	1	2
Irritable	1	2
Tense	1	2

\* Responses to this question total 56.

Percent has been rounded off to the nearest whole number.

TABLE 18

Changes Noted in Wife By Husband During Pre-Biopsy Period

Changes in Wife	Frequency	Percent of Total Responses*
No Change	22	34
Tense	8	12
Nervous	3	5
Cries Easily	7	11
Grouchy	2	3
On Edge	4	6
Short-Tempered	2	3
Preoccupied/More Quiet	8	12
Smokes More	1	2
Difficulty Sleeping	2	3
More Affectionate	2	3
Started Smoking Again	2	3
Spends More Time With Children	2	3

\* Responses to this question total 65.

Percent has been rounded off to the nearest whole number.

time period.

"Who is most affected?" was another question posed to the couple during the pre-biopsy interview. Forty out of the fifty-six couples said the woman was most affected by the experience because it was her body that was experiencing the health problem. Ten couples identified the husband as being most affected. A poignant explanation for this was offered by one husband who said, "Mentally, I would say I am most affected. It's easier to be the person needing the surgery than the person who is sitting there waiting for the answer or the situation to get better. You are not at all involved. You have absolutely no control over or no involvement in what is going on. All you can do is sit and wait".

Five couples identified both spouses as being equally affected by the anticipated breast biopsy. Finally, one couple said their young children were most affected and were sensitive to the tension both parents were feeling during the pre-biopsy period.

When asked what was most helpful to the couple during the pre-biopsy period, a variety of answers were offered with couples often identifying more than one answer. These are summarized in Table 19. The factors identified cannot be seen as mutually exclusive categories. One couple may have said they could count on each other for support and also have said they found keeping busy and not thinking about the biopsy to be a helpful strategy. Percentages are reported for the total number of responses obtained for this question (n=87).

Coping strategies involving the marital relationship were reported by 40% of the responses. Specifically talking about it was suggested by

TABLE 19

Factors That Helped Couples Deal with Pre-Biopsy Experience

Factors	Frequency	Percent of Total Responses*
<u>Marital Relationship</u>		
Talking About It	13	15
Supportive of Each Other/Togetherness	15	17
Ability to Share Feelings Openly With Spouse	3	3
Knowing Relationship Will Not Change	3	3
Spending Time Together	2	2
<u>Diversion</u>		
Keeping Busy/Trying Not to Think About It	17	20
<u>Information</u>		
From Reading, From Physician	3	3
Talking to Nurse Researcher		
re: Information	8	9
re: Being Able to Talk About It	3	3
<u>Support</u>		
Support of Family & Friends	3	3
Belief and Trust in God	2	2
Prayed About It	2	2
<u>Other</u>		
Don't Talk About It	5	6
Nothing is Helpful	3	3
Positive Thinking	1	1
Confidence in Surgeon	2	2
Haven't Tried Anything	3	3

\* Responses to this question total 87.

Percent has been rounded off to the nearest whole number.



only 15% of responses. The nature and depth of the communication was often unclear. It was difficult to know whether the couple were talking about the instrumental aspects of the biopsy or intimately sharing emotional concerns. One couple explained their response by saying, "She tells me what the doctors have said and I maybe ask for clarification on some things. We haven't gotten into conversations like what happens if you have to have your breast removed".

Discrepancies between husband and wife in terms of communication were also noted. One woman said, "I would like to talk about it but I find that he is a very hard person to talk to. I think he is about as emotional as a stone. He likes to put his head in the sand whereas I come from a family that blurts everything out and yells at each other". Similarly, one husband said, "We don't talk much about the biopsy. I like to take one step at a time. It is fine to try and plan ahead for the future, but you can only go so far and then you start tripping yourself up. She tends to look at the grim side of things: 'What if?, What if?, and What's going to happen to the kids?' I don't like to dwell on that sort of thing".

Counting on the support obtained from the relationship was also identified as an important helpful factor by 25% of the responses. Perhaps this aspect may have addressed shared emotional communication about the biopsy. As one couple said, "We discussed it at home and cuddled up over it". Another interesting response was that three wives commented that they were assured that whatever the outcome of the biopsy (or breast cancer surgery), they were not concerned about their husbands leaving them. This they found very reassuring: "I would not have to

worry about losing him".

Keeping busy and trying not to think about it appeared to be a coping response (20%) found helpful. Information was reported as being helpful by 15% of the responses. It was interesting to note that having an opportunity to talk with the investigator by virtue of the couple's consent to participate in the research project, was identified as a helpful factor either because the interview provided information or provided the opportunity for the couple to talk about shared concerns which they might not have otherwise done.

Finally, 6% of the responses suggested that not talking about it was a helpful strategy. One husband advised, "We don't talk about it or we would go crazy. My biggest concern right now is to keep her calm". Another couple said that it was too premature to talk about. "We just have to wait to be told in black and white what the result of the biopsy is. When and if we are confronted with it (cancer), we will sit down and cry our eyes out and then we will discuss what has to be done".

Suggestions for health care professionals are presented in Table 20. Again, percentages are reported out of a total of 63 responses with some couples identifying more than one response. Over half (57%) of the responses said that more information (verbal or written) about the biopsy procedure itself and cancer treatment alternatives needs to be provided. One woman said, "I really don't know a whole lot about the biopsy at this point in time...nothing...just that they are going to remove it... that is all I know". Another response again illustrates the need for more information: "I have heard the word biopsy a hundred times but really what are they going to do? The doctor didn't say anything else.

TABLE 20

Suggestions for Health Care Professionals During the Pre-Biopsy Time  
Period

Suggestions	Frequency	Percent of Total Responses*
No Suggestions/Adequate Information Provided	7	11
Need for Information About Biopsy Procedure and Cancer Treatment Alternatives	31	49
Need for Written Information About Biopsy/ Cancer Alternatives	5	8
Need for Information About Prevention of Breast Lumps/Breast Screening	3	5
Decrease Waiting Time for Biopsy	12	19
Opportunity for Whole Family to Talk About It	2	3
Need for Information About How to be Helpful/ Supportive to Wife	1	1
Use Words People Can Understand (e.g. "Benign"/"Malignant")	2	3

\* Responses to this question total 63.

Percent has been rounded off to the nearest whole number.

So I walked out of there and went home and looked it up in the encyclopedia and tried to get a little information out of there". A contrasting view was provided by a woman who said, "I don't understand what will be happening but I am a great believer that sometimes you are better off not knowing some of these things".

The next most frequent suggestion (19%) was to find ways to decrease the waiting time required between learning that a biopsy was advised and actually having it done. Some couples reported waiting up to 6 weeks "in hell" for word about when the biopsy would be performed.

An interesting suggestion was provided by 3% of the responses which asked for clearer wording to be used. Words used by health care professionals such as "benign" and "malignant" were reported to be confusing.

One last observation about the pre-biopsy interview responses was the amount of involvement the husband wanted to have with the surgeon who was consulted about the breast lump. The investigator had observed that the husband would occasionally accompany his wife to the appointment and would remain in the waiting area while his wife was seen by the surgeon. None of the husbands who participated in the study saw the surgeon during the pre-biopsy period. Of the thirty husbands who commented on this observation, 20 (66%) said they preferred not to be included with their wives in a discussion with the surgeon before the biopsy was performed. Explanations ranged from, "It's too soon to get excited about this problem" to "I'm not good at that type of thing. My wife will tell me what is going to happen". One husband said, "From what I understand, there is no threat until the results of the biopsy come back and we know for sure what we are dealing with. I'm not be-

littling the surgery--certainly there is concern and apprehension, but no threat and so therefore support is not required. To go and evaluate her ability to understand and interpret what the doctor is saying is not necessary". Another husband suggested he, "would certainly like to meet with the doctor after the biopsy if there is a problem".

Ten husbands (33%) indicated they would have liked an opportunity to talk to the surgeon. "I think I would feel a little better if I had talked to him", one husband said. "I feel left out", was another husband's response. An interesting response was offered by one husband who compared the difference between having a child with a health problem and having a wife who required surgery. "When one of the kids was sick, the doctor stopped and drew a picture of exactly what would happen and what the operation was going to be. But when it was my wife, I didn't get that kind of involvement. I wasn't invited to the doctor's office and told what was happening--that it could be bad or I didn't have to worry at all. There was none of that in this situation."

#### Diagnosis and Follow-up Time Period: Malignant Couples

The second interview occurred at six to eight weeks following breast cancer surgery. This interview was called the diagnosis time period because the diagnosis was known and the benign and malignant groups were differentiated. For this reason, the results of the interviews were organized into the malignant couples' experience at the diagnosis and follow-up periods followed by a presentation of the benign couples' experience for the same time periods. Grouping like-diagnosis couples together allowed for a comparison of changes over time.

Eight couples who received the diagnosis of breast cancer were seen in a conjoint interview. The type of breast cancer surgery varied within the group. Two women had a segmental resection performed; the remaining six had a modified radical mastectomy, with one woman requiring both breasts to be removed. At the time of the interview, six of the eight women were receiving chemotherapy. Two were prescribed oral anti-cancer agents only, while the remaining four were also receiving intravenous medication.

In response to the question of who had been told about the diagnosis, all eight couples responded, "everybody". One husband spontaneously answered, "the whole world!". "Anybody who wants to listen", said one wife. "It involves so many people...the people I work with...and people that my husband works with...and the people I play golf with...so it is just all the people that we are around all the time. Their reactions have been just super. Not only did the women come up to the hospital but the husbands came too. People were just wonderful". This same theme was corroborated by all the couples. No one reported receiving negative reactions from the people who were told about the cancer diagnosis.

A wide variety of problems were reported by the wives during this time period. They included reactions to the chemotherapy such as: fatigue, hot flushes, and flu-like symptoms; lack of energy related to the surgery; discomfort from the mastectomy such as tightness, numbness, phantom sensations and arm pain; discomfort from the prosthesis; putting on weight related to a decision to quit smoking; difficulty making a decision about adjuvant treatment; and adjusting to breast loss. Con-

cerning the last complaint, three of the six women who had received a mastectomy specifically reported feeling unbalanced in terms of weight distribution, feeling "frumpy" and "sensitive" about the breast loss, and needing to choose different clothes to wear than previously.

All but one husband in the group of eight men had seen his wife's scar. An interesting comment in this regard was made by one husband who said, "I wasn't expecting such a large scar. It was different than what I thought. I didn't expect to see the breast completely removed. I thought they would somehow leave the breast, so I was a little bit shocked to see it". The wife of this man described her decision to have him see the scar: "It was two weeks after I came home from the hospital. He wasn't quite ready for it right away. I was afraid to show him too. One day I needed some help with my bandages because my daughters weren't around. So, I said, 'Well, you might as well see it now'. I wondered what he would think. I wasn't too worried but I still had an uneasy feeling." The size of the scar and extensiveness of the surgery, particularly the incision in the region of the armpit to remove lymph nodes, was also startling to several of the women.

Changes noted in the wife by the husband were varied. The most frequent change was signs of fatigue reported by 50% (4) of the husbands. "She's getting back to her normal self" was a common expression. It is interesting to note the choice of present tense ("getting back") versus the use of the past tense.

The wives reported positive changes in their husbands. Only one wife indicated no change was observed in her husband at this time period. The remaining seven women said their husbands were "more support-

ive", "more loving and affectionate" and "helped around the home more".

When asked what change had occurred in their marital relationship, seven couples (87.5%) reported an improvement; one couple reported no change. Responses included feeling closer, sharing more feelings and affection, and appreciating each other more. One husband said, "I guess you start to realize how temporal things are...you may have limited time together. You really appreciate the other person more."

"What has been most helpful for you as a couple in dealing with this situation?", was another question asked during the interview. Responses (n=13) included support from friends and family (38% of responses) and information from reading or from the nurse researcher (31% of responses). Confidence in the doctor accounted for 15% of the total responses. The remaining answers each accounted for 7.5% of the total responses. They included keeping busy, religious faith and prayers of others, and knowing marital partners could support each other.

The last question asked at this interview focused on identifying a present major concern. All eight couples (100%) said they were most concerned about recurrence of cancer.

The follow-up interview occurred within five to six months following breast cancer surgery. Again, eight couples participated in the interview. The questions asked at this time period were similar to those asked at the diagnosis interview in order to get a time perspective of differences in concerns and alterations in the relationship. Responses of the malignant couples at the follow-up time period are compared with those obtained at the diagnosis interview in Table 21.

Change in the wife noted by the husband indicates that 66% of the



TABLE 21

Comparison of Responses of Malignant Couples at Diagnosis Interview  
Versus Follow-up Interview

Category	Diagnosis Interview		Follow-up Interview	
	Response	Frequency	Response	Frequency
Changes in Wife	More Tired	- 4	Forgetful	- 1
	Getting Back to Normal	- 3	Back to Normal	- 5
	Lifestyle Change (exercises more, watches diet)	- 1	More Independent	- 1
			Tired	- 2
			Short-Tempered	- 2
			Spends More Quality Time with Kids	- 1
			Allows Self to Lean on Others	- 1
			Positive Outlook	- 2
Changes in Husband	More Supportive	- 3	Back to Normal	- 2
	Helps Around House		No Change	- 3
	More	- 4	More Helpful	- 2
	More Loving	- 1	Sensitive to Wife's Feelings	- 1
	Sensitive to Wife's Feelings	- 1	Quit Smoking	- 1
	No Change	- 1	Talks More	- 1
Changes in Relationship	Become Closer	- 4	Become Closer	- 2
	Appreciate Each Other More	- 1	Talk More	- 1
	Talk About Different Things	- 1	No Change	- 2
	Share More Verbal Feelings	- 1	Back to Normal	- 2
	No Change	- 1	Appreciate Each Other More	- 1
Factors Helpful to Couple in Dealing With Cancer Experience	Keeping Busy	- 1	Support from Friends	- 3
	Support from Friends and Family	- 5	Talking to Other Couples	- 1
	Religious Faith and Prayer	- 1	Talking to Women With Same Experience	- 1
	Knowing We Can Support Each Other	- 1	Going Away By Ourselves	- 1
	Confidence in Doctor	- 2	Attitude of Husband	- 3
	Information From Reading	- 2	Getting Information Time	- 1
	Information From Nurse Researcher	- 2	Taking Responsibility Ourselves	- 1
			Supporting Each Other	- 1

responses (n=15) to this question focused on positive changes such as returning back to normal, having a positive outlook, and becoming more independent. Symptoms attributed to chemotherapy such as being tired, forgetful and short-tempered accounted for 33% of the responses to this question versus 50% at the diagnosis time period.

Changes in the husband's behaviour reported by the wife showed a decrease in positive changes over time (from 90% of the total responses to the question at the diagnosis time period to only 40% at the follow-up period). Fifty percent of the total responses at the follow-up period suggested life had returned to normal or no change in the husband's behaviour had been observed. One woman said that when she heard her husband "growl", she knew that things had returned to normal!

Similar results were reported for changes in the marital relationship with the high frequency (87.5%) of reported positive changes at the diagnosis period being reduced to 50% of the responses by reports of "back to normal" and no change at the follow-up interview. A woman who had reported an increase in expression of feelings between the couple at the diagnosis interview said, "we are getting back into the rut again".

Three couples reported an enduring change in their children's behaviour which continued through the follow-up period. Two couples spoke of more phone calls made to them by their adult children while one couple reported that their adult children came to dinner less often and when they did, they were more helpful in the kitchen.

Identification of factors which were helpful to the couple revealed a similar theme when compared to the diagnosis time period. As well, fear of recurrence was also presented as a major concern of all the

couples at this interview.

An interesting observation was made concerning the language used to describe the cancer experience at this interview. Almost all of the couples talked about having "had cancer" in the past tense as opposed to "having cancer now". One woman said, "I have to keep sort of reminding myself of that because I don't think of myself as having cancer. As a matter of fact, every time I take my pills, I think it doesn't feel right to me. I dread going to the Cancer Center and looking at everybody there...this is something I will have to get over". "I felt like my wife had cancer and now it is gone", said a husband whose wife was still receiving chemotherapy.

#### Diagnosis and Follow-up Time Period: Benign Couples

Thirty-six couples diagnosed as having benign breast disease were interviewed six to eight weeks following the biopsy. This interview was called the diagnosis interview. The general theme of the responses of both husbands and wives at this time period was relief at having escaped the diagnosis of cancer. The following comments speak to this mitigation of threat: "a great weight has been taken off my shoulders", "I was more worried than I let on", "You don't realize until it is over how much you are really worrying about it", and "I spent an awful lot of emotional energy on not knowing the outcome".

When asked to describe the biopsy experience, several concerns were voiced. Eleven couples (30.5%) commented on the lack of personal attention they received from the surgeon or other health care professionals at the time of the biopsy procedure. The experience was likened to an

"assembly line" where the impersonal and casual attitudes of the professionals seemed almost callous in their disregard of the importance of the event to the patient or her husband. Women reported being talked about, but not talked to especially during the biopsy done with a local anesthetic. "You listen to the comments of the doctors and nurses as they talk to each other. No one tells you what is happening. It is like you are not even there...and I heard him say, 'if we take too much out, she won't have anything left'".

Another concern was the lack of follow-up after the biopsy. Several couples said they were not told when to see the surgeon or when the stitches were to be removed. One woman said, "Nobody seems to care postoperatively. You have the surgery and that is it. It is out of the surgeon's realm and he doesn't care anymore. He has done his thing and that is it. Instead of telling you what to expect, you have to find out yourself". In fact, a third of the couples did not see the surgeon again because the office nurse removed the stitches and confirmed the benign results. Two of the couples never did hear about the results and were told to assume that if the surgeon did not request to see them, the results were all right. This seeming disregard of the trauma of the breast biopsy by the surgeon, in particular, led three couples to speculate about whether a female surgeon would, "react with more compassion under these circumstances".

Waiting for the biopsy and then waiting again to know the biopsy results was another concern reported by 21 (58%) of the couples. As one husband said, "Both of us were quite capable of handling any news, but just the not knowing what was happening was the worst of it". Another

response was, "The week following the biopsy before I was told the results was the worst week of all." Again, the impression the couples received was that the health care professionals involved did not appreciate how stressful this waiting experience was for them. Some couples waited for up to two weeks before learning the diagnosis. Husbands seemed to be affected by this waiting too: "It was a long week until we got the biopsy results. I wasn't used to him sitting around the house so much--usually he was out doing things. I kept thinking how glad I would be when we got the results and he got back to his routine. I don't really know if he even realized that he was doing this, but I did".

In conjunction with the biopsy experience, couples were asked if anything had occurred which they had not expected. The answers to this question are summarized in Table 22. Of interest were comments about the unexpected distress felt at the time of the actual procedure such as, "I was so tense that I even got sick to my stomach while I was waiting for the surgery"; "I was just beside myself I was so afraid"; and "It was more upsetting than I thought and very exhausting". Particular comments about the after-effects attributed to prolonged emotional distress were also noted. One woman said, "I was fine until I got in the car to go home and then it hit me. I started crying and shaking". Similar responses such as "I felt totally wiped out" and "I was a nervous wreck" were reported. One husband described the experience by saying, "I think she had kept herself up, artificially, for so long before surgery that when it was over, she crashed physically, mentally and emotionally".

TABLE 22

Unexpected Events of Breast Biopsy Experienced by Benign Women

Events	Frequency	Percent of Total Responses*
Effects of General Anesthetic ("drowsy", "nausea")	3	9
Hematoma	2	5
More Pain Than Expected	4	11
Less Pain Than Expected	3	8
Bruising	2	5
More Emotionally Upsetting than Anticipated	8	21
Decreased Ability to Breastfeed	1	3
Large Scar	2	5
"Disappointed" about Benign Results	3	8
Let-down Feelings Post-op	5	13
Procedure Took Longer Than Expected	2	5
Experience of Local vs. General Anesthesia	3	8

\* Responses to this question total 38.

Percent has been rounded off to the nearest whole number.

A related response was the feeling of "disappointment" at finding benign results. This experience was reported by three (9%) of the responses. "We had pretty well adjusted to expecting the worst and when the results came back, I felt quite depressed. I couldn't understand this when I knew I should be so happy". Another comment suggested, "I had already told myself this was cancer and I was up so high preparing myself for it that when the doctor told me it was benign, I was glad but it was like a disappointment. It took a week to come out of this".

Questions which were similar to the pre-biopsy interview were also included in the diagnosis interview to assess changes in response over time and provide a retrospective review of the experience. The question, "What changes have you noticed in your wife since the biopsy?" was directed to the husband. Answers to this question are presented in Table 23. Of the 38 responses to this question, 42% of the responses indicated no change in the wife's behaviour had been observed. Fifty-four percent of the responses indicated a positive change had occurred such as, "more relaxed, less preoccupied, and back to normal self". Only 5% of the responses indicated a negative change such as, "more tired" and "spacey".

Changes in the husbands as described by the wives indicated 42% of the 36 responses to this question reported no change (see Table 24). The remaining 58% of the observations spoke to the husband's relief of tension and greater appreciation of his wife expressed by answers such as "He's being nicer to me", "He's helping more", etc.

Changes in the marital relationship following benign diagnosis are outlined in Table 25. No change in the relationship was reported by 78%

TABLE 23

Changes in Wife Reported by Husband (Benign) at Diagnosis Interview

Changes	Frequency	Percent of Total Responses*
No Change	16	42
More Relaxed	7	18
Less Preoccupied	2	5
Less Depressed	1	3
Has Returned Back to Normal	5	13
More Concerned About Others	1	3
Relieved	3	8
Positive Attitude	1	3
More Tired	1	3
"Spacey"	1	3

\* Responses to this question total 38.

Percent has been rounded off to the nearest whole number.



TABLE 24

Changes in Husband Reported by Wife (Benign) at Diagnosis Interview

Changes	Frequency	Percent of Total Responses*
No Change	15	42
Appreciates Wife More "He is nicer to me."	8	22
More Helpful Around the House	1	3
Less Tense, More Relaxed	4	11
Sleeps Better	1	3
Relieved	5	14
Less Edgey	1	3
More Happy	1	3

\* Responses to this question total 36.

Percent has been rounded off to the nearest whole number.

TABLE 25

Changes in Relationship Reported by Benign Couples at Diagnosis Interview

Changes	Frequency	Percent of Total Couples*
<u>No Change in Relationship</u>	28	78
<u>More Satisfaction</u>		
Things Are Better	3	8
Less Tension	1	3
Spend More Time Together	2	6
<u>Less Satisfaction</u>		
Changed Sexual Involvement	1	3
Lack of Communication	1	3

\* n=36 couples.

Percent has been rounded off to the nearest whole number.

of the couples. As one wife said, "I don't think it (the biopsy experience) has brought us closer or any of those magical things you see on TV shows". However, 6 (17%) couples did report greater satisfaction through answers such as, "things are getting better" or "we're spending more time together". Two couples reported less satisfaction in their relationship related to lack of communication and a change in sexual involvement because of the redness and scarring at the biopsy site. When this particular wife was asked when she thought things would return to normal for her, she replied, "I think when the redness goes away, I hope. The breast is such a private part and a scar there is different than being on a stomach, for instance. I feel it is, sexually speaking, undesirable when it is scarred and red like this".

Similar to the pre-biopsy time period, couples were asked to identify what they had found to be helpful in dealing with the biopsy experience (see Table 26). Twenty-nine percent of the total 58 responses indicated that talking about the biopsy or treatment options between the couple was helpful. Whether this meant talking about instrumental issues related to the biopsy or affective ones as well remains unclear. One couple reported talking about, "everything in relation to the surgery, further surgery, and treatment. We even discussed death and that type of thing". In contrast, another husband said, "We both communicate very well. We never did discuss what would happen if it was cancer. We believed it was going to be benign and if it wasn't we would talk about that later". His wife responded by saying, "A lot of things I kept to myself...I didn't want to worry him".

The experience related to participation in the research project

TABLE 26

Factors Helpful to Benign Couples Reported at Diagnosis Interview

Factors	Frequency	Percent of Total Responses*
<u>Marital Relationship</u>		
Talked With Each Other	14	24
Discussed Treatment Options	3	5
Good Marriage Relationship		
"Someone to lean on"	5	9
Support of Husband	3	5
<u>Information</u>		
Talking to Nurse Researcher		
re: Information	10	17
re: Information to Talk Together		
About Biopsy	5	9
Information From Reading	4	7
Information From Doctor	3	5
<u>Support</u>		
Supportive Attitude of Friends	3	5
Religious Faith and Prayers	2	3
Talked to Others (Learned About		
Other's Experience)	2	3
<u>Other</u>		
Positive Outlook	2	3
Not Worrying About It	1	2
Not Talking About It	2	3
Keeping Busy	1	2

\* Responses to this question total 58.

Percent has been rounded off to nearest whole number.

also appeared to be of benefit to some couples. Twenty-six percent of the responses identified talking to the nurse researcher as helpful because of the information provided and/or because it provided the couple an opportunity to talk about the event together. Three conversations are presented to illustrate this finding:

Couple Number 1 - Husband: "I would have to say that sitting down and talking with you was the most helpful" Wife: "Yes, it was just having someone here who had the answers...not knowing the outcome...but being able to tell us how to put into perspective what would be happening". Husband: "I felt better about it just because we were able to talk openly about it".

Couple Number 2 - Husband: "I think our talk with you helped us greatly. No one ever tells you what to expect". Wife: "But some people don't want to talk about it and you thought I was talking about it too much". Husband: "I think there should be more talking to someone who knows about it".

Couple Number 3 - Wife: "I think coming and talking to you was helpful. You explained some of the things and it kind of put us in touch with what was happening and helped us understand. It was hard getting through to the doctor to ask all of these questions. Also, you were asking my husband and me questions that otherwise we might not have asked each other. We had to listen to each other answer the questions and that really helped."

Involvement of the social support subsystem in the information about the results of the biopsy was assessed by asking, "Who have you told about the biopsy now that did not know before? The general re-

sponse to this question was that because it was good news, a number of new people had been told who were either more emotionally distant than close friends and family, such as co-workers, or people who specifically weren't told before, such as extended family, children and aging parents. An interesting observation was made by one couple about their friend's discomfort with knowing how to relate to them during the biopsy experience: "One friend never called for four days and when she did call, she said that she was just so scared that she didn't know how to handle it. Even her husband could not even discuss it with her. We had them over for supper last week so that he could see that I was really OK. It's funny how you get different reactions from people".

Finally, the couples were asked what changes they anticipated for themselves as a consequence of receiving benign results (see Table 27). Thirteen (36%) couples said they did not anticipate any change. Six women (17%) said they planned to practice breast self-examination either more often or more carefully. Ten couples (27%) said the experience had caused them to appreciate life and relationships more with resulting changes in priorities or decisions about time management. Lastly, 6 (17%) couples reported lifestyle changes they planned to make related to diet, exercise, etc.

The final conjoint interview occurred at five to six months post-biopsy. This was called the follow-up interview. Again, similar questions were posed to the couple to assess changes over time. As expected, many other events had occurred for the couple over the intervening months. A frequent response was, "The biopsy isn't on my mind very much anymore", "It's like water under the bridge", or "It was like a hang-

TABLE 27

Anticipated Changes as a Consequence of Benign Biopsy Results

Changes	Frequency	Percent of Couples*
No Change	13	36
More Frequent/Careful Breast Self-Examination	6	17
Become More Aware of Own Mortality	1	3
Appreciate Life More "live today for today"	3	8
Take More Trips Together/ Do More Things Together	3	8
Re-evaluate Philosophy of Life	1	3
Spend More Time with Children	1	3
Spend More Time Together	2	6
Decided to Quit Smoking	1	3
Eat Less Fat in Diet	1	3
Decrease Caffeine Intake	3	8
Exercise More	1	3

\* n=36 couples.

Percent has been rounded off to nearest whole number.

over--two days later you are all over it and then you forget about it". However, while the biopsy was something which had happened in the past, several couples commented, "We have learned so much from it".

When asked to describe changes in themselves which they attributed to the biopsy experience, half of the responses to the question indicated that the biopsy had caused no enduring change to occur (see Table 28). Eight (20%) of the responses suggested there was an improvement in the marital relationship: "feeling closer", "doing more things together", and "greater appreciation for my wife". Other changes had to do with the practice of breast self-examination and lifestyle changes. One woman poignantly said that the biopsy and other events over the past six months made her realize, "moments of the present are really precious".

Two verbatim observations which were offered about the biopsy in retrospect did not fit the above categories. They are presented below:

Woman: "I still feel angry about having the biopsy done. I think it was treated as minor procedure by the surgeon. "I'm sure to him it was a very common thing, but to me it was a bit of a shock and a bomb shell and I was really not aware of even what questions to ask before I had it."

Woman: "If I had to have another biopsy, I would probably be more forward and ask questions. I wouldn't take it for granted that I was going to get any answers. I would be more aggressive in my questioning and not so damn placid. I would be expecting more from the medical profession."

Similar to the previous interviews, the couple was again asked to identify what was the most helpful to them as a couple in terms of going



TABLE 28

Changes Attributed to Biopsy Experience by Benign Couples at Follow-up  
Interview

Changes	Frequency	Percent of Total Responses*
No Change	20	50
Appreciate Wife More	2	5
Do More Things Together	1	3
Feel Closer to Each Other	4	10
Notice News Items in Media re Breast Cancer	3	8
Wife Talks More Openly	1	3
Appreciate Life More	2	5
Check Breasts More Often	3	8
Check Breasts Less Often	1	3
Eat Less Red Meat	1	3
Drink Less Coffee	1	3
Decided to Seek Counselling	1	3

\* Responses to this question total 40.  
 Percent has been rounded off to nearest whole number.

through the biopsy experience. Table 29 presents the responses to this question. Similar themes emerged again making it evident that even five or six months later, the couples still had some very clear ideas about what they had found helpful. Talking to each other, support from husband and each other, and involvement in the research project accounted for 61% of the responses. "Just knowing my husband was behind me and I could talk to him and he didn't find it or me repulsive", was one woman's response. Involvement in the research project provided one couple a chance to, "discuss things that we really would not have discussed ourselves--so many things would have gone unanswered". Another couple said, "Having the conversation with (the investigator) left us with a certain peace of mind".

#### Summary of the Results

In this section, the results of the quantitative and qualitative analyses are summarized and discussed in relation to the research questions.

Research Question 1: What is the effect of the biopsy, diagnosis and treatment of breast disease on the level of psychological distress experienced by both the woman and her spouse?

Husbands and wives together reported the highest levels of psychological distress at the biopsy time period which dropped considerably at the diagnosis time period and remained at the same lower level at the follow-up time period. Comparison with norms indicated that the distress reported by both the woman and her spouse did not reach abnormal levels, implying an absence of psychopathology. The malignant husbands

TABLE 29

Factors Helpful to Benign Couples Reported at the Follow-up Time Interview

Factors	Frequency	Percent of Total Responses*
<u>Marital Relationship</u>		
Support from Husband/Each Other	8	16
Talking to Each Other	8	16
<u>Information</u>		
Involvement in Research Project	14	29
Positive Attitude	5	10
Information From Doctor	3	6
<u>Support</u>		
Talking to Other People	3	6
Support of Family and Friends	2	4
Found Out Results Same Day of Biopsy	2	4
<u>Other</u>		
Confidence in Coping Ability	2	4
Keeping Busy	2	4

\* Responses to this question total 49.

Percent has been rounded off to nearest whole number.

reported the highest levels of distress at the biopsy time followed by the benign wives, the malignant wives and the benign husbands. The females reported higher distress at the follow-up time than the males.

Qualitative results indicated fear of cancer and its consequences were rated as the primary concern by 71% of the wives and 91% of the husbands during the pre-biopsy period. The pre-biopsy time period had an effect on both women and their spouses. Seventy-one percent of the wives and nine percent of the husbands reported that they were most affected by the pre-biopsy experience as compared to their spouses. Nine percent of the subjects indicated both spouses were equally affected.

The presence of distress was confirmed by changes in the wife's behaviour as reported by the husband and vice versa. A difference in behaviour which appeared to be related to the presence of psychological distress was reported for 63% of the responses used to describe the wives' responses to the pre-biopsy period and 28% of the responses used to describe the husbands' behaviour. This decreased to 6% of the responses for the benign wives and 0% of the responses for the benign husbands reporting distress at the diagnosis time period. For the malignant couples, 50% of the responses for the wives and 0% of the responses for the husbands indicated distress at the diagnosis time period. Changes in the husbands' behaviour in a positive direction were frequently noted by the wives at all time periods.

Research Question 2: What is the effect of the biopsy, diagnosis and treatment of breast disease on marital intimacy?

The categories of perceived marital intimacy (e.g., emotional,

social, sexual, intellectual and recreational) did not change significantly over time, nor were differences noted between husbands or wives and malignant versus benign groups. There is some suggestion that malignant husbands reported an increase in perceived emotional intimacy from the pre-biopsy to the follow-up time periods. As well, the malignant group of spouses appear to have reported higher levels of social intimacy as compared to the benign group; levels of intellectual intimacy appear to have increased over time for all groups. These findings need to be interpreted very cautiously.

Qualitative results suggest that positive changes in the marital relationship over time were reported by 87.5% of the malignant couples and 50% of the malignant couples for the diagnosis and follow-up time periods respectively. The marital relationship of the benign couples appeared to be less affected. Only 17% of the benign couples reported a positive change in the marital relationship at the diagnosis time period which decreased to 13% reporting a positive change in the relationship at the follow-up period. The majority of responses indicated no change had occurred.

Factors considered helpful to couples were reported over the three time periods. The category of obtaining support from the marital relationship by activities such as talking with each other and the category of having information about the biopsy procedure and cancer treatment alternatives were reported frequently by both benign and malignant couples as being helpful.

Research Question 3: What is the effect of the biopsy, diagnosis and treatment of breast disease on the quantity and quality of social

support reported by the woman and her spouse?

Wives reported a slightly larger quantity and quality of social support than did the husbands. Sources of support came primarily from spouse and family, with a gradient of support supplied by friends, then co-workers, then neighbours. Health care professionals were identified infrequently as a source of support at both the biopsy and follow-up time periods. Statistical differences related to time, sex and diagnosis could not be examined because of insufficient data at the follow-up time. However, examination of the raw data appears to suggest that the malignant husbands and wives reported an increase in the quantity and quality of social support over time.

Qualitative results for this question indicate that a limiting of news to the social support system may occur during the biopsy but that once the diagnosis is confirmed, many people inside and outside of the support system are told without negative consequences.

Research Question 4: What is the relationship between psychological distress, marital intimacy and social support? Psychological distress is negatively related to emotional, social and intellectual intimacy and does not appear to be related to social support. Social intimacy appears to be positively correlated to quality and quantity of social support.

Supplementary Information: Questions from the semi-structured interview provided insight into the impact of the biopsy, diagnosis and treatment of breast disease on the woman and her spouse. Several couples reported that the importance of the biopsy experience is not appreciated by health professionals. Suggestions for improving delivery

of services in this area indicate a need for more information about the biopsy procedure itself and the treatment alternatives if cancer is diagnosed. Decreased waiting time for the biopsy and for the results of the biopsy were also suggested as ways to minimize the negative effects of this experience on the couple.

## CHAPTER FIVE

### DISCUSSION AND IMPLICATIONS

This chapter will include a restatement of the purpose of the study, and a discussion of the results obtained. The limitations of the study and the implications for research counselling will also be presented.

#### Restatement of the Purpose

The study had three main objectives: to describe the experience of women and their spouses during the pre-biopsy time period when the diagnosis of breast cancer was a possible outcome; to compare the experiences of couples who were diagnosed as having benign breast disease with those couples who were diagnosed as having breast cancer; and to describe the ripple effect of these experiences on psychological distress, marital intimacy, and social support. Data collection points were within two weeks prior to the biopsy, 6-8 weeks post-biopsy or post-cancer surgery and at 5-6 months. Fifty-six husband/wife dyads were initially



interviewed at the pre-biopsy time period. This number was reduced to 44 couples at the second and third data collection points.

### Discussion of the Results

The effect of the biopsy, diagnosis and treatment of breast disease on psychological distress, marital intimacy and social support was assessed by doing a quantitative and qualitative analysis of the data which were collected from the research instruments and the semi-structured interview. The findings related to each variable will be discussed in the following sections.

#### Psychological Distress

That the experience of breast biopsy with its attendant fears and concerns is a stressful experience for most women is not a new finding. Similar reports by Scott (1983a) and Maguire (1976) found levels of anxiety and depression in samples of pre-biopsy women. That husbands also appear to find the experience stressful has been speculated in the clinical literature (Thomas, 1978) but has not been previously documented. Large variation in the standard deviations on the measure of psychological distress suggests that there may have been factors, other than the biopsy experience itself, which had an effect on the subjects' reports of distress.

One such factor may have been the varying degree of threat perceived in the biopsy experience. The theoretical work of Lazarus and Folkman (1984) emphasized that an event has the potential to create threat, harm or challenge, depending on a dynamic interaction between

several identified person and situation factors. A partial listing of these factors which also have the potential to be part of the pre-biopsy threat include: previous experience with the event or that which has been seen, read, or heard about; uncertainty as to whether the event will occur or not which creates mental confusion from having to consider first one possible outcome then another; the length of the anticipation time; and the timing of the event in the person's life situation.

Another factor relative to this sample was the finding that the lump had been discovered anywhere from a few days to eight years prior to the first interview. This may also have affected perception of the degree of threat present in this experience. All of these factors may account for the high variability of scores which suggests that some of the subjects experienced more distress than others. Using the mean score to test for differences does not allow for examination of these individual variations.

It was interesting to note that when the groups were differentiated at the pre-biopsy time by eventual diagnosis, the malignant husbands reported the highest levels of distress. One reason for this finding might have been communication from the surgeon concerning the seriousness of the lump. For example, the malignant group may have been told the lump "looked suspicious", thus increasing the subjects' perception of threat and affecting their level of psychological distress. As well, the sample size of the malignant male group was small ( $n=11$ ) increasing the chance for the mean to be affected by extreme scores.

The levels of distress significantly decreased from the pre-biopsy to the diagnosis time and remained at the lower levels for the follow-up

time, even for the group who had confirmation of malignant findings. This finding suggests that it may be uncertainty about the outcome which makes the pre-biopsy experience distressing, even more so than receiving the diagnosis of cancer.

Similar levels of distress reported for the benign and malignant groups at the diagnosis time period (6-8 weeks post-surgery) were consistent with those reported by Bloom, Ross, and Burnell (1978) who also used POMS to test for negative mood states. At two months post-mastectomy, the women in their intervention group had standard scores within one standard deviation of the college norms for POMS with the exception of the confusion subscale which fell below one standard deviation of the standard score.

The suggested absence of psychopathology implied by these scores is contrary to the findings by Maguire (1976) who reported anxiety, judged to be of psychiatric proportions, in 24% of the cancer group and 14% of the benign group of women at the pre-biopsy time period. However, Vachon, Lyall, Rogers, Cochrane, and Freeman (1981-82) reported low levels of psychological distress in their sample of 64 women undergoing radiotherapy for breast cancer. Both of these studies used instruments other than POMS to measure distress. What remains unclear is whether the amount of distress, albeit within "normal" limits, warrants intervention by a mental health professional.

Contrary to what what would be expected, no correlation was found between psychological distress and social support. The literature suggests that social support is a moderating variable of life stress (Cassel, 1974; Cobb, 1976); thus, a negative correlation between the

variables was anticipated. The lack of a relationship between the POMS subscales (and total mood disturbance score) and the total functional and total network properties of NSSQ was also found by Norbeck, Lindsey, and Carrieri (1983). In the development of the social support instrument (NSSQ), they administered POMS to 75 subjects in conjunction with the NSSQ to test for construct validity of their instrument. They reported a low, but significant relationship between the total loss score and the depression and confusion subscales of POMS. These findings led them to speculate that perhaps POMS is not a sensitive measure of symptomatology for a nonclinical population.

#### Marital Intimacy

The quantitative findings related to marital intimacy suggest that perceived marital intimacy was not differentiated over time between males or females and between benign or malignant groups. This is similar to another study which found marital adjustment, reported by women on a four-point rating scale, unaffected by mastectomy (Morris, Greer, & White, 1977). Several factors may have contributed to this finding. Small sample size of the malignant group may again, have been a factor. The degree of marital intimacy prior to the onset of the breast problem was unknown making it difficult to assess the impact of biopsy and diagnosis experiences. The instrument (PAIR) was designed for diagnostic use by marital therapists and may not have been sensitive to the specific changes experienced by couples dealing with an illness. Subjects reported difficulty answering questions on this instrument, particularly those related to expected intimacy, because of awkward wording and be-

cause the use of double negatives cast doubt on which answer to choose (e.g., strongly disagree or strongly agree). As well, a comparison with the norm revealed a social desirable response set may have affected the subjects' reports of their marital satisfaction.

Qualitative findings did, however, suggest that there were changes in the behaviours and perceptions of the marital couple with regard to their relationship, particularly for the small ( $n=8$ ) group of malignant couples. These changes were in a positive direction with greater appreciation for the spouse and for the relationship being reported. The higher frequency of positive relationship change reported by the malignant versus benign couples may be attributed to the small sample size and also to receiving the diagnosis of a potentially life-threatening illness. Wellisch (1985, p. 196) described receiving the diagnosis of breast cancer as, "a crisis that could jolt the partners into a recognition that their relationship will not last forever and now is the time to work at support, communication and mutual affection". These factors might also explain the quantitative finding that malignant males, in particular, reported an increase in mean scores of emotional intimacy from the pre-biopsy to the follow-up interview. These data confirm previous reports indicating positive change occurred in the marital relationship following the diagnosis of breast cancer (Maguire, 1976; Gates, 1980).

The finding that perceived social intimacy was correlated to quantity and quality of social support is not surprising. The items of social intimacy in PAIR describe the experience of having common friends and sharing similarities in social networks. Thus, it is likely that

spouses who reported having friends in common and spending time together with friends also reported higher numbers and quality of relationships in their social networks.

Negative correlations between psychological distress and perceived emotional, social and intellectual intimacy were noted. It might be speculated that couples who talked not only about the events of the illness (intellectual intimacy) but about their feelings as well (emotional intimacy) experienced less distress than couples who did not use these coping strategies to deal with the biopsy, diagnosis and treatment of breast disease.

#### Social Support

Findings of this study related to social support documented women as reporting more people in their network and reporting higher quality and quantity of social support than men. Other investigators have noted similar findings (McFarlane, Neale, Norman, Roy, & Streiner, 1981).

The observed increase in mean scores of quantity and quality of social support reported over time by the malignant couples contrasts with reports from cancer patients who indicated a shrinking of social networks with the diagnosis of cancer (Peters-Golden, 1982). However, the sample size of malignant subjects was small and for this reason extreme scores may have affected the mean. Procedures to test for statistical differences in the means could not be done because of the small size. As well, the instrument used to assess social support was lengthy and required the subject to identify a listing of people considered important to them. With the stress of the pre-biopsy period,

the ability to recall may have been impaired, thus accounting for the increase of persons listed on the instrument from the pre-biopsy to the follow-up interview. Conclusive results are therefore not available for this measure.

Qualitative results further document a low frequency of complaints that the social network reacted to the probability or reality of breast cancer by feeling sorry or avoiding the couple which does not support the findings of Wortman and Dunkel-Schetter (1979). Both benign and malignant couples in this study did, however, report a desire to withhold information from certain members of the social network until the diagnosis was confirmed.

One final comment about the findings, in general, merits attention. This study was original in its use of a conjoint interview and its inclusion of the husband in the longitudinal data collection points beginning with the pre-biopsy time period. The similarities in responses between women and their spouses of both benign and malignant groups were more pronounced than the differences. It is clear that the pre-biopsy experience creates stress and that the diagnosis of cancer requires adaptation efforts. Furthermore, the parallel reactions of the husbands emphasize the fact that the biopsy, diagnosis and treatment of breast disease is a family affair.

#### Limitations of the Study

Several limitations to the data are presented under the following headings: sample, instrumentation, and participation in the study.

### Sample

The subjects of this study were a non-probability, convenience sample who self-selected themselves by agreeing to participate in the study. They may have been more concerned about the possibility of breast cancer, more self-disclosing, more interested in research, or different in other ways from the couples who refused to participate in the study. In addition, confounding demographic and medical influences cannot be eliminated in a non-probability sample. For these reasons, the sampling procedure poses a serious threat to the external validity of this study.

The malignant sample was small (N=11 couples) which decreased to (N=8), limiting statistical power. This was particularly problematic as comparisons were being made to a much larger benign sample of N=45 couples at the pre-biopsy time and N=36 couples at the diagnosis time period. Detecting differences between the malignant and benign groups based on such a small sample size was difficult. For example, small numbers and missing data precluded statistical investigation of differences between groups over time on the social support measure.

Although there was relative diagnostic uniformity within the groups, especially compared to much of the breast cancer literature, still, there were vastly different amounts of time which had elapsed from the time the breast problem was first detected. Reports varied from a few days to eight years. In addition, the malignant group of women had experienced various surgeries, from removal of some breast tissue to removal of both breasts. This treatment variability within the sample may have had an effect on the women's responses which could



not be isolated when the malignant females were grouped together.

Nothing is known about the women and their spouses who refused to participate in the study in terms of how they differ from the present sample. It would be interesting, but methodologically impossible, to compare couples who are willing to participate in a study of this kind versus those who are not.

Finally, research has suggested a defensive response style of denial about the seriousness of the illness may be operative and functional over the short-term in the breast cancer experience (Watson, Greer, Blake, & Shrapnell, 1984). This may account for the relative lack of problems reported by the malignant group in the areas of psychological distress, marital intimacy and social support. This may also account for the frequency of the malignant couples' use of the past tense to describe their experience of having "had cancer".

#### Instrumentation

The results of this study are based on self-reports of the subjects and so are affected by pressures of self-presentation, social desirability, interest in the study, etc., despite the fact that the investigator was skilled in interviewing techniques.

Interviewing subjects in the pre-biopsy time period and using a longitudinal design were deliberate design attempts to establish baseline measures for the variables and to avoid data collection at only one point in time. However, levels of psychological distress, marital intimacy and social support prior to the onset of the breast problem remain unknown.

The issue of priority of causal influences also requires consideration. Were the changes observed in the measures related to the stress of the illness experience or to other events which occurred during or preceeding the six-month testing period?

#### Participation in the Study

The experience of being involved in the research project may have affected the subjects' responses. In light of the fact that 15% to 29% of the responses of both the benign and malignant groups reported benefit from talking with the investigator, the couples themselves may have had a different pre-biopsy and diagnosis experience than those not involved in the research project.

#### Implications for Further Research

An increase in sample size is the primary issue for further research. The present study was severely limited because of the small malignant sample. The first and most pressing recommendation for further research therefore needs to be replication with a larger sample. Multivariate analysis necessary to analyze predictive variables is not possible without a sufficient number of subjects. The problem with acquiring an adequate sample size is that only one in four breast biopsies confirm malignant results, making it difficult to obtain a large sample of breast cancer patients. The statistical comparison of larger benign and malignant groups would allow for generalizability of the results.

Ideally, design considerations require a prospective study starting

with an at-risk population in order to rule out findings related to the threat or reality of the breast cancer experience as opposed to premorbid functioning. However, this is difficult and costly. Inclusion of the pre-biopsy time period is an attempt to address this problem but is itself fraught with subject accrual difficulties.

Instrumentation is another issue for consideration by future research efforts. Research using different data collection methods is required to determine the effect of the biopsy, diagnosis and treatment of breast disease on the marital subsystem. Self-report measures seem to be one way to obtain information about relationship systems. Observation of marital interaction may also be a useful indicator of the relationship. As well, research on marital or family interaction may eventually lead to identification of interactional patterns which predispose, precipitate or maintain the illness of breast cancer.

Another recommendation for further research is to explore differences in the high degree of variability observed in this sample. To begin to understand why scores were varied with regard to psychological distress, differences in perception of threat need to be examined more closely. Variability of marital intimacy scores may be better understood by looking at differences between couples and within couples and relating this congruence or lack of it to other variables.

Maguire and Van Dam (1983) address the issue of variability by focusing on specific sample characteristics which should be identified and accounted for by all psychosocial breast cancer research. They recommend studies should include the following descriptors of the sample:

"details of how the samples were obtained; how representative

they were of the population from which they were drawn; whether diagnosis was a 1- or 2-stage procedure; what physical treatments (with what complications) were given since diagnosis; the incidence of recurrent disease; whether patients had a confiding tie, previous psychiatric illness or preoperative depression; and the number and characteristics of those who refused to take part". (p. 1740)

Following descriptive and correlational research, it would be interesting to design a quasi-experimental study to assess the benefits on several outcome variables of having couples involved in pre-biopsy counselling as compared to couples without intervention. Of particular interest would be couples who receive the diagnosis of breast cancer and whether early intervention at the pre-biopsy time period make a difference in their individual, marital and social adjustment to the breast cancer experience.

#### Counselling Implications

The results of this study suggest that couples frequently found receiving information and obtaining support from within the marital relationship helpful in coping with the illness experience of breast disease. These findings have implications for involvement of the spouse or significant other at the pre-biopsy time period.

While the biopsy experience is not necessarily a crisis for every couple, high levels of distress were reported by both husbands and wives when the outcome of the biopsy was uncertain and the possibility of breast cancer a major concern. Seeing the couple together in a conjoint

counselling interview during or shortly after consultation with the specialist surgeon may be helpful in answering requests for information and enhancing the couple's coping response to the threat of the biopsy. This would require the cooperation of the surgeon and the mental health specialist in the negotiation of complementary roles for the provision of health care oriented to the couple versus the individual patient. Maguire (1976, p. 391) speaks to this need by suggesting from clinical experience that surgeons may be, "reluctant to probe too deeply into the women's reactions for fear that their inquiries might precipitate even greater distress than [is] already present".

The role of the counsellor would involve assisting the couple to deal with the impact that detection of a lump has on them, become aware of the possible ramifications of receiving the diagnosis of cancer, and utilize appropriate support systems (Lambert & Lambert, 1985). The counsellor must be skilled in marital counselling, understand the impact of illness on families, and be knowledgeable about the medical procedures and problems which are specific to the diagnosis and treatment of breast disease.

The pre-biopsy counselling interview would provide a unique opportunity for the marital partners to express their concerns to each other through the presence of a third party. Assessment questions could be formulated to invite expression about feelings and concerns and allow the couple to share sensitive issues that they may have been reluctant to explore with each other. In this way, openness of marital subsystem communication may be enhanced.

An exploration of what the couple understands about the impending

biopsy would not only assess the couple's perception of threat but would also identify information deficits. "Much patient anxiety is a function of their medical misconceptions about the illness" (Kaplan, 1984, p. 2363). Difficulty processing information in an anxious state, the uncertainty of the diagnosis, and lack of involvement of the partner in discussion of the treatment alternatives often results in an incomplete and unclear understanding. Morris, Greer, and White (1977) found that when information, both affective and factual, was received by breast cancer patients, their fear was reduced. When information was not provided, patients showed an increase in anxiety and hostility, and they adopted dysfunctional coping styles.

The counsellor could provide information as need indicates in specific areas such as: clarification of the purpose of diagnostic tests; explanation of what to expect and anticipated sensory feelings during the biopsy depending on whether the biopsy will be done in an inpatient or outpatient setting, with a local or general anesthetic, using a one-stage or two-stage procedure, and requiring special pre-operative procedures such as needle marking; suggestions about the post-operative management of pain, swelling, bruising, fatigue and suture care; and discussing about how and when results of the biopsy will become known.

It is crucial that the counsellor allow the couple to guide the amount of information which is provided by asking them what they want to know. Research on information desired by cancer patients suggests there may be a need not to know which serves a protective function (Bean, Cooper, Albert, & Kipnis, 1980; McIntosh, 1974).

If requested by the couple, the counsellor may also be a resource

for discussion of the query, "What if they find cancer?" The prevalence of recent media attention and conflicting information about the treatment of breast cancer suggests that this question must be dealt with carefully and accurately. There are several publications which may be suggested as recommended reading for the couple (Kushner, 1984; Morra & Potts, 1980; NIH, 1982).

The pre-biopsy interview might also serve to make couples aware of resources available should they be needed later, particularly if the diagnosis of cancer is received. The couple may require assistance in reviewing treatment alternatives, making decisions regarding the acceptance or rejection of available treatment, or dealing with the impact of receiving confirmation of a potentially life-threatening illness.

The conjoint interview provides the potential for creating change within the marital subsystem: increased understanding about what to expect during the operative procedure; more realistic perceptions of the illness; increased emotional communication; and overt rather than covert expression of what each partner needs from his or her spouse and from the larger support system. It also conveys understanding and appreciation for the fact that the ripple effect of the breast biopsy and diagnosis experience may have a profound influence, not only on the woman, but on her larger relationship systems as well.

# REFERENCES

- Abrams, K. S. (1981). The impact on marriage of adult-onset paraplegia. Paraplegia, 19, 253-259.
- Baider, L., Amikam, J. C., & De-Nour, A. K. (1984). Time-limited thematic group with post-mastectomy. Journal of Psychosomatic Research, 28, 343-330.
- Baider, L., & Sarell, M. (1984). Couples in crisis: Patient-spouse differences in perception of interaction patterns and the illness situation. Family Therapy, 11(2), 115-122.
- Bard, M., & Sutherland, A. M. (1955). Psychological impact of cancer and its treatment: Adaptation to radical mastectomy. Cancer, 8, 656-672.
- Bean, G., Cooper, S., Albert, R., & Kipnis, D. (1980). Coping mechanisms of cancer patients: A study of 33 patients receiving chemotherapy. CA--A Cancer Journal for Clinicians, 30, 256-260.
- Beavers, W. R. (1983). Hierarchical issues in a systems approach to illness and health. Family Systems Medicine, 1, 47-55.
- Berkman, L. F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda County residents. American Journal of Epidemiology, 109, 186-294.
- Blazer, D. G. (1982). Social support and mortality in an elderly community population. American Journal of Epidemiology, 115, 684-694.
- Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. Social Science and Medicine, 16, 1329-1338.
- Bloom, J. R. (1984). Response. Cancer (supplement), 53, 2323-2326.
- Bloom, J.R., Ross, R.D., & Burnell, G. (1978). The effect of social support on patient adjustment after breast surgery. Patient Counseling and Health Education, 1, 50-59.
- Bloom, J. R., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Social Science and Medicine, 19, 831-837.
- Brackney, B. E. (1979). The impact of home dialysis on the marital dyad. Journal of Marital and Family Therapy, 5(1), 55-60.
- Bransfield, D. D. (1982-83). Breast cancer and sexual functioning: A review of the literature and implications for future research.



International Journal of Psychiatry and Medicine, 12, 197-211.

- Broadhead, W. E., Kaplan, B. H., Sherman, A. J., Wagner, E. H., Schoenbach, V. J., Grimson, R., Heyden, S., Tibblin, G., & Gehlbach, S. H. (1983). The epidemiologic evidence for a relationship between social support and health. American Journal of Epidemiology, 117, 521-537.
- Brody, H. (1973). The systems view of man: Implications for medicine, science and ethics. Perspectives in Biology and Medicine, 17 (Autumn), 71-92.
- Brown, G. W., & Harris, T. O. (1978). Social origins of depression: A study of psychiatric disorder in women. New York: Free Press.
- Campbell, D. T., & Stanley, J. C. (1963). Experimental and quasi-experimental designs for research. Chicago: Rand McNally College Pub. Co.
- Caplan, G. (1974). Support systems. In G. Caplan (Ed.), Support systems and community health (pp. 1-39). New York: Behavioral Publications.
- Cassel, J. (1974). An epidemiological perspective of psychosocial factors in disease etiology. American Journal of Public Health, 64, 1040-1043.
- Checkryn, J. (1984). Cancer recurrence: Personal meaning, communication, and marital adjustment. Cancer Nursing, 7, 491-498.
- Chelune, G. J., Robison, J. T., & Kommer, M. J. (1984). A cognitive international model of intimate relationships. In V. J. Derlega (Ed.), The development of intimate relationships. New York: Academic Press.
- Chelune, G. J., & Waring, E. M. (1984). Nature and assessment of intimacy. In P. McReynolds, & G. J. Chelune (Eds.), Advances in Psychological Assessment Volume 6 (pp. 277-311). San Francisco: Jossey-Bass.
- Clinebell, H.J., & Clinebell, C.H. (1971). The intimate marriage. New York: Harper & Row.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.
- Cooper, E. T. (1984). A pilot study on the effects of the diagnosis of lung cancer on family relationships. Cancer Nursing, 7, 301-308.
- Corbin, J. M., & Strauss, A. L. (1984). Collaboration: Couples working together to manage chronic illness. Image: The Journal of Nursing Scholarship, 16(4), 109-115.

- Costello, C. G. (1982). Social factors associated with depression: A retrospective study. Psychological Medicine, 12, 329-334.
- Crowne, D. P., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. Journal of Counselling Psychology, 24, 349-354.
- Dahms, A. (1972). Emotional intimacy. Boulder, Colorado: Pruett.
- Dean, A., and Lin, N. (1977). The stress-buffering role of social support: Problems and prospects for systematic investigation. The Journal of Nervous and Mental Disease, 165, 403-417.
- Dohrenwend, B. S., & Dohrenwend, B. P. (1974). Stressful life events: Their nature and effects. New York: John Wiley.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. Science, 196, 129-136.
- Ervin, C. (1973). Psychologic adjustment to mastectomy. Medical Aspects of Human Sexuality, 7, 42-65.
- Filsinger, E. E., & Lewis, R. A. (1981). Assessing marriage. New behavioral approaches. Beverly Hills: Sage Publications.
- Funch, D. P., & Mettlin, C. (1982). The role of support in relation to recovery from breast surgery. Social Science and Medicine, 16, 91-98.
- Gates, C. C. (1980). Husbands of mastectomy patients. Patient Counselling and Health Education, 2, 38-41.
- Gerard, D. (1982). Sexual functioning after mastectomy: Life vs. lab. Journal of Sex and Marital Therapy, 8, 305-315.
- Goin, M. K. (1982). Psychological reactions to surgery of the breast. Clinics in Plastic Surgery, 9, 347-354.
- Gotay, C. C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science and Medicine, 18, 605-613.
- Gottesman, D., & Lewis, M. S. (1982). Differences in crisis reactions among cancer and surgery patients. Journal of Consulting and Clinical Psychology, 50, 381-388.
- Grandstaff, N. W. (1976). The impact of breast cancer on the family. Frontiers of Radiation Therapy and Oncology, 11, 146-156.
- Grolnick, L. (1972). A family perspective of psychosomatic factors in illness: A review of the literature. Family Process, 11, 457-486.

- Hames, J., & Waring, E. M. (1980). Marital intimacy and non-psychotic emotional illness. Psychiatric Forum, 9, 13-19.
- Haskell, D. H., Pugatch, D., & McNair, D. M. (1969). Time-limited psychotherapy for whom? Archives of General Psychiatry, 21, 546-552.
- Helmrich, S. P., Shapiro, S., Rosenberg, L., Kaufman, D. W., Slone, D., Bain, C., Miettinen, O. S., Stolley, P. D., Rosenshein, M. B., Knapp, R.C., Leavitt, T., Schottenfeld, D., Engle, R.L., & Levy, M. (1983). Risk factors for breast cancer. American Journal of Epidemiology, 117, 35-45.
- Herz, F. (1980). The impact of death and serious illness on the family life cycle. In E. A. Carter & M. McGoldrick (Eds.), The family life cycle: A framework for family therapy (pp. 223-240). New York: Gardner.
- Hinton, J. (1975). The influence of previous personality on reactions to having cancer. Omega: Journal of Death and Dying, 6, 95-111.
- Hughes, J. (1982). Emotional reactions to the diagnosis and treatment of early breast cancer. Journal of Psychosomatic Research, 26, 277-283.
- Hutchinson, W. B., Thomas, D. B., Hamlin, W. B., Roth, G. J., Peterson, A. V., & Williams, B. (1980). Risk of breast cancer in women with benign breast disease. Journal of the National Cancer Institute, 65, 13-20.
- Jamison, K. R., Wellisch, D. K., & Pasnau, R. O. (1978). Psychological aspects of mastectomy: 1. The woman's perspective. American Journal of Psychiatry, 135, 432-436.
- Kahn, R. L. (1979). Aging and social support. In M.W. Riley (Ed.), Aging from birth to death: Interdisciplinary perspectives (pp. 77-91). Boulder, Colorado: Westview Press.
- Kahn, R., & Antonucci, T. (1980). Convoys over the life course: Attachment, roles and social support. In P. B. Baltes & O. Brim (Eds.), Life-span development and behavior. Boston: Lexington Press.
- Kaplan, B. H. (1984). Summary of the informal discussion of measuring the social environment of the patient. Cancer (supplement), 53, 2363.
- Kelley, P. T. (1980). Counselling needs of women with a maternal history of breast cancer. Patient Counselling and Health Education, 2, 118-124.
- Klein, R. F., Dean, A., & Bogdonoff, M. D. (1967). The impact of ill-

- ness upon the spouse. Journal of Chronic Diseases, 20, 241-248.
- Knobf, M. K. T. (1984). Breast cancer. The treatment revolution. American Journal of Nursing, 84, 1110-1120.
- Krouse, H. J., & Krouse, J. H. (1981). Psychological factors in post-mastectomy adjustment. Psychological Reports, 48, 275-278.
- Kushner, R. (1984). Alternatives. Cambridge, Massachusetts: Kensington Press.
- Lambert, V. A., & Lambert, C. E. (1985). Psychosocial care of the physically ill (2nd ed.). Englewood Cliffs, New Jersey: Prentice-Hall.
- Lazarus, R. S., Averill, J. R., & Opton, E. M. (1974). The psychology of coping: Issues of research and assessment. In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), Coping and adaptation (pp. 249-315). New York: Basic Books.
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- Levin, D. N., Cleeland, C. S., & Dar, R. (1985). Public attitudes towards cancer pain. Cancer, 56, 2337-2339.
- Lewis, F. M., & Bloom, J. R. (1978-79). Psychosocial adjustment to breast cancer: A review of selected literature. International Journal of Psychiatry in Medicine, 9(1), 1-17.
- Lewis, F. M., Ellison, E. S., & Woods, N. F. (1985). The impact of breast cancer on the family. Seminars in Oncology Nursing, 1, 206-213.
- Lewis, J. M., Beavers, W. R., Gossett, J. T., & Phillips, V. A. (1976). No single thread: Psychological health in family systems. New York: Brunner/Mazel.
- Lief, H. (1978). Sexual concerns of mastectomy patients. Medical Aspects of Human Sexuality, 12, 5758.
- Lindsey, A. M., Norbeck, J. S., Carrieri, V. L., & Perry, E. (1981). Social support and health outcomes in postmastectomy women: A review. Cancer Nursing, 4, 377-384.
- Locke, J. H., & Wallace, K. M. (1959). Short marital adjustment and prediction tests: Their reliability and validity. Marriage and Family Living, 21, 251-255.
- Lowenthal, M. F., & Haven, C. (1968). Interaction of adaptation: Intimacy as a critical variable. American Sociological Review, 33, 20-30.

- Lubin, J. H., Brinton, L. A., Blot, W. J., Burns, P. E., Lees, A. W., & Fraumeni, J. F. (1983). Interactions between benign breast disease and other risk factors for breast cancer. Journal of Chronic Diseases, 36, 525-531.
- Magery, C. J., Todd, P. B., & Blizzard, P. J. (1977). Psychosocial factors influencing delay and breast self-examination in women with symptoms of breast cancer. Social Science and Medicine, 11, 229-232.
- Maguire, G. P., Lee, E. G., Bevington, D. J., Kuchemann, C. S., Crabtree, R. J., & Cornell, C. E. (1978). Psychiatric problems in the first year after mastectomy. British Medical Journal, 1, 963-965.
- Maguire, P. (1976). The psychological and social sequelae of mastectomy. In J. G. Howells (Ed.), Modern perspectives in psychiatric aspects of surgery (pp. 390-421). New York: Brunner/Mazel.
- Maguire, P., & Van Dam, F. (1983). Psychological aspects of breast cancer; workshop report. European Journal of Cancer and Clinical Oncology, 19, 1735-1740.
- Marshall, J. R., & Funch, D. P. (1983). Social environment and breast cancer. A cohort analysis of patient survival. Cancer, 52, 1546-1550.
- Mayou, R., Foster, A., & Williamson, B. (1978). Psychosocial adjustment in patients one year after myocardial infarction. Journal of Psychosomatic Research, 22, 447-453.
- McFarlane, A. H., Neale, K. A., Norman, G. R., Roy, R. G., & Streiner, D. L. (1981). Methodological issues in developing a scale to measure social support. Schizophrenia Bulletin, 7, 90-100.
- McIntosh, J. (1974). Processes of communication, information seeking and control associated with cancer: A review of the literature. Social Science and Medicine, 8, 167-187.
- McNair, D. M., Fisher, S., Kahn, R. J., & Droppleman, L. F. (1970). Drug-personality interaction in intensive outpatient treatment. Archives of General Psychiatry, 22, 128-135.
- McNair, D. M., Lorr, M., & Droppleman, L. F. (1981). EITS manual for the profile of mood states (2nd ed.). San Diego, California: Educational and Industrial Testing Service.
- Mead, M. (1976). Male and female. A study of the sexes in a changing world. New York: Morrow.
- Medalie, J. H., & Goldbourt, V. (1976). Angina pectoris among 10,000 men. American Journal of Medicine, 60, 910-921.

- Metze, E. (1978). Couples and mastectomy. In P. C. Brand & P. A. van Keep (Eds.), Breast cancer. Psycho-social aspects of early detection and treatment (pp. 25-31). Baltimore: University Park Press.
- Metzger, L. F., Rogers, T. F., & Bauman, L. J. (1983). Effects of age and marital status on emotional distress after mastectomy. Journal of Psychosocial Oncology, 1(3), 17-33.
- Meyerowitz, B. E. (1980). Psychosocial correlates of breast cancer and its treatments. Psychological Bulletin, 87(1), 108-131.
- Meyerowitz, B. E., Watkins, I. K., & Sparks, F. C. (1983). Psychosocial implications of adjuvant chemotherapy. Cancer, 52, 1541-1545.
- Mirin, S. M., Shapiro, L. M., Meyer, R. E., Pillard, R. C., & Fisher, S. (1971). Casual versus heavy use of marijuana: A redefinition of the marijuana problem. American Journal of Psychiatry, 127, 1134-1140.
- Moos, R. H. (1974). Family environment scale - Form R. Palo Alto, California: Consulting Psychologists Press.
- Moos, R. H. (1982). Coping with acute health crises. In T. Millon, C. Green, & R. Meagher (Eds.), Handbook of clinical health psychology (pp. 129-151). New York: Plenum.
- Morra, M., & Potts, E. (1980). Choices: Realistic alternatives in cancer treatment. New York: Avon.
- Morris, T. (1983). Psychosocial aspects of breast cancer: A review. European Journal of Cancer and Clinical Oncology, 19, 1725-1733.
- Morris, T., Greer, H. S., & White, P. (1977). Psychological and social adjustment to mastectomy: A two-year follow-up study. Cancer, 40, 2381-2387.
- Morrow, G. R., Hoagland, A., & Carnrike, C. L. M., Jr. (1981). Social support and parental adjustment to pediatric cancer. Journal of Consulting and Clinical Psychology, 49, 763-765.
- Nathan, P. E., Titler, N. A., Lowenstein, L. M., Solomon, P., & Rossi, A. M. (1970). Archives of General Psychiatry, 22, 419-430.
- National Institutes of Health (1982). The breast cancer digest. A guide to medical care, emotional support, educational programs, and resources (NIH Publication No. 82-1691). Bethesda, Maryland: National Cancer Institute.
- Norbeck, J. S., Lindsey, A. M., & Carrieri, V. L. (1981). The development of an instrument to measure social support. Nursing Re-

search, 30, 264-269.

- Norbeck, J. S., Lindsey, A. M., & Carrieri, V. L. (1983). Further development of the Norbeck social support questionnaire: Normative data and validity testing. Nursing Research, 32, 4-9.
- Northouse, L. L. (1981). Mastectomy patients and the fear of cancer recurrence. Cancer Nursing, 4, 213-220.
- Oberst, M. T., & James, R. H. (1985). Going home: Patient and spouse adjustment following cancer surgery. Topics in Clinical Nursing, 7(1), 46-57.
- Olsen, E. (1970). The impact of serious illness on the family system. Postgraduate Medicine, 47, 169-174.
- Parloff, M. B., Kelman, H. C., & Frank, J. D. (1954). Comfort, effectiveness and self-awareness vs. criteria of improvement in psychotherapy. American Journal of Psychiatry, 111, 343-351.
- Perlmutter, M. S., & Hatfield, E. (1980). Intimacy, intentional meta-communication and second-order change. American Journal of Family Therapy, 8, 17-23.
- Peters-Golden, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. Social Science and Medicine, 16, 483-491.
- Peterson, Y. (1979). The impact of physical disability on marital adjustment: A literature review. The Family Coordinator, 1, 47-51.
- Pillard, R. C., & Fisher, S. (1970). Aspects of anxiety in dental clinic patients. Journal of the American Dental Association, 80, 1331-1334.
- Polit, D. F., & Hungler, B. P. (1983). Nursing research. Principles and methods (2nd ed.). Philadelphia: J.B. Lippincott.
- Polivy, J. (1977). Psychological effects of mastectomy on a woman's feminine self-concept. The Journal of Nervous and Mental Disease, 164(2), 77-87.
- Quint, J.Q. (1963). The impact of mastectomy. American Journal of Nursing, 63, 88-92.
- Renneker, R., & Cutler, M. (1952). Psychological problems of adjustment to cancer and the breast. Journal of the American Medical Association, 148, 833-838.
- Rogers, J., & Durkin, M. (1984). The semi-structured genogram interview: I. protocol, II. evaluation. Family Systems Medicine, 2, 176-187.

- Rosser, J. E. (1981). The interpretation of women's experience: A critical appraisal of the literature on breast cancer. Social Science and Medicine, 15, 257-265.
- Scanlon, E. F. (1984). The case for and against two-step procedure for the surgical treatment of breast cancer. Cancer (supplement), 53, 677-680.
- Schaefer, M. T., & Olson, D. H. (1981). Assessing intimacy: The Pair inventory. Journal of Marital and Family Therapy, 7, 47-60.
- Schain, W. (1976). Psychological impact of the diagnosis of breast cancer on the patient. Frontiers of Radiation Therapy and Oncology, 11, 68-89.
- Schain, W. (1985). Breast cancer surgeries and psychosexual sequelae: Implications for remediation. Seminars in Oncology Nursing, 1, 200-205.
- Schain, W. S., Wellisch, D. K., Pasnau, R. O., & Landsverk, J. (1985). The sooner the better: A study of psychological factors in women undergoing immediate versus delayed breast reconstruction. American Journal of Psychiatry, 142, 40-46.
- Schmale, A. H. (1980). Clinical trials in psychosocial medicine: Methodologic and statistical considerations. Part 1. Introduction. Cancer Treatment Reports, 64, 441-443.
- Scott, D. W. (1983a). Anxiety, critical thinking and information processing during and after breast biopsy. Nursing Research, 32, 24-28.
- Scott, D. W. (1983b). Individual response to breast cancer. Topics in Clinical Nursing, 4(4), 20-37.
- Siegel, K. (1983). Research issues in psychosocial oncology. Journal of Psychosocial Oncology, 1(1), 101-104.
- Silberfarb, P. M., Maurer, L. H., & Crouthamel, C. S. (1980). Psychosocial aspects of neoplastic disease: I. Functional status of breast cancer patients during different treatment regimens. American Journal of Psychiatry, 137, 450-455.
- Silberfarb, P. M., Philibert, D., & Levine, P. M. (1980). Psychosocial aspects of neoplastic disease. II. Affective and cognitive effects of chemotherapy in cancer patients. American Journal of Psychiatry, 137, 597-601.
- Silverberg, E. (1985). Cancer Statistics, 1985. CA - A Cancer Journal for Clinicians, 35(1), 19-35.
- Spinetta, J. J. (1984). Development of psychometric assessment methods



- by life cycle stages. Cancer (supplement) 53, 2222-2225.
- Statistics Canada (1981). Cancer in Canada (Cat. 82-207). Ottawa.
- Steinberg, M. D., Juliano, M. A., Wise, L. (1985). Psychological outcome of lumpectomy versus mastectomy in the treatment of breast cancer. American Journal of Psychiatry, 142, 34-39.
- Sullivan, H. S. (1953). The interpersonal theory of psychiatry. New York: Norton.
- Taylor, S. E., Lichtman, R. R., Wood, J. V., Bluming, A. Z., Dosik, G. M., & Leibowitz, R. L. (1985). Illness-related and treatment-related factors in psychological adjustment to breast cancer. Cancer, 55, 2506-2513.
- Thomas, S. G. (1978). Breast cancer: The psychosocial issues. Cancer Nursing, 1, 53-60.
- Townsend, C. M., Jr. (1980). Breast lumps. Clinical Symposia, 32(2), 3-32.
- Vachon, M. L. S., Lyall, W. A. L., Rogers, J., Cochrane, J., & Freeman, S. J. J. (1981-1982). The effectiveness of psychosocial support during post-surgical treatment of breast cancer. International Journal of Psychiatry in Medicine, 11, 365-371.
- von Bertalanffy, L. (1950). An outline of general systems theory. British Journal of the Philosophy of Science, 1, 134-165.
- Ware, J. E. (1984). Conceptualizing disease, impact and treatment outcomes. Cancer (supplement), 53, 2316-2323.
- Waring, E. M., McElrath, D., Mitchell, P., & Derry, M. E. (1981). Intimacy and emotional illness in the general population. Canadian Journal of Psychiatry, 36, 167-172.
- Waring, E. M., & Patton, D. (1984). Marital intimacy and depression. British Journal of Psychiatry, 145, 641-644.
- Waring, E. M., Reddon, J. R., Corvinelli, M., Chalmers, W. S., & Vander Laan, R. (1983). Marital intimacy and mood states in a normal sample. Journal of Psychology, 115, 263-273.
- Watson, M., Greer, S., Blake, S., & Shrapnell, K. (1984). Reaction to a diagnosis of breast cancer. Relationship between denial, delay and rate of psychological morbidity. Cancer, 53, 2008-2012.
- Welch, D. A. (1981). Waiting, worry and the cancer experience. Oncology Nursing Forum, 8(2), 14-18.
- Wellisch, D. K. (1981). Family relationships of the mastectomy pa-

- tient: Interactions with the spouse and children. Israeli Journal of Medical Science, 17, 993-996.
- Wellisch, D. K. (1984). Work, social, recreation, family, and physical status. Cancer (supplement) 53, 2316-2323.
- Wellisch, D. K. (1985). The psychologic impact of breast cancer on relationships. Seminars in Oncology Nursing, 1, 195-199.
- Wellisch, D. K., Jamison, J. R., & Pasnau, R. O. (1978). Psychological aspects of mastectomy: II. The man's perspective. American Journal of Psychiatry, 135, 543-546.
- Wood, Y. R. (1984). Social support and social networks: Nature and measurement. In P. McReynolds & G. J. Chelune (Eds.), Advances in Psychological Assessment Volume 6 (pp. 312-353). San Francisco: Jossey-Bass.
- Woods, N. F., & Earp, J. L. (1978). Women with cured breast cancer. Nursing Research, 27, 279-285.
- Worden, J. W., & Weisman, A. D. (1975). Psychosocial components of lagtime in cancer diagnosis. Journal of Psychosomatic Research, 19, 69-79.
- Worden, J. W., & Weisman, A. D. (1977). The fallacy in post mastectomy depression. American Journal of Medical Science, 273, 169-175.
- Wortman, C. B. (1984). Social support and the cancer patient. Conceptual and methodologic issues. Cancer (supplement), 53, 2339-2360.
- Wortman, C. B., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer: A theoretical analysis. Journal of Social Issues, 35, 120-155.
- Wright, L. M., & Bell, J. M. (1981). Nurses, families and illness: A new combination. In D. Freeman & B. Trute (Eds.), Treating families with special needs (pp. 199-205). Ottawa: The Canadian Association of Social Workers.
- Wright, L. M., & Leahey, M. (1984). Nurses and families. A guide to family assessment and intervention. Philadelphia: F.A. Davis.

## APPENDICES

## APPENDIX A

PATIENT INFORMATION SHEET

PATIENT INFORMATION SHEET

WHEN YOU ARE FACED WITH THE THREAT OF BREAST CANCER, WHAT IMPACT DOES THIS HAVE ON YOU? WHAT EFFECT DOES THIS HAVE ON YOUR SPOUSE, OTHER FAMILY MEMBERS AND FRIENDS?

These are research questions being asked by a nurse researcher at the University of Calgary. Your surgeon has been asked to provide this information sheet to women who, like yourself, will be scheduled for a breast biopsy. The idea that you require a breast biopsy may have a variety of thoughts and feelings attached to it. It is not the intent of this research to create an inconvenience for you at this time. Rather, it is hoped that you may see this as an opportunity to share in the development of further knowledge about how families are affected by illness.

The purpose of this study is to learn more about your experience with the threat of illness over a period of time. It involves asking you and your spouse to answer a set of interview questions and a written questionnaire. This would be scheduled at a time that is convenient to you and your spouse.

At this time you are being asked for your permission to allow the surgeon to release your name to me (the nurse who will be conducting this research). There are several options available to you:

- A. You may decide now that you would like the surgeon to forward your name to me. If so, please write your name, address, and phone number on the attached sheet and leave it with your surgeon. I will then contact you sometime within the next day or so to further explain the study and will set up an appointment to get together with you and your spouse. Please understand that you are only giving permission to have the surgeon give me your name.
- B. You may want some time to think about this request. Perhaps you'd like to discuss it with your spouse, your family physician, your surgeon, or others before making a decision. If so, you can tell your surgeon of your decision at a later date. You may also wish to contact me directly for more information.
- C. You may decide now that you do not wish the surgeon to give your name to me. If so, please indicate this to your surgeon. Please be assured that your decision will not result in any detriment or prejudice towards you.

Thank you for your consideration.

A P P E N D I X     B

C O N S E N T     F O R M

CONSENT FORM

This research project, "Impact of The Threat of Breast Cancer" is being conducted by a nurse researcher at the University of Calgary. Its purpose is to learn more about your experience with the threat of illness over a period of time. Specifically, this study is designed to learn about the impact of this experience on you and your family. It involves answering a set of interview questions and a written questionnaire that asks about your present thoughts and feelings and those of your spouse. If you desire, you can discuss any other concerns you may have following the questionnaire.

IN AGREEING TO PARTICIPATE IN THIS STUDY, I UNDERSTAND THAT:

- over the course of the next six months, I may be asked to participate in a similar interview at three different times. These times will be scheduled at a mutually convenient time with me and my spouse. My participation will involve approximately two hours to answer interview questions and a written questionnaire.
- I have the right to refuse to answer any of the questions.
- information collected from me will be kept confidential.
- information about the study will not use my name, therefore my participation in the study will be anonymous.
- I have the right to drop out of this study at any time and this will not result in any detriment or prejudice toward me or my spouse.
- the nurse researcher has the corresponding right to terminate my involvement in this study at any time.
- if I would like further clarification and/or counselling during my involvement in this study, prearranged services are available.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signed

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If you would like a summary of the results when they become available, please check the box below and print your name and address in the space provided.

☐ Yes, I would like a summary of the results.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
Postal Code

## APPENDIX C

CERTIFICATION OF INSTITUTIONAL  
ETHICS REVIEW



EDUCATION JOINT COMMITTEE ON RESEARCH ETHICS

CERTIFICATION OF INSTITUTIONAL  
ETHICS REVIEW

This is to certify that the Education Joint Committee  
on Research Ethics at The University of Calgary has  
examined and approved the research proposal

by: (Applicant) Tanice M. Bell

of the Department of: Educational Psychology

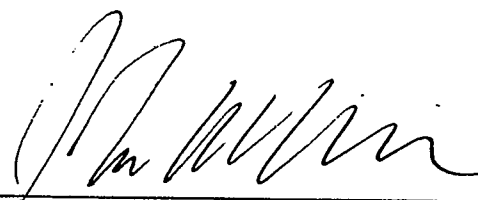
to: (Agency) \_\_\_\_\_

entitled: "Impact of Breast Cancer  
on the Mental Subsystem"

(the above information to be completed by the applicant)

Date

Sep 12/83

  
Chair, Education Research  
Ethics Committee