

A Comparison of Social Support Between
Lumpectomy Patients and Mastectomy Patients

By

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CHAPTER I

INTRODUCTION

Few words in the English language carry the emotional power associated with the word cancer. It is a disease that, to some, raises insurmountable fears and images of a slow, tortured death (Sontag, 1979). The fears associated with cancer create barriers to communication, which, in turn, diminish appropriate social support (Peters-Golden, 1982). Descriptors such as the "wall of silence" (Morris, Greer, & White, 1977) and "conversational isolation" (Woods & Earp, 1978) reflect the social response experienced by many breast cancer patients.

An estimated one out of every eleven women in the U.S. will develop breast cancer during her life (American Cancer Society, 1985). Virtually every woman diagnosed with breast cancer will undergo some type of surgical intervention, either simple, modified, or radical mastectomy or lumpectomy (Meyerowitz, 1983). Women not only deal with the fears and stigma associated with cancer (Peters-Golden, 1982), but also with the loss of a body part and the potential loss of health (Woods & Earp, 1978). In addition, the feeling of unacceptability to their families, friends, and work associates may create a sense of social loss in these women (Bard & Sutherland, 1955; Quint, 1963).

The psychosocial impact of the cancer diagnosis and the treatment of mastectomy is well documented. Peters-Golden (1982) pointed out that mastectomized women frequently lose some social

support due to the stigma attached to the cancer diagnosis. The lack of an opportunity for any type of confiding, supportive relationship increases women's risk of psychosocial distress (Morris, et al., 1978). Cancer patients in general develop compromising social strategies in an attempt to break through the communication barriers and gain some validation and support (Wortman & Dunkel-Schetter, 1979).

Women diagnosed with breast cancer have been treated with lumpectomies since the 1920's (Bluming, 1981), yet, the literature to date does not adequately address their social support needs or losses as distinct from mastectomized women. Although it seems logical that lumpectomy patients experience the same fears and stigma associated with cancer as the mastectomy group, the cancer support societies may not recognize this population as a vulnerable group. In one metropolitan area, women treated with lumpectomies are not eligible to receive a supportive visit from a volunteer due to the limited extent of the surgery (American Cancer Society, Rehabilitation Volunteer Visitor Program Guidelines, 1983). In a pilot study conducted by this investigator, a breast cancer patient described her feelings, "You have to have a breast removed before you get any support."

It appears lumpectomy patients may be a relatively neglected cancer population. In the absence of breast removal, women are not expected to need as much support as mastectomized women, therefore, they have not become a targeted group for psychosocial

intervention. However, given the documentation of distress due to the stigma of cancer alone, the lumpectomy group, like the mastectomy group, most likely experiences an increased need for social support.

Findings from social support research indicate that social support is an important factor in buffering stress and decreasing the risk of illness (Broadhead, et al., 1983; Cobb, 1976). Literature reflecting the relationship of social support to psychosocial adaptation among cancer patients, and breast cancer patients in particular, indicates the social support is an important factor in adjustment during various times of distress (Jamison, Wellisch & Pasnau, 1978; Morris et al., 1977; Weisman & Worden, 1976; Woods & Earp, 1978). Supportive relationships have been characterized by a willingness and openness to discuss cancer and cancer related topics (Meyerowitz, 1983) as well as providing information (Funch & Mettlin, 1982; Lierman, 1982) and emotional support (Funch & Mettlin, 1982).

The general consensus of literature favors the buffering hypothesis of social support. However, research is criticized for assuming that social support is unidirectional and always beneficial. Cobb (1976) maintained that social support moves in both directions; that is, a person belongs to "a network of mutual obligations." Therefore, supportive relationships must be examined in the context of a two-way process.

In a recent study of the stress buffering effects of social

support, Revenson, Wollman and Felton (1983) attended to the fact that interpersonal relationships may act as a source of stress as well as a source of support. Social support became more of a stress both for those cancer patients who were unable to reciprocate naturally supportive behaviors (warmth, understanding, tangible aid, or simply spending an enjoyable time with someone) and for those whose interactions with healthy individuals were mixed and negative. Thus, cost, conflict and reciprocity of social support appear to be important facets of social support to consider when examining the buffering effect of social support on patients' adjustment to a major illness such as cancer.

Purpose

The purpose of this study was to examine the differences between lumpectomy and mastectomy patients' perceptions of social support. The cost, conflict, and reciprocity of each groups' supportive relationships were also examined.

Nursing Rationale

The increasing incidence of breast cancer suggests a concurrent increase in the need for social support. The concept of social support corresponds with the nature of nursing practice (Norbeck, 1981, 1982). Historically, nurses have had a holistic approach to patient care, focusing on an assessment of the person-environment fit for the purpose of promoting and maintaining positive mental health. Nurses may be an integral part of breast cancer patients' formal support network

(i.e. doctors, ministers, counselors, etc.). Further, when the cancer diagnosis disrupts important informal supportive relationships (i.e. family, friends, work associates, etc.) nurses may facilitate adaptation through interventions aimed at strengthening the informal support system.

The impetus for this study came from a pilot study during which a number of lumpectomy patients expressed their perceived lack of social support. Mastectomy patients have been identified throughout the literature as a vulnerable group that experiences significant distress due to the traumatic impact of breast cancer and its subsequent treatment. Lumpectomy patients, on the other hand, have gone unnoticed by cancer support societies. Lumpectomy patients in one major metropolitan area were not eligible to receive a supportive visit from a cancer rehabilitation program volunteer due to the limited extent of the surgery. In addition, this investigator found in the pilot study that the conflicting opinions of physicians concerning the effectiveness of lumpectomy as a treatment choice led to an increase in lumpectomy patients' fears of recurrence and need for social support. The lumpectomy patient is a cancer patient who suffers from the stigmatizing impact of cancer, but may receive no extra support beyond that of minor surgery. It is possible that the lumpectomy patient does not receive the support necessary to deal with the diagnosis and treatment of cancer. Thus, the type of surgical treatment of the breast cancer may have an effect upon the social support available

to this population. The purpose of this study was to explore any differences in the perceived social support of both lumpectomy and mastectomy patients.

CHAPTER II

REVIEW OF LITERATURE

The scope of the problem under study requires an understanding of the literature in four areas: (a) social support and health, (b) social network characteristics, (c) psychosocial impact of breast cancer, and (d) the relationship between social support and the impact of breast cancer.

Social Support and Health

Social Support is a multidimensional construct that has been claimed to serve several different functions. Health related social support research has examined various dimensions of social support including cohesion and expressiveness of family environment, sensitivity, physical availability, and presence of a confidant (Dimond, 1979); network structure (Wilcox, 1982); emotional support, informational support, and tangible support (Tilden, 1983), to cite only a small number of studies. Review of social support research by Broadhead, et al. (1983) indicated that the dimensions studied included a wide range from "littermates in animal studies (to) social disorganization, rapid social change, acculturation, . . . children having been wanted, family competence, and emotionally supportive intervention by clinicians" (p. 531). Selected studies related to health outcomes will be reviewed here.

Thirty-six hemodialysis patients participated in a study conducted by Dimond (1979) that examined the relationship between

social support factors, medical status and adaptation to a long-term illness. Three dimensions of social support were included in this study: family environment (as measured by two subscales of the Family Environment Scale, family cohesion and family expressiveness); level of spouse support (as measured by nurses' observations of spouses' encouragement, sensitivity, availability, and involvement in the patient's care); and presence of a confidant (as measured by one item). Medical status was measured by the number of medical complications that were related to chronic renal failure (i.e., low hematocrit, infections, fluid overload). Adaptation was measured through scores on the Behavior Morale Scale and through scores on the Sickness Impact Profile (SIP). The three subscales of SIP revealed data on the subjects' changes in social functioning since the onset of dialysis. Findings suggested that family cohesion (helpfulness and supportive behavior of the family) was the primary source of support which related to higher morale and fewer changes in social functioning since the onset of dialysis. Those patients with significantly better morale reported that their families were supportive of their free expressions of feelings about dialysis. This held true even when the number of medical complications was controlled. There was a positive relationship between spouse support and adaptation to dialysis as well, but the presence of a confidant was only positively related to social adaptation until the number of medical problems increased.

Tilden (1983) sampled 141 healthy adult women in the second

trimester of pregnancy and examined the effects of negative life stress (as measured by the Sarason Life Experiences Survey) and social support (as measured by the Social Support Questionnaire) on emotional disequilibrium during normal pregnancy. Emotional disequilibrium was a factor analyzed construct determined by the women's reported state and trait anxiety (as measured by the Spielberger State-Trait Anxiety Inventory), depression (as measured by the Lubin Depression Adjective Checklist), and self-esteem (as measured by the Rosenberg Self-Esteem Scale). Subfacets of social support included emotional support, informational support, and tangible support. Emotional disequilibrium was found to be separately effected by both life stress and social support. When the women's marital and partner status was statistically controlled, the separate effects of life stress and social support were still significant. Life stress was responsible for 29.7% of the variance in emotional disequilibrium while social support accounted for 3.11%. While Tilden (1983) stated that the findings of this study should be accepted cautiously due to the cross-sectional design and the newly developed social support tool, the study provides some evidence that social support may have a significant (although small) positive effect on emotional disequilibrium in pregnancy. Life stress accounted for a large part of the variance in emotional state.

Most studies to date have indicated that social support is positively related to physical and psychological well-being;

however, some major weaknesses should be noted. Thoits (1982) pointed out three major problems in social support research. First, social support is not adequately conceptualized or operationalized. Second, studies have failed to determine the direction and nature of the relationship between life events and social support. Finally, research on the direct effects of social support on distress is scant in comparison to the number of studies that focus on the buffering effect of social support on distress. Despite these weaknesses a large body of social support research indicates that social support has a buffering effect on distress and is positively related to physical and psychological well-being.

Social Support Network Characteristics

Social network is the structural component of social support. Social network and corresponding ties make up the web of social relationships that surround an individual (Mitchell, 1982). Several studies have related network characteristics to particular health outcomes. Berkman and Syme's (1979) examination of social networks, host resistance, and mortality found that people who lacked social ties had higher mortality rates than those with extensive social ties. This was still true when physical health, number of cigarettes smoked daily, and other medical problems were controlled. Cohen and Sokolovsky (1978) found that recidivism increased in schizophrenics whose networks were small, low in multiplexity, and lacking in reciprocal relationships. Gallo (1982) examined the relationship between social networks and health

of the elderly. The characteristic of social networks found to have the greatest positive effect on the elderly's health status was reciprocity.

The relationship between network properties and women's psychosocial adjustment to separation and divorce was examined by Wilcox (1982). Fifty single women, an average of 18 months post-separation and divorce, were asked in semi-structured interviews to report information on their support network 6 months prior to the initial separation and at the time of the interview. In addition, subjects completed the Profile of Mood State (POMS), and the Langners 22-item Symptom Checklist. Women were assigned to either the "successfully adjusted" (SA) group or the "unsuccessfully adjusted" (UA) group based on their POMS score and other ratings of their adjustment made by the interviewers. Brief interviews were also conducted with the former spouses to collect data on the overlap (boundary density) between husband-wife network. Findings suggested that neither range (number of network members) nor density (how many network members know each other) of the groups' networks differed prior to divorce. However, at the time of the interview the mean network range for the "unsuccessfully adjusted" group was 11.1 compared to 14.9 for the "successfully adjusted" group ($p < .01$). In addition, significant differences were found between the groups' overlap in network members. The UA group had more overlap (36%) in husband-wife network than did the SA group (17.4%). Hence, receiving support from separate sources may be

associated with less distress. The author suggested that these findings may be related to the UA group's report that prior to divorce many of their friends had been spouses of their husband's work associates. This study required that women retrospectively report network characteristics of their social support; and thus, a limitation is that the subjects' initial perceptions may have changed with time.

Pattison, DeFrancisco, Wood, Fraxier, & Crowder (1975) attempted to map out the psychosocial systems of families. Pilot study data drawn from a normative urban population of 200 subjects and small samples of neurotic and psychotic subjects were reported. Based on Adams' (1967) theory of interaction and social network, the Pattison Psychosocial Kinship Inventory was developed and examined the following variables: (a) amount of contact, (b) degree of emotional intensity, (c) positive emotion, (d) instrumental aid, and (e) degree of reciprocity. The questionnaire asked the subjects to list his or her important people, under the categories of family, relatives, friends, co-workers, and social organizations, and to rate them on the above five variables.

Data suggested that the healthy person has 20 to 30 people in his or her intimate psychosocial network. An average of five to six people comprised each subgroup and the relationships were rated positively on all five interpersonal variables. About one half to two thirds of the subject's network members knew each other. Members of the nuclear family were rated as the most highly valued

member of the network and most often sought for affective and instrumental assistance. Friends were rated as the second most important network members. Significant relationships were found in multiple categories. In contrast, patterns among neurotic persons indicated that they have 10 to 12 people in their social network, which often included people who were dead or lived far away. Ratings on interpersonal variables were lower than for normals. Also, the neurotic population tended to have several negative relationships that were maintained because the women felt obligated, such as a relationship with a boss. These findings suggest the neurotic individual has an impoverished social network lacking in connectedness. Pattison et al. found that the psychotic population's social network consisted of only four to five people, usually family. Ratings on interpersonal variables were consistently ambivalent and non-reciprocal. Patterns among psychotic persons suggested they live in an exclusive, small social matrix. Thus, individuals with few sources of support and relationships lacking reciprocity and connectedness may be at greater risk for mental health problems. Alternately, mental health problems may precede low reciprocity and connectedness within social networks.

Psychosocial Impact of Breast Cancer

The literature related to the psychosocial impact of breast cancer can be divided into three areas: (a) women's reactions to cancer in general, (b) women's reactions to breast cancer, and (c)

psychological studies of lumpectomy versus mastectomy patients. These will be discussed separately.

Women's Reactions to Cancer in General

Based on findings of past research, as well as clinical experience, Wortman and Dunkel-Schetter (1979) developed a detailed theoretical analysis of cancer patients' interpersonal relationships. These authors indicated that cancer patients experience an intense need to gain feedback and understanding related to their responses to the cancer diagnosis and may try several strategies in an attempt to break through the communication barriers in order to gain some personal validation and support. Patients may either focus on their feelings toward illness concerns and treatment or they may pretend that they are coping well. Both are attempts to enhance the support they do receive. Neither of these strategies results in the understanding and feedback that the cancer patient needs. In an earlier study, Quint (1963) had found similar results. Quint (1963) followed 21 mastectomized women for 1 year following surgery. Clinical data, collected through interviews, indicated that after the initial crisis of diagnosis and treatment most of the 21 women were left alone to deal with the impact of breast cancer and its treatment; family and friends were preoccupied with their own responses to the illness. For most of these women, who had healed physically, fears of recurrence and death remained the primary concerns up to 1 year after treatment.

In a longitudinal study using the concept of "existential

plight," defined as the first 100 days after diagnosis and start of treatment, Weisman and Worden (1976) examined cancer patients' reactions to cancer, resolution of problems, vulnerability, total mood disturbance and predominant concerns. Data were collected through semi-structured interviews and questionnaires. The Minnesota Multiphasic Personality Inventory and a Thematic Apperception Test were used to collect data on subjects' psychological functioning. Rating scales to measure subjects' general coping strategies, resolution of problems, predominant concerns, and vulnerability were developed by the investigators. This study, which included a convenience sample of 120 newly diagnosed cancer patients (breast, colon, lung, Hodgkin's Disease, and malignant melanoma), controlled for the type of cancer, but not for the type of breast cancer treatment. Fear of death was found to be the major concern for cancer patients regardless of type. Moreover, the fear of death contributed most to patients' vulnerability to psychosocial distress (as measured by the Profile of Mood States).

In a non-surgical cancer population ($n = 30$), Galyen (1985) examined the relationship between the presence of a confidant relationship and psychological adjustment to multiple myeloma and lymphatic cancer. The confidant relationship was characterized by intimate mutual disclosure and high frequency of contact. Subjects had been diagnosed with cancer within one year prior to being in the study and half of the sample reported having a confidant. Psychological adjustment was determined by the Spielberger

State-Trait Anxiety Inventory and the Lubin Depression Adjective Checklist. A fourth instrument (Cost, Conflict, and Reciprocity of Social Support) was used to examine the quality of the confidant relationship.

Findings did not reach statistical significance, however, trends were in the hypothesized direction. Presence of a confidant was associated with lower state anxiety and state depression scores. Female subjects reported higher anxiety scores. Subjects who were married or who had completed more years of education were more likely to have confidants. There was a greater sense of reciprocity in those subjects' relationships with confidants when compared to the most important relationship of subjects without a confidant.

Women's Reactions to Breast Cancer

In a study of breast cancer patients by Worden and Weisman (1977), the reactions of 40 women who were newly diagnosed with breast cancer were compared with 50 women who were diagnosed with other types of cancer. No differences were found between the two groups' reactions to the diagnosis -- 20% of both mastectomized patients and female cancer patients in general were reportedly depressed. The mastectomized women's distress peaked at approximately 8 to 10 weeks after receiving the diagnosis. Their predominant concerns were about death, which took priority over physical symptoms. At 3 months post-diagnosis 80% of the women had adapted well; and yet, approximately 20% continued to show signs of

depression, lowered self-esteem, chronic fatigue, and concern about the future.

Through structured psychiatric interviews, Peck (1972) collected data on 50 patients' emotional responses to cancer and cancer treatment. Most of the sample were breast cancer patients who had been treated with mastectomy and radiation. Forty-one of the 50 patients interviewed were assessed to have moderate to severe anxiety reactions and 37 were noted to have a depressed affect.

Several other studies examining women's reactions to breast cancer showed comparable results. Lee and Maguire (1975) showed similar results through psychological testing of 400 breast cancer patients using the Spielberger State Anxiety and Zung Depression Scales. Patients in this study were tested before attending the breast clinic and at 3 months post-surgery. A control group from a general surgery clinic was utilized. Data indicated that 45% of the breast cancer patients had scores indicative of marked anxiety and depression compared to 18% of the control group. Three months post-operative, 34% of the cancer patients were still reporting moderate to marked degrees of anxiety or depression compared to 7% of the controls. Similarly, Morris et al. (1977) used 160 subjects pre-biopsy as their own controls. Sixty-four of the women who had breast cancer were followed over a period of 2 years. Morris et al. reported that of these 64 women, 59 were treated with simple mastectomy, 4 were treated with a lumpectomy, and 1 received a

needle biopsy only to establish diagnosis. Three months post-surgery, 46% of the 64 women reported psychological distress (as measured by the Hamilton Rating Scale for Depression). However, at 1 year following surgery, 70% of the women were reportedly free of any psychological distress. Two years after surgery further improvement was noted in 45 of the women. However, 29% of the 64 women in this study continued to have psychological difficulty severe enough to require psychiatric intervention.

In a study by Jaimison et al. (1978), 41 women were surveyed through mailed questionnaires at approximately 20 months post-mastectomy. The questionnaire examined various aspects of mastectomy procedure, emotional responses before and after the surgery, perception of the effect of the mastectomy on relationships and spouses, and attitudes toward surgeons and nursing staff. In addition, subjects completed the Locke-Wallace Marital Adjustment Test, the Rotter Internal-External Locus of Control Scale and the Eysenck Personality Inventory. Although 60% of the 41 women surveyed reported an excellent or good emotional adjustment, 24.4% reported suicidal ideations immediately following the mastectomy. In addition, tranquilizers and alcohol use had increased in at least one third of the women in this study.

In summary, anxiety reactions, denial, depression, and different coping strategies are experienced when one is faced with the diagnosis of cancer in general, and breast cancer in particular (Weisman & Worden, 1976). The defenses used are often adaptive

until a threshold of distress is reached (Weisman & Worden, 1976; Woods & Earp, 1978). While most of the studies reviewed (Jaimison, et al., 1978; Lee & Maquire, 1975; Morris, et al., 1977; Weisman & Worden, 1976) indicated that the majority of women diagnosed with breast cancer were coping well, there was a significant 20% that continued to struggle with depression, anxiety, low self-esteem, and concerns about the future.

Psychological Studies of Lumpectomy Versus Mastectomy Patients

Recently, researchers have begun to examine the psychosocial impact of lumpectomy (Margolis, Carabell, & Goodman, 1980) and to compare the psychological outcome of lumpectomy versus mastectomy (Sanger & Reznikoff, 1981; Steinburg, Tuliano & Wise, 1985; and Schain, Edwards, Gorrell, DeMoss, Lippman, Gerber, & Lichter, 1983). Margolis et al. (1980) studied 51 women who chose lumpectomy over mastectomy for treatment of stage I or II breast cancer. The psychological factors associated with the choice of lumpectomy with radiation therapy over mastectomy were explored through in-depth interviews conducted by a psychiatrist, and a psychoanalyst. Subjects ranged in age from 25 to 74 with median age of 49. Subjects were either in radiation treatment or had finished with treatment at the time of their participation in this study. Findings suggested that 96% of the women interviewed chose lumpectomy with primary radiation over mastectomy because they were concerned about feeling deformed, mutilated, and less feminine. Eighty-two percent stated that these body image concerns were more

closely related to how they felt about their bodies rather than how their husbands or male friends felt. Ninety-four percent reported that their breasts were important sexual organs; however, only 41% stated that possible effects on sexuality influenced their treatment of choice. This study did not examine women's psychological reactions to the cancer diagnosis. However, the study is significant because it is the first published research examining lumpectomy patients' reactions to that form of treatment.

In a similar study, Sanger and Reznikoff (1981) compared the psychological functioning of 20 lumpectomy patients whose treatment included primary radiation to 20 modified radical mastectomy patients. The sample was matched within 5 years for age, time post-surgery, and marital status. At the time of participation in this study, subjects' time post-surgery ranged from 2 months to 4 - 1/2 years. Thirty women were married, 2 were widowed, and 1 was divorced. None of the subjects had any other concurrent major illness and all were free of recurrence or distant metastasis at the time of participation. Of the 20 treated with modified radical mastectomy, none were aware of surgical alternatives, and all unquestionably accepted their surgeons' course of treatment. Neither the lumpectomy subjects nor the mastectomy subjects were randomly selected for participation. Subjects either volunteered or were referred into the study by their physicians. The Rorschach test, the Homonyms test, and Body Cathexis Scale were used to measure body image variables: body boundary, body anxiety, and

body satisfaction. The Barrons Ego Strength Scale was given to measure overall psychological adjustment. Finally, the Locke Marital Adjustment Test was used to investigate the differential effects that the two surgical treatments may have had on marital satisfaction. One investigator administered all the instruments during one session. Subjects were asked to rate their body satisfaction (Body Cathexis Scale) both prior to surgery and at the time of testing.

Significant differences were found between the two groups' scores on body boundaries and present body satisfaction. The lumpectomy group reported clearer body boundaries and greater present body satisfaction. The authors suggested that a lower number of body boundary responses by the mastectomized group reflected the increased damage to these subjects' external bodies. No differences were found between the groups' overall psychological functioning, body anxiety, or marital satisfaction. The investigators suggest that no differences were found between the two groups' overall psychological functioning because it was a highly select group of mastectomized women who volunteered to participate (surgeons would not allow the investigator to approach women who were distressed). This study's findings of no differences in the two groups' body anxiety is similar to findings from other studies that fears of recurrence are equally predominant in both women treated with lumpectomy and mastectomy.

Steinburg, et al. (1985) compared the psychological functioning of 46 modified radical mastectomy patients and 21 lumpectomy patients who were treated over a 3 year period between 1977 and 1980. This sample was matched for time post surgery, (mastectomy, 15.8 months; lumpectomy, 14.5 months), stage of disease, (stage I or II), and age, (mastectomy, 31 to 64 years; lumpectomy, 41 to 68 years). Half of the lumpectomy patients had been given a choice of treatment. The author did not know whether the mastectomy patients had been given a choice. Subjects were contacted several weeks after surgery. The Profile of Mood States, Beck Depression Inventory, and a 94 item questionnaire developed by the author, which assessed physical, vocational, social, marital, and sexual functioning, were mailed to the subjects's homes. One investigator picked up the questionnaires in the subjects' home. A structured interview was conducted using the Schedule for Affective Disorders and Schizophrenia-Change, version SADS-C. Subjects were asked to rate their marital and sexual functioning before surgery, 6 months post-operatively, and currently.

There were no differences in the women's retrospective ratings of self-image and importance of the breast before surgery. Subjects in both groups reported, retrospectively, that they felt less feminine and less attractive during the 6 months following surgery. At 14 months post-surgery, lumpectomy patients reported feeling as feminine and attractive as they did before surgery. Mastectomy patients, however, continued to feel less attractive and

feminine. Steinburg, et al. (1985) also reported that Lumpectomy patients were significantly more at ease than mastectomy patients in discussing their sexual feelings post-operatively with friends and doctors. At 14 months there was no difference in the amount of emotional distress (tearfulness, difficulty in working, insomnia, pessimism, and decreased libido) or depression reported by the two groups. In addition, there was no difference between the two groups' report of consciousness about their health, frequency of medical check-ups, or fear of recurrence.

Controlling for bias due to self-selection of treatment, Schain et al. (1983) attempted to clarify the nature and degree of differences in women's psychosocial adaptation to modified radical mastectomy and lumpectomy. Iridium implant was a part of the treatment protocol for lumpectomy patients. Thirty-nine of 65 patients approached agreed to participate. One dropped out. The 38 who completed participation represented the larger population in terms of age, stage of disease, and socio-economic status.

After positive biopsy for breast cancer, subjects were given the pros and cons of the two treatment procedures. All subjects had their axillary nodes removed. Anyone with one or more nodes involved also received adjuvant chemotherapy. Twenty women received a modified radical mastectomy and eighteen received a lumpectomy. All subjects were evaluated and followed by the same group of physicians, nurses, therapists, and psychologists. Both groups received a questionnaire which elicited responses in the

following areas: physical symptoms, psychological symptoms (anger, sadness), reaction to cosmetic outcome, sexual reactions, and psychosocial adjustment. Mastectomized women received their questionnaires 56 to 610 days post-operatively; subjects treated with lumpectomy plus radiation received their questionnaires 74 to 603 days post-operatively. Compared to mastectomized women, lumpectomy patients consistently reported a greater percentage of physical symptoms in the five areas evaluated: 1) soreness in affected breast: lumpectomy, 82%; mastectomy, 50%; 2) limited arm motion: lumpectomy, 69%; mastectomy, 28%; 3) swollen arm: lumpectomy, 53%; mastectomy, 42%; 4) pain: lumpectomy, 75%; mastectomy, 41%; and 5) fatigue: lumpectomy, 82% mastectomy, 58%. However, like other studies cited, the mastectomy group had significantly more negative reactions to their nude bodies (lumpectomy - 22% versus mastectomy - 60%). More mastectomy patients reported sadness; however, both groups reported fairly high degrees of anxiety and depression. Hence, this study supports findings from previous studies that most psychological distress is due to the cancer diagnosis.

Findings regarding lumpectomy patients' experience with that form of treatment suggest that lumpectomy patients feel better about their bodies and feel more feminine than mastectomy patients. However, there is evidence to indicate that women treated with lumpectomy continue to have difficulty in coping with fears of recurrence and also experience significant degrees of anxiety and depression.

The Relationship between Social Support
and the Impact of Breast Cancer

The relationship between psychosocial adjustment to breast cancer and social support is marked by the same difficulties indicated by Thoits (1982) for social support studies as a whole. Most studies relating breast cancer to social support are descriptive or retrospective and correlational in design.

Peters-Golden (1982) examined 100 breast cancer patients' perceptions of attitudes of others toward them, as well as 100 healthy individuals' attitudes and beliefs about cancer in general, and breast cancer in particular. A significant finding was the way in which healthy individuals' fear affected their behavior toward cancer patients. A major discrepancy was found between the well populations' expectation of support for themselves were they to develop cancer (only 15% expected to be avoided by others) and their willingness to support others who have cancer (56% admitted that they would avoid someone with cancer). Moreover, in contrast to the well populations' reported expectations and behavior, 72% of the breast cancer patients reported that they were in fact treated differently after people knew of their diagnosis. Caution should be used in generalizing the findings of this study since a retrospective descriptive design was used. However, the study points out the importance of considering cancer stigma when examining the supportive, or non-supportive nature of cancer patients' relationships.

Quint (1963) interviewed 21 mastectomized women over a period of 1 year and gathered clinical data about their experiences, their need for support, and a rationale for why women were often without friends or family with whom to talk. Most of the women in this study were supported by concerned family and friends during the initial diagnosis and treatment, but friends and family soon expected the mastectomy patients to return to normal. In addition, two topics were found to be taboo: death and disfigurement. Findings of this study suggested a loss of support when these women were still dealing with fears of recurrence and death. This loss of social support occurred at a time when women needed emotionally supportive assistance.

These findings are substantiated by Lierman (1982) who examined the effects of a program of professional psychological preparation and supportive care during the hospitalization phase on women diagnosed with breast cancer and treated with mastectomy. One hundred and eight subjects were randomly assigned to the experimental and control groups. The experimental protocol included pre-operative nursing history and needs assessment. The intervention strategy focused on support in the form of information giving about prosthesis, exercises, possible emotional and physical aspects of surgery; exploration of and possible anticipations of post-hospital experiences, and considerations of coping alternatives; sources of support; community resources; and feelings. Lierman (1982) visited subjects twice daily while in the

hospital and sent mailed questionnaires at 1 and 3 months. Findings of this study indicated that supportive care can be effective while in the hospital and in the acute phase of recovery, but that long-term support is needed to assist these women as they move into their roles in the home and community. The results of this study correlate with previous findings that the peak period of distress for breast cancer patients is 2 to 3 months post-surgery (Weisman & Worden, 1976) when the patient is being expected to return to normal (Quint, 1963).

Woods and Earp (1978) used a 4-point scale to measure various dimensions of social support among 49 women 4 years post-mastectomy. Woods and Earp (1978) measured the social support dimensions of helping and listening, and compared the presence and type of social support to the number of physical symptoms. Persistent physical symptoms as a result of surgery included swelling, numbness, stiffness, weakness, trouble moving, pain and poor healing. While there was no association between number of depressive symptoms and level of social support in women with a high number of surgical symptoms, there was a positive association between depressive symptoms and level of social support in women with a low number of surgical symptoms. The authors concluded that the subjects' depressive symptoms were not affected by social support when their number of physical symptoms reached a peak.

Through structured interviews, Funch and Marshall (1983) examined the relationship between negative (objective and

subjective) life stresses, and survival from breast cancer. The roles of age and social support (marital status, number of relatives and friends, and organizational involvement) were also examined. Two hundred and eight breast cancer patients were interviewed during the years 1958-1960. Subjects were asked to report three objective stress events (death, illness, unemployment of someone in the household) and three subjective stress events (number of months in which the respondent felt tired, felt upset, or perceived the family income as inadequate) that may have occurred during the 5 years preceding their cancer diagnosis. Survival was calculated 20 years later. Then, the relationships between stress and survival were examined for three age groups (premenopausal, perimenopausal, and postmenopausal). Subjective stress was related to survival for the youngest group (40 years and younger) while objective stress was related to survival for the oldest group (60 years and older). Neither stress was related to those subjects ages 46-60. Organizational involvement was related to survival ($r = 0.14$, $p < 0.05$) for the younger and older women in particular. Neither marital status nor the number of friends and relatives was related to survival.

Funch and Mettlin (1982) studied the relationship between three forms of social support (social, professional, financial) and recovery from breast surgery. Semi-structured interviews were conducted with a convenience sample of 151 mastectomy patients who had had no evidence of metastasis for the previous 3 to 9 months.

Social support was defined as the degree of perceived support received; professional support paralleled Cobb's (1976) definition that primarily focused on information giving; and financial support was tapped by questions that examined the family's resources and how breast cancer had affected these resources. Physical recovery was measured by two criteria: number of surgical complications or physical problems, and the extent to which the women had returned to normal activities. Psychological adjustment was measured by Bradburn's Psychological Well-Being Scale. Findings indicated that physical recovery was significantly related to financial support while support from family and friends and professional support were significantly related to emotional adjustment.

In contrast, Jaimison et al. (1978), who examined the psychological dimension of 41 mastectomized women through standardized tests and questionnaires, found that medical professionals (physicians and nurses) were perceived to be the least supportive to these women. Yet, similar to Funch and Mettlin, those individuals perceived by the mastectomized women to be most supportive were spouses and friends.

Meyerowitz (1983) examined women's coping strategies and quality of life after being treated with a mastectomy. Meyerowitz (1983) measured the dimensions of social support in terms of physical availability, level of interest in cancer related concerns, over-all supportiveness, and frequency of discussions of cancer topics. Subjects in this study who perceived moderate

support reported the lowest distress while subjects who perceived either high or low support reported highest distress. These findings may point to the question of how mutual is the exchange between cancer patients and their friends and families. While the authors did not interpret these findings in light of social exchange theory, those patients with high distress and high support may be distressed because they may feel guilty for receiving more support than they can return. On the other hand, those who receive very little of what they need may experience anger. Hence, these findings may suggest that those cancer patients who perceived moderate support may have reported that their relationships are characterized by balanced reciprocity.

Both Wortman and Dunkel-Schetter's (1979) theoretical paper and Peters-Golden's (1982) study provide evidence that the well population's interactions with cancer patients in general are marked with conflict between negative feelings about the disease and unrealistic beliefs about the appropriate way cancer patients should be treated. Thus, the findings of Peters-Golden's (1982) study may be interpreted in terms of conflict, cost, and reciprocity. This study suggested that there is a significant discrepancy between healthy individuals' expected social support benefits and the breast cancer patients' actual experience of the loss of social support benefits. While healthy individuals expected to receive social support should they develop cancer, a significant number (56% of 100 interviewed) reported that they

would not give a cancer patient support. Similarly, Wortman and Dunkel-Schetter (1979) suggested that cancer patients' relationships may be different; that is, the cost and conflict of cancer patients' relationships may be higher due to the compromised communication strategies they must use in order to gain feedback about their response to the illness. Thus conflict, cost and reciprocity of supportive relationships may be affected by the cancer diagnosis.

Recently, in a longitudinal study, Revenson et al. (1983) examined the relationship between naturally occurring, supportive relationships (as measured by a questionnaire) and psychological adjustment (as measured by Rosenberg's Self-Esteem Scale and Pearlin & Schooler's Mastery Scale). The impetus for this study grew from the knowledge that interpersonal relationships may act as a source of stress or a source of support. A convenience sample of 32 non-hospitalized adult cancer patients filled out the questionnaire at the time of hospitalization and 7 months later. The sample consisted of lymphoma, leukemia, and multiple myeloma patients. Presence of social support in this study was found to be related to poor adjustment to the illness. Those patients not undergoing chemotherapy or radiation treatment or those experiencing many physical limitations had poorer adjustment: for these patients social support became a threat to their autonomy, self-esteem, mastery, acceptance of death, and acceptance of the patient role. The investigators relate these findings to Wortman

and Dunkel-Schetter's (1979) clinical evidence that cancer patients' social interactions "are often colored with ambivalence, pity and false optimism, or at least perceived by the patient as such; (and) in this way, seemingly positive social interactions may carry negative overtone" (p. 328). Social support became more of a stress, both for those cancer patients who could not return the natural helping behaviors (e.g., warmth, helpful advice, tangible aid, or spend a pleasant time with someone) and for those whose interactions with healthy individuals were mixed and negative. Thus, cost and conflict of social support may be high when healthy individuals' communications to cancer patients are ambivalent and when cancer patients cannot reciprocate the same or similar support.

Hence, breast cancer diagnosis and treatment poses a real threat to women's social support. In addition, the cancer diagnosis may not only negatively affect supportive relationships by increasing the cost and conflict within those relationships, but also by interfering with the relational reciprocity. However, inconsistencies of measurement and other methodological problems of studies make it difficult to interpret with certainty the relationship between social support and the impact of breast cancer.

Summary of the Review

The literature has suggested that: (a) social support may have a buffering effect on major life stress and may increase one's ability to cope; (b) individuals with few sources of support and relationships lacking reciprocity are at greater risk for health

problems and psychosocial distress; (c) cancer diagnosis has a profound impact on psychosocial well-being; (d) breast cancer diagnosis and treatment poses a real threat to women's social support; and (e) conflict, cost, and reciprocity of supportive relationships may be negatively affected by the cancer diagnosis. In addition, it should be noted that few studies in the literature address lumpectomy patients' psychosocial experience of that form of treatment.

Conceptual Framework

This study is based on social exchange theory (Ridley & Avery, 1979; MacDonald, 1981) and Weiss' (1974) model of social support. According to social exchange theory (Ridley & Avery, 1979; MacDonald, 1981), people come together for the purpose of exchanging goods and commodities that may be material, non-material, or both. In this exchange, individuals' efforts are aimed at minimizing losses or punishments and maximizing rewards. Reciprocity refers to the directional flow of the elements exchanged, that is, the give-and-take process of relationships. This exchange is contingent upon each person returning to the other an equally valuable favor. Ideally, the exchange will be equally and mutually rewarding.

This exchange occurs within and between individuals' primary and secondary relationships (Weiss, 1974). Based on relational needs, Weiss (1974) defined six categories of social support that occur in the exchange process: attachment or intimacy, social integration, opportunity for nurturance, reassurance of worth, assistance, and the obtaining of guidance. Thus, individuals' beliefs, attitudes, and understandings are developed and maintained through the give-and-take process of primary and secondary relationships. Through this primary group of family and close friends, needs for warmth, closeness, and emotional support are met. Hence, primary relationships are necessary for psychosocial well-being. The exchange of support between an individual and secondary relationships may be less emotionally laden, focusing

on instrumental support.

The cancer diagnosis is stigmatizing and may interrupt the flow of exchanges between cancer patients and their primary relationships. Often family and friends have difficulty discussing cancer-related concerns of death, pain, or mutilation. Hence, the conflict and cost of social exchange for these women may increase. An imbalance in the flow of exchange may result in the cancer patient expending extra effort to receive support, resulting in feelings of anger. In those relationships where the cancer patient may receive more support than she can give, feelings of guilt may result. Thus, interference in the exchange of social support when emotional distress is high may lead to a sense of anomie and to feelings of despair.

For the breast cancer patient, the psychological impact of the disease as well as the treatment may affect the flow of exchange with important others. Therefore, social support needs to be viewed in the larger context of social exchange theory which points to the importance of reciprocity in relationships when evaluating the potential benefits or limitations of support.

Research Questions

The following research questions were examined in this study:

1. Are there differences between post-surgery lumpectomy and modified radical mastectomy patients' social support network characteristics?
2. Are there differences between post-surgery lumpectomy and

modified radical mastectomy patients' perceptions of social support?

3. Are there differences between post-surgery lumpectomy and modified radical mastectomy patients' perceptions of conflict within the social support network?
4. Are there differences between post-surgery lumpectomy and modified radical mastectomy patients' perceptions of cost of social support?
5. Are there differences between post-surgery lumpectomy and modified radical mastectomy patients' perceptions of reciprocity of social support?
6. Are there differences between post-surgery lumpectomy and modified radical mastectomy patients' perceptions of equity of social support?

CHAPTER III

METHODS

This chapter describes study methods and includes a rationale for the design of the study, criteria for selection of the sample, definitions, data collection methods and procedures used. Last, instruments used for data collection and means to protect the subjects are discussed.

Design

This was an ex post facto correlational field study. The purpose of this study was to provide additional information on the relationship between social support and two surgical treatments for breast cancer (lumpectomy and mastectomy). A pilot study was done in preparation for the main study.

The sample was divided into two groups: those treated with lumpectomy and those treated with mastectomy. Pilot study data obtained through semi-structured interviews and main study data resulting from social support measures were examined to determine if relationships existed between type of surgical treatment (independent variable) on women's social support (dependent variable) can only be inferred in a study of this design. That is, the findings cannot be interpreted in a cause-and-effect manner because the independent variable was not manipulated and the sample was not randomized.

Sample

A convenience sample of 15 women for the pilot study was drawn

from women in treatment for breast cancer at a private, non-profit hospital. Potential subjects were contacted as inpatients undergoing surgery or receiving adjuvant chemotherapy, or as outpatients receiving radiation therapy or attending follow-up appointments with the radiation oncologist. The criterion for selection into the pilot study was the surgical treatment of either lumpectomy or mastectomy for breast cancer.

A convenience sample of 19 women for the main study was drawn from women in treatment at five private hospitals. Four of the five hospitals required the treating physicians' permission before contacting potential subjects. Hence, due to physicians withholding permission, some eligible subjects were not contacted at four of the five hospitals participating in this study.

Before contacting potential subjects each subject's medical record was reviewed to determine eligibility for the study.

Criteria for admission to the study were as follows:

1. a diagnosis of breast cancer;
2. no previous personal history of cancer;
3. no axillary nodal involvement or distant metastasis;
4. no adjuvant chemotherapy;
5. no other concurrent major illnesses;
6. no other member of household simultaneously in cancer treatment.

Women who had a previous personal history of cancer were excluded to avoid differences in the two groups' reported social

support that may have differentially affected womens' social support through increased physical symptoms (i.e. fatigue, pain, alopecia, nausea, and vomiting). The last two criteria (no other concurrent major illnesses and no other member of the household simultaneously in cancer treatment) were controlled to reduce the possibility of the two groups' social support being affected by those variables rather than the subjects' cancer diagnosis and treatment.

Definitions

Key terms used in this study were:

Conflict: The perception of contention or discord within support relationships (Tilden, 1984, p. 5).

Cost: The actual commodities spent in a relationship (i.e. time, effort, thought, services, material things; Tilden, 1984, p. 5).

Reciprocity: The give and take process, "the reciprocated exchange of support between persons" (Tilden, 1984, p. 5).

Equity: The balance of giving and receiving in a relationship, the overall relational equity (Tilden, 1984, p. 6).

Lumpectomy: The surgical removal of the tumor mass and small amount of surrounding tissue. In addition, a small amount of the axillary lymph nodes may be dissected to determine stage of disease (Breast Cancer Digest, 1979, p. 28).

Mastectomy: Simple mastectomy refers to the procedure where only the breast is surgically removed, leaving the axillary nodes

and muscles intact. Modified radical mastectomy refers to the surgical removal of the breast, some fat, and most of the axillary lymph nodes, but the chest muscles are left intact (Breast Cancer Digest, 1979, p. 28).

Procedures

Procedures for contacting potential subjects in the pilot study are summarized in Figure 1. Potential subjects were identified by key informants at one private hospital. After the investigator was notified, subjects' medical records were reviewed by the investigator to confirm a breast cancer diagnosis. Subjects were not excluded from the pilot study who had other major medical problems or whose cancer had progressed to distant sites. Subjects were informed that the purpose of the interview was to explore the social support needs of breast cancer patients as well as to increase nurses' understanding of the breast cancer experience. All subjects in the pilot study were interviewed alone by the investigator in their hospital rooms, or in one of the medical examining rooms in the radiation oncology department. The semi-structured interview schedule was made up of five questions (Appendix A). Two questions, derived from the American Cancer Society's Questionnaire for breast cancer volunteers, were used in addition to three other social support questions. One oncology clinical nurse specialist and two psychiatric, mental health clinical nurse specialists reviewed the questions for content validity.

Subjects were given every opportunity to decline participation. Interviews lasted 30 to 60 minutes.

Procedures for contacting subjects in the main study at four of the hospitals are summarized in Figure 2. Procedures for approaching subjects at one private hospital varied slightly and are summarized in Figure 3. At the first four hospitals, potential subjects were identified by key informants. After notification, the investigator reviewed medical records to determine eligibility

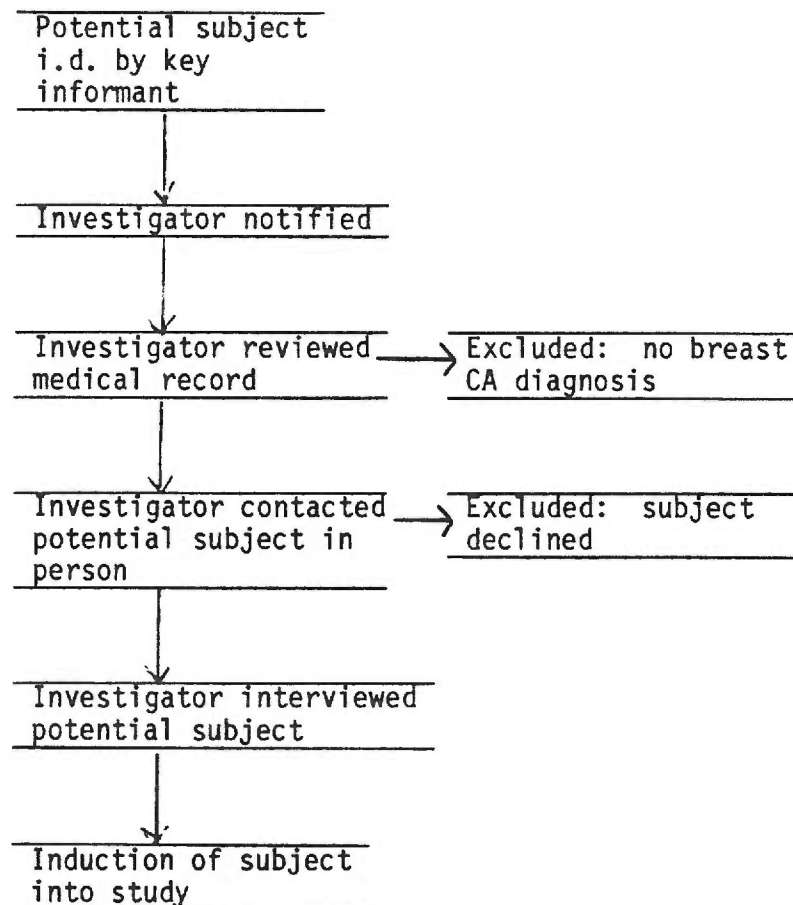


Figure 1 Procedure followed to select subjects into pilot study at one private hospital.

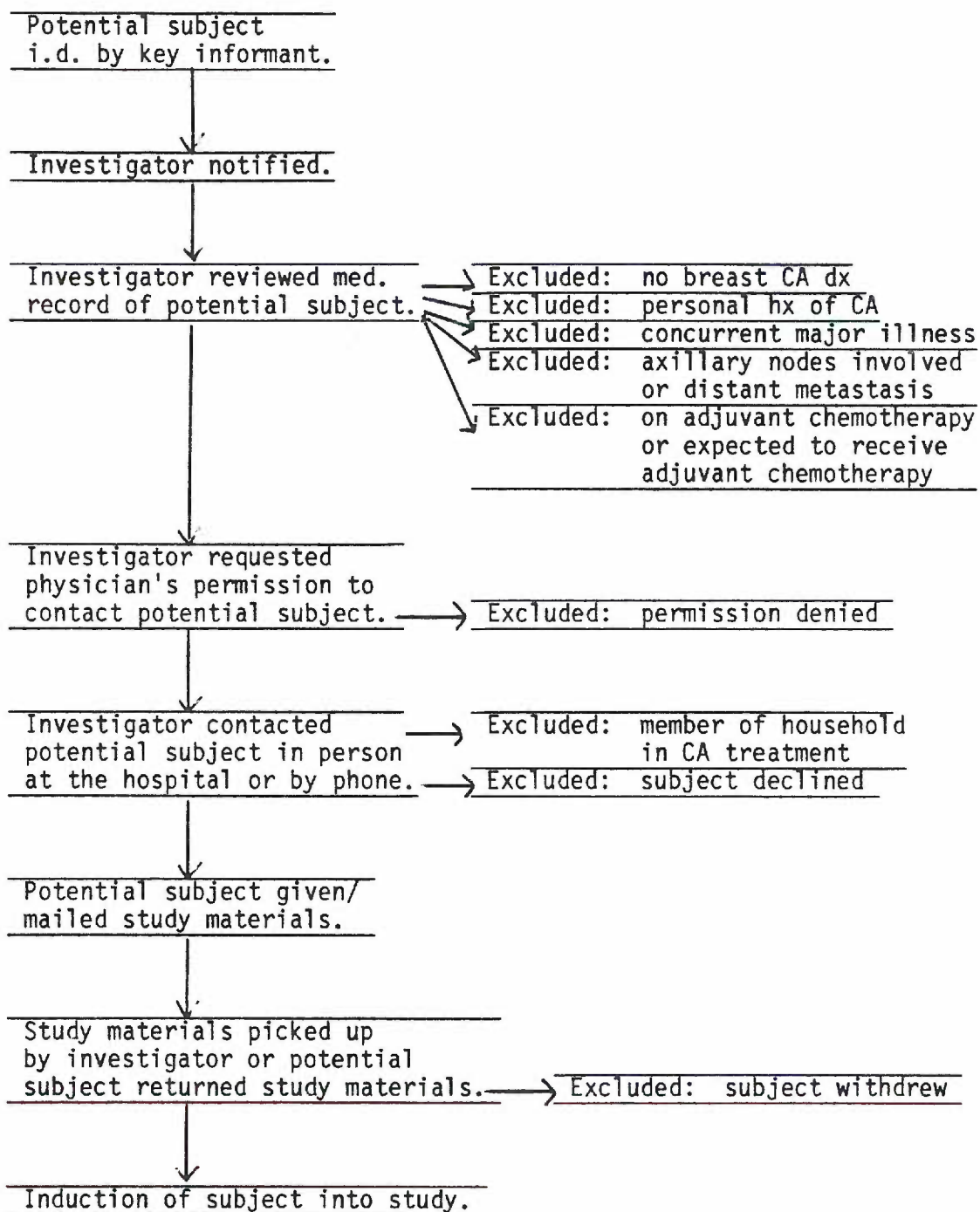


Figure 2 Procedure followed to select subjects into main study at four private hospitals.

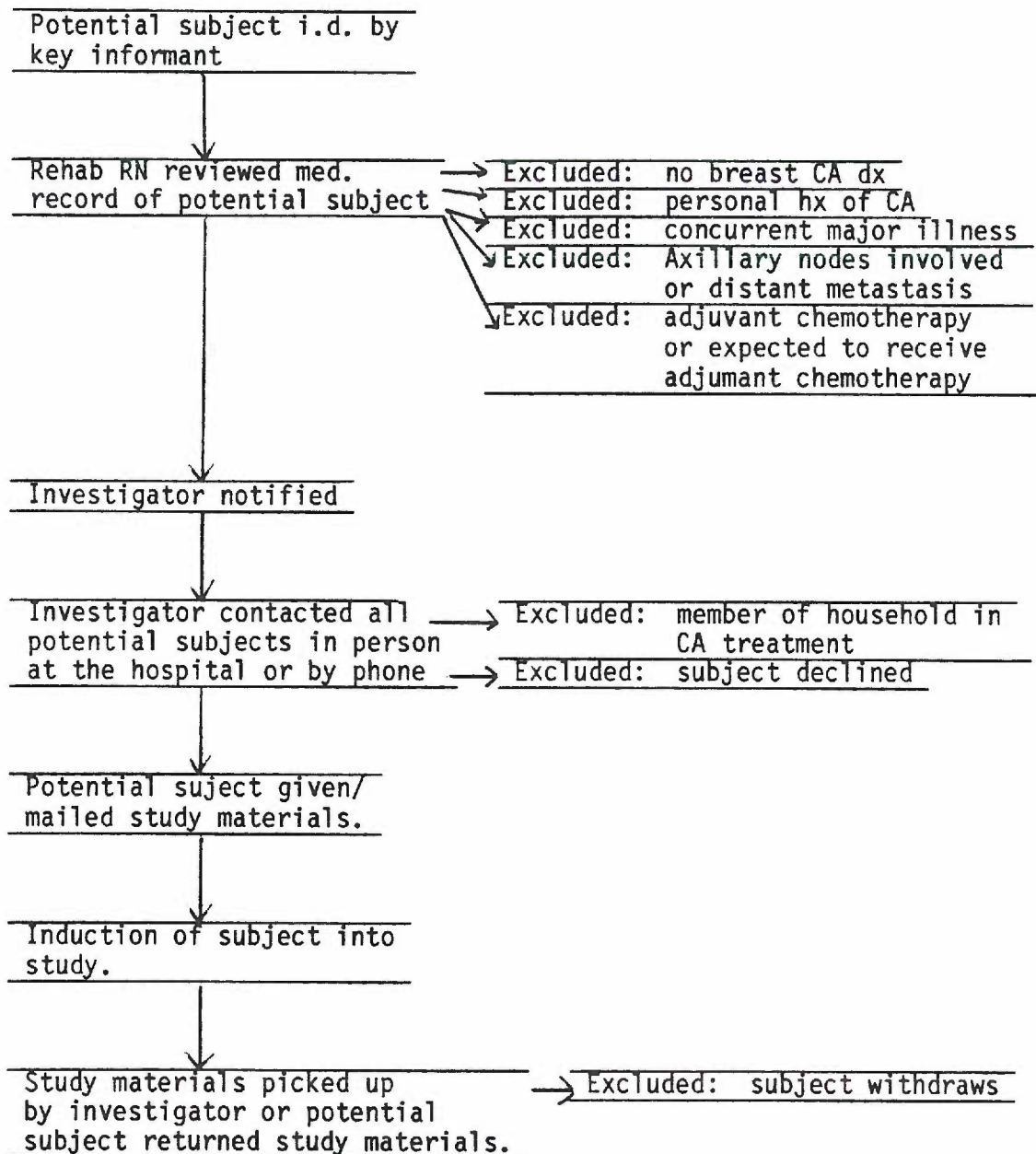


Figure 3 Procedure for selection of subjects into mail study at one private hospital.

of the potential subjects. Physician's permission was then obtained to contact eligible subjects.

Potential subjects were contacted as soon after surgery as possible. Due to difficulty in acquiring physicians' permission before potential subjects left the hospital, some subjects were contacted by telephone at home. In addition, some lumpectomy patients were referred to a data collection agency for radiation 2 or 3 months after receiving the surgical treatment at a facility not participating in this study. Those lumpectomy patients were contacted by the investigator either in person in the radiation oncology department or by telephone in their homes.

Procedures for data collection at the fifth hospital varied slightly from the first four. As noted in Figure 3, the key informant identified potential subjects and reviewed the medical record to determine eligibility. Identification of potential subjects through the cancer rehabilitation department ensured physicians' permission to contact eligible subjects. Then, the investigator's method of approaching subjects was the same as it was at the first four hospitals.

Recognizing that research investigating social support may increase awareness of social support conflicts and deficits, instruments were chosen that were brief, easy to complete, and did not require highly personal or detailed accounts from the subjects. Approximately 25 minutes were required by subjects to complete the study instruments.

Instruments

In the main study, Part II of the Personal Resource Questionnaire (PRQ, Brandt and Weinert, 1981, Appendix B) was used to measure perceptions of social support. Cost, Conflict, and Reciprocity of Social Support (CCARSS, Tilden, 1984, Appendix C) was used to measure the cost, conflict, and reciprocity of subjects' supportive relationships. Network characteristics and demographic information was obtained from the final page of the CCARSS questionnaire.

Personal Resource Questionnaire

Part II of the PRQ was chosen for its brevity and because it measures five of Weiss' (1974) six categories of social support dimensions (obtaining guidance is omitted). Part II contains a 25-item Likert scale that rates items from "strongly agree" (7) to "strongly disagree" (1). Using Cronbach's alpha, an internal consistency reliability coefficient of .89 was found for Part II of the Personal Resource Questionnaire. Criteria used to test for predictive validity included a measure of family functioning and dyadic satisfaction and dyadic consensus.

Intercorrelations for Part II were modest for the subscales of intimacy, social integration, worth, and assistance (ranging from .58 to .62, $p < .001$) and low for the nurturance subscale (ranging from .26 to .38, $p < .001$). Construct validity was measured by comparing scores on the Personal Resource Questionnaire to scores on the Zung Depression Scale, the Spielberger State-Trait Anxiety Scale, and the Profile of Mood

States (POMS). By using Pearson's product moment correlation, the following results were obtained: Zung Depression Scale ($r = .20$ to $.42$), State Anxiety ($r = .37$ to $.42$), Trait Anxiety ($r = -.22$ to $.47$), and POMS ($r = -.10$ to $.46$). Test-retest reliability was not done (Weinert, 1982), but is planned. As a result of the PRQ's (Part II) low to modest internal consistency coefficients for the five subscales, only a single score measuring perceived social support was used in this study.

Cost, Conflict, and Reciprocity of Social Support

The Cost, Conflict, and Reciprocity of Social Support Questionnaire (Tilden, 1984) was chosen over other instruments because it specifically measures those three dimensions of social support that have not been examined elsewhere. In addition, the CCARSS (Appendix C) was chosen because it requires that the subject make a forced choice of the five most important supportive relationships, which is similar to Weiss' (1974) conceptualization of a small "primary group," whose function it is to provide emotional support.

CCARSS first collects structured data of social support by having the subject list, in order of importance, their supportive relationships numbering up to 20. Twenty-five items, using a five-point Likert scale, are repeated for each of the first five people named. The items are divided into five subscales: Cost, Received Benefits, Debits, Equity, and Conflict. Subjects' perceptions of cost of supportive relationships are measured in

terms of time, thought, effort, services, and material things. "Received Commodities" or "Benefits" are related to subjects' perceptions of what is received from important relationships (the seven items include affection, status, information, money, goods, appreciation, and services). Debits are related to the subjects' perceptions of what is returned to important relationships, and includes the same items as benefits. Three items measure subjects' perceptions of conflict within important relationships in terms of stress, trouble, and worry. Subjects' perceptions of equity of important relationships are measured by three items in terms of satisfaction with the balance of receiving and giving, desire to change the balance, and overall equality of the relationship.

A pilot sample of 28 well-educated, middle class females participated in the initial testing of the CCARSS. By using Cronbach's alpha, internal consistency scores ranged from .64 to .85. Fifty-four percent of the subjects reported highest satisfaction with the same relationships that had the highest cost, yet, Pearson's r was not significant in any of the five relationships when used to examine the correlation between cost and satisfaction.

Reciprocity scores in this sample of 28 females indicated that their first three relationships were fairly equitable; however, in the last two relationships debt increased and credit decreased. Reciprocity did not significantly correlate with

satisfaction. However, an Eta statistic computed between satisfaction and reciprocity indicated a significant curvilinear relationship ($\eta = .47$) in the first relationship, and a similar trend was reported for the other four relationships. These findings suggest that if an individual is either giving or receiving too much in a relationship, satisfaction with the reciprocity will be low. These findings have important implication for individuals (and perhaps women in particular) dealing with the impact of a major illness. Further testing of the instrument is currently in progress.

Demographic Information and Network Characteristics

Demographic information for the pilot study was obtained from medical records and interviews, and included age, educational level, and marital status. Demographic information in the main study was obtained from the final page of the CCARSS questionnaire, and included age, marital status, education level, race, and occupation. Network characteristics, also obtained from the final page of the CCARSS, included number of persons in the subjects' household, and the number of family members living within a 50 mile radius of the subject, number of persons in the subjects' network (ranging from 0 to 20), and the first five supportive relationships numbered in order of importance.

Protection of Human Rights

The design and conduct of both studies was carefully planned to hold confidential any information provided by subjects.

Attempts were made to minimize any risks to the subject. Subjects were asked to complete an informed consent form (Appendix C). Interview data from the pilot study were coded in order to protect the subjects' identity. The main study was reviewed and accepted by the Oregon Health Sciences University Committee on Human Research. In addition, the main study was reviewed and accepted by the institutional review boards of all five private hospitals.

Protection of Confidentiality

Subjects in the main study were assigned code numbers and instructed not to write their name on any study documents except the informed consent. The coded instruments, consent forms, and identification key were kept in separate locations in locked files. These files were only accessible to the investigator. The subjects were informed that participation was completely voluntary and that they could withdraw at any time. The subjects were informed that their participation (or refusal to participate) would have no effect on their treatment. Last, subjects were informed that should they choose to withdraw from the study, all materials completed by them and all records identifying them with the study would be destroyed.

Minimizing Risk to Subjects

Emphasis was placed on the voluntary nature of this study as well as the option to withdraw at any time. All women also received a card with a phone number for reaching the investigator,

a psychiatric/mental health nurse practitioner, as needed for either clarifying the study or for arranging a time to discuss in person the subject's feelings of distress.

CHAPTER IV

RESULTS

This chapter is divided into two parts: the qualitative findings of the pilot study and the quantitative findings of the main study. A description of the pilot study sample is followed by content analysis of the data collected through semistructured interviews. Then, a description of the main study sample is followed by results of the quantitative analysis. Finally, there is a discussion of the findings related to each research question.

Qualitative Findings

Characteristics of the Pilot Study Sample

Eight of the 15 women had elected to be treated with a unilateral lumpectomy in conjunction with irridium implant. Five of the eight women treated with lumpectomy also had axillary nodes involved and were therefore treated with adjuvant chemotherapy as well. Seven of the 15 women had elected to be treated with modified radical mastectomy. Of those 7, 4 were treated with chemotherapy and 1 received chemotherapy and external beam radiation.

The lumpectomy group was free of any other major medical illnesses. One mastectomized woman had a history of back injuries and two had histories of cardiac problems. No one in the lumpectomy group had a personal history of cancer and only one woman in the mastectomy group had a personal history of cancer. In the lumpectomy group one person had extensive bone

metastasis. In the mastectomy group two women had extensive bone metastasis, and of these, one had liver metastasis as well.

A significant difference in age between the two pilot study groups was found. Ages ranged from 29 to 64 with a mean of 43.8 for the lumpectomy group and from 42 to 77 with a mean of 60.7 for the mastectomy group. The two groups did not differ in marital status or educational level. Six of eight lumpectomy women were married, and two of eight were single (one divorced, one widowed). Six of seven mastectomy women were married, and one was single (never married). The mean educational level was 12.5 years for the lumpectomy group, and 11.5 years for the mastectomy group.

Thus, the two groups were similar demographically with respect to marital status, educational level, presence of chemotherapy and incidence of metastasis. However, the mastectomy group was older and somewhat more likely to have another major medical illness present.

Analysis of Semistructured Interviews of Pilot Study

Following the interview, women's responses to the questions were recorded as verbatim as possible. After all of the interviews were completed, data were analyzed looking for similarities and differences between and within groups. Based on subjects' responses, three major content areas emerged: affective experience at the time of surgery; support persons at different points in their course of treatment; and current concerns.

Affective Experience at Time of Surgery

Lumpectomy Group. All of the eight women treated with a lumpectomy reported overwhelming fears of death as well as fears of mutilation at the time of their surgery. In addition, five of these women reported feelings of frustration and anger with physicians who either did not discuss alternatives to surgical treatment or insisted on mastectomy as the only form of treatment. Those five women searched out physicians who advocated lumpectomy as a form of treatment. One woman stated:

"I wanted to save my breast, especially if I was going to die anyway. I couldn't see scarring up my body if I didn't have to."

Four of the women described feelings of isolation, which they related to the cancer diagnosis as well as to their surgical treatment choice. One woman stated:

"I had been healthy all my life. With one phone call I became a cancer patient and as a cancer patient I had no dreams, plans, or aspirations . . . I still feel alone with this. I am so worried that I made the wrong [treatment] choice."

Two women spoke specifically of fears of death, pain and sickness from chemotherapy.

Mastectomy Group. Six of the seven women treated with mastectomy reported fears of dying at the time of their surgical treatment. One of the seven women reported that it was her husband she was most concerned about. One subject stated:

"It's not the mastectomy that bothered me so much then--I just knew I wasn't ready to die. I told them to take my breast off if it might save my life."

Four women discussed fears of mutilation. One 42 year old woman described her fears of mutilation and her experience with the cancer diagnosis:

"My mother could not even say 'cancer' or 'mastectomy.' She used to tease me by saying I had a 'vasectomy.' God, that hurt a lot."

Two women expressed anger because they were undiagnosed for a period of time. One woman, who was undiagnosed for 2-1/2 years, stated that she "finally received medical attention when she had a clutching pain in her chest."

Thus, fears of death and mutilation were common for both groups of women. In addition, the lumpectomy group focused on feelings of frustration and anger with physicians who did not readily discuss or offer alternatives to treatment. Lumpectomy women tended to seek out physicians advocating conservative breast treatment. It is not known if mastectomy women actively sought that form of treatment.

Social Support During Course of Treatment

Lumpectomy Group. When asked to whom they turned during the course of breast cancer treatment, the majority of women (62.5%) referred to immediate family (i.e., spouses, daughters, sons). Two mentioned their "church family" and God as being very important emotional supports. One 64 year old widowed woman, who was 2 days post operative, reported that she had turned to her close friends for support. She had not told her family of her diagnosis and treatment because she was afraid that cancer was contagious.

When asked to describe how their available social support had changed during the course of treatment, the responses were similar. Five women felt very strongly that their families would have offered emotional support longer had they chosen a mastectomy rather than a lumpectomy. They felt that a "lumpectomy" was treated like a minor procedure, which minimized the support system's perception of the seriousness of the diagnosis. One woman described her feelings: "Really, you have to have a breast removed to get any support." Three lumpectomy subjects, who were no longer in treatment, reported that while they felt a great deal of support during treatment, family and friends had soon expected them to stop talking about their cancer fears and concerns. One 54 year old woman described increased feelings of isolation in relationship to her specific cancer concerns:

"My husband and daughters are still supportive--we just don't talk about it (the cancer diagnosis) any more."

Two women reported marital difficulty resulting from the breast cancer diagnosis and treatment. One woman said the turmoil she went through to receive a lumpectomy combined with the anxiety she felt over the cancer diagnosis resulted in so much conflict with her husband that he left her. One woman reported that initially the crisis of her diagnosis and treatment with lumpectomy brought her closer to her husband and parents. When she suffered metastasis to her skeletal system, her husband began to distance himself from her. She said that as the illness progressed

"I needed more help [physically and emotionally] and yet, it became more difficult for me to ask for anything from him. The hopelessness of my situation became pretty obvious."

Mastectomy Group. When the seven mastectomy subjects were asked to whom they turned during the course of treatment, the majority of women (71.0%) referred to immediate family (i.e. spouses, daughters, sons). One named her brother and God. She stated that she could ask her brother to take her to the hospital, but only God would listen to how frightened she was. The last subject named her doctors and nurses as her primary supports; this subject was suffering from extensive bone

metastasis and reported that she currently relied on various people in the hospital community because her husband and parents were preoccupied with their own concerns over her illness. Aunts, sisters, and friends were named by three of the seven women in this group.

Responses varied among members of the mastectomy group when asked to describe how their social support changed during the course of treatment. Two mastectomy subjects said that the most difficult loss of support occurred during hospitalization when they had decreased personal contact with their husbands. Two subjects expressed concern and frustration over the changes in their ability to reciprocate tangible support (i.e. cooking, washing clothes, cleaning the house). These two women expressed strong feelings of guilt because their husbands were now assuming the homemaking duties.

Two mastectomy subjects expressed ambivalent feelings about support received from their mothers. One woman, who was 3 days post-operative, and one woman, who had distant metastasis, described their relationship with their mothers as both supportive and stressful. Both subjects' mothers had been described as "helpful," providing them with physical assistance; and yet, when the subjects suggested their mothers look at their surgical scars, both mothers refused. In addition, one of these two women expressed sadness and anger related to her mother's and father's response:

"They are always trying to make me feel like a hero. I'm no hero. . . . Nobody wants to die, but they can't deal with that."

Another mastectomy subject stated that her husband "never was a talker;" therefore, she received emotional support from a water therapy group she attended. Chemotherapy reportedly made her too sick to attend the group, resulting in a significant support loss for her. Finally, the last mastectomy subject whose husband had retired 3-1/2 years prior to her diagnosis, denied any major changes in her social support. However, she did note that some friends called less often, and some people just couldn't talk about cancer."

Thus, both groups of women named spouses, daughters, and sons as primary sources of support during the course of their treatment. The support between the subjects in both groups and their primary supportive relationships became more conflicted as symptoms of the illness progressed. Both groups described feelings of isolation as well as difficulty in gaining the support needed for them to talk of fears of recurrence and death. Differences in the two groups were demonstrated by the lumpectomy groups' rationale for their perceived losses of social support. The lumpectomy group verbalized changes and losses in social support when their illness concerns were minimized due to the limited extent of surgery. The mastectomy groups' rationale

for changes or losses in social support included their own inability to reciprocate social support, an increase in symptoms due to chemotherapy, and decreased personal contact with their husbands during hospitalization.

Current Concerns

Lumpectomy Group. Six of eight women in the lumpectomy group described fears of recurrence as their overriding present concern. One of the six women expressed her fear:

"I worry all the time. What am I supposed to do? They say you're never 'cured' . . . Do I plan for it to come back?"

Again, the fears of recurrence were linked to conflict they experienced in choosing a lumpectomy over a mastectomy. Coupled with their fears of recurrence were feelings of isolation.

Two lumpectomy subjects' most prominent concerns were pain and death. In addition, one was concerned with her decreasing energy level, which interfered with her ability to communicate with her parents. One was concerned with how her family would cope after she died.

Mastectomy Group. In the mastectomy group, four of seven women described fears of death and cancer recurrence. Two women in this group, who had distant metastasis, were primarily concerned with pain, and their husbands' emotional well being. One woman in this group denied fears of recurrence or death. She was primarily concerned with the swelling in her hand and arm.

Thus, current concerns for both groups emphasized fears of recurrence and death. In addition, both groups reported concerns related to the progression of illness symptoms and treatment sequelae.

Summary

In general, the majority of both groups of women identified fears of recurrence and death as their main concern throughout their illness. For both groups, spouses and children were primary sources of support. However, a majority of subjects in both groups expressed difficulty in gaining the support needed for them to talk of these prominent fears.

Quantitative Findings

Characteristics of the Main Study Sample

A sample of 19 Caucasian women diagnosed with breast cancer participated in the main study. Eight women had elected to be treated with a unilateral lumpectomy. Seven of those women also received an irridium implant and one received external beam radiation. Eleven women had elected to be treated with mastectomy: nine had a unilateral modified radical mastectomy; one had a unilateral simple mastectomy; and one had a left simple mastectomy and a right modified radical mastectomy. One mastectomized woman received external beam radiation.

The two groups did not differ significantly in age, marital status, completed years of education or occupation. The mean age for the lumpectomy subjects was 60.2 years and for the mastectomy subjects the mean age was 61.3 years. In the lumpectomy group, four subjects were married, two were widowed, and two were single (never married). The marital status for the mastectomy group was: five married, four widowed, and two single. The average educational level was 11.5 and 12.6 years for the lumpectomy group and mastectomy group respectively. One mastectomy subject's occupation was categorized as semi-professional. Two mastectomy subjects did not report their occupations. Otherwise, occupational status was similar between the two main study groups: 1. clerical and sales: lumpectomy, two of eight; mastectomy, three of eleven; 2. skilled, manual: lumpectomy, two

of eight; mastectomy, two of eleven; 3. unskilled, domestic:
lumpectomy, none of eight; mastectomy, one of eleven; 4.
homemaker: lumpectomy, four of eight; mastectomy, two of eleven.

Analysis of Research Questions of the Main Study

Students' t test for independent groups was used to test the differences in means of scores between the lumpectomy and mastectomy groups with respect to each of the six research questions. In all cases, the criterion for statistical significance was at the .05 probability level. Cronbach's alpha internal consistency-reliability estimates were calculated for the CCARSS. Alpha coefficients of all subscales ranged from .76 to .92.

Research Question One, Network Characteristic Differences.

Four items related to network characteristics: the number of persons living in the same household as the subject, the number of kin that live within a 50 mile radius of the subject, the number of persons in the subject's network (ranging from 0 to 20), and the first five supportive relationships numbered in order of importance. No significant differences were found between any of these group means. For the number of persons living in the household with the subject, there was a mean of 1.5 for the lumpectomy group and a mean of 2.0 for the mastectomy group. The lumpectomy group had a mean of 3.25 for the number of kin living within a 50 mile radius compared to the mastectomy group who had a mean of 3.0. Network size averaged 9.75 for the

lumpectomy group and 8.18 for the mastectomy group. All 19 subjects named at least 5 people in their network. In the total network for both groups, 83.2% consisted of relatives with the remaining 16.8% of the total network for both groups consisting of friends, neighbors, and clergy.

There was a bimodal distribution between spouses and daughters as the most important network person for both groups (Table 1). Three of the lumpectomy women (75%) and four of the mastectomy women (80%) named spouse as the first person in their network. Two married subjects, one lumpectomy and one mastectomy (25% and 20%, respectively) chose a daughter first. Of two widowed lumpectomy subjects and four widowed mastectomy subjects, five reported daughters as the first person in their network, (100% and 75%, respectively). The remaining widowed subject named another relative. Of the four single subjects (lumpectomy, 2; mastectomy, 2), one subject in each group chose a friend (50% and 50% respectively), and two chose other relatives as the most important source of support, (50% and 50%, respectively).

As the second most important network person, four (100%) married lumpectomy subjects and one (20%) married mastectomy subject named daughters. Of the remaining mastectomy subjects, two (40%) named sons and two (40%) named other relatives. Among the widowed subjects one (50%) of the lumpectomy subjects chose a daughter and one (50%) chose a son, while one (25%) mastectomy subject chose a daughter, one (25%) chose a son, and two (50%)

Table 1: Main Study Comparison of Lumpectomy Subjects and Mastectomy Subjects: Their Two Most Important Relationships.

| | | Married Subjects | | Widowed Subjects | | Single Subjects | |
|---|----------|------------------|-------|------------------|-------|-----------------|-------|
| | | Lump | Mast | Lump | Mast | Lump | Mast |
| | | (N=4) | (N=5) | (N=2) | (N=4) | (N=2) | (N=2) |
| M | Spouse | 75% | 80% | - | - | - | - |
| O | Daughter | 25% | 20% | 100% | 75% | - | - |
| S | Son | - | - | - | - | - | - |
| T | Friend | - | - | - | - | 50% | 50% |
| | Other | | | | | | |
| | Relative | - | - | - | 25% | 50% | 50% |
| S | Spouse | - | - | - | - | - | - |
| E | Daughter | 100% | 20% | 50% | 25% | - | - |
| C | Son | - | 40% | 50% | 25% | - | - |
| O | Friend | - | - | - | - | 50% | - |
| N | Other | | | | | | |
| D | Relative | - | 40% | - | 50% | 50% | 100% |

chose other relatives for the second most important person. Among the single subjects, one lumpectomy subject (50%) named a friend and one (50%) named another relative while two (100%) single mastectomy subjects named other relatives as the second most important network person. Three out of eight lumpectomy subjects chose non-relative persons as their third most supportive relationship whereas the mastectomy group predominantly had relatives throughout their first four relationships. The fifth most important support person named for both groups included a combination of friends and distant relatives.

Research Question Two, Social Support. Mean scores of perceptions of social support were compared for the lumpectomy and mastectomy group (Table 2). Differences in group item means were not significant (5.2 and 5.3 for the lumpectomy and mastectomy groups, respectively, in a possible scale of 1-7).

Table 2: Comparison of Mean PRQ Scores Between the Lumpectomy Group and the Mastectomy Group.

| Scale | Group N = 8 N =11 | \bar{X} | Standard error | Pooled variance estimate | |
|-------------------------------|-------------------------|-----------|----------------|--------------------------|------------------------|
| | | | | t value | two tailed probability |
| Perceptions of Social Support | | | | | |
| | Lumpectomy Group | 5.2 | 0.19 | | |
| | Mastectomy Group | 5.3 | 0.07 | -0.68 | 0.50 |
| Score range: 1-7 | | | | | |

Research Question Three, Conflict. No significant differences between the lumpectomy and mastectomy group means of conflict were found (Table 3). Also level of conflict (relatively low for both groups) neither increased nor decreased across the network for either group (Figure 4). Individual means in each of the five people named were also examined. However, none of the means were found to differ significantly between the lumpectomy and mastectomy groups. Thus, not only did the lumpectomy and mastectomy groups report a similar level of conflict for the primary network persons, but also this level of conflict is relatively low and does not vary across the first five persons of that network.

Table 3: Comparison of Mean CCARSS Subscale Scores Between the Lumpectomy Group and the Mastectomy Group.

| Subscale | Group | X | Std. Error | Pooled variance estimate | |
|----------|--------|-------|------------|--------------------------|------------------------|
| | | | | t Value | Two-tailed probability |
| | N = 8 | | | | |
| | N = 11 | | | | |
| Conflict | Lump | 6.41 | 1.15 | -0.05 | 0.96 |
| | Mast | 6.50 | 1.28 | | |
| Cost | Lump | 7.82 | 1.52 | -0.55 | 0.59 |
| | Mast | 8.87 | 1.17 | | |
| Credit | Lump | 12.42 | 1.03 | -0.82 | 0.42 |
| | Mast | 13.37 | 0.64 | | |
| Debit | Lump | 12.57 | 1.50 | -0.73 | 0.48 |
| | Mast | 13.73 | 0.80 | | |
| Equity | Lump | 1.95 | 0.26 | -0.88 | 0.39 |
| | Mast | 2.27 | 0.25 | | |

Lump = Lumpectomy group; Mast = Mastectomy group; Conflict: range 0-15; Cost: range 0-25; Benefit: range 0-35; Debit: range 0-35; Equity: range 0-15

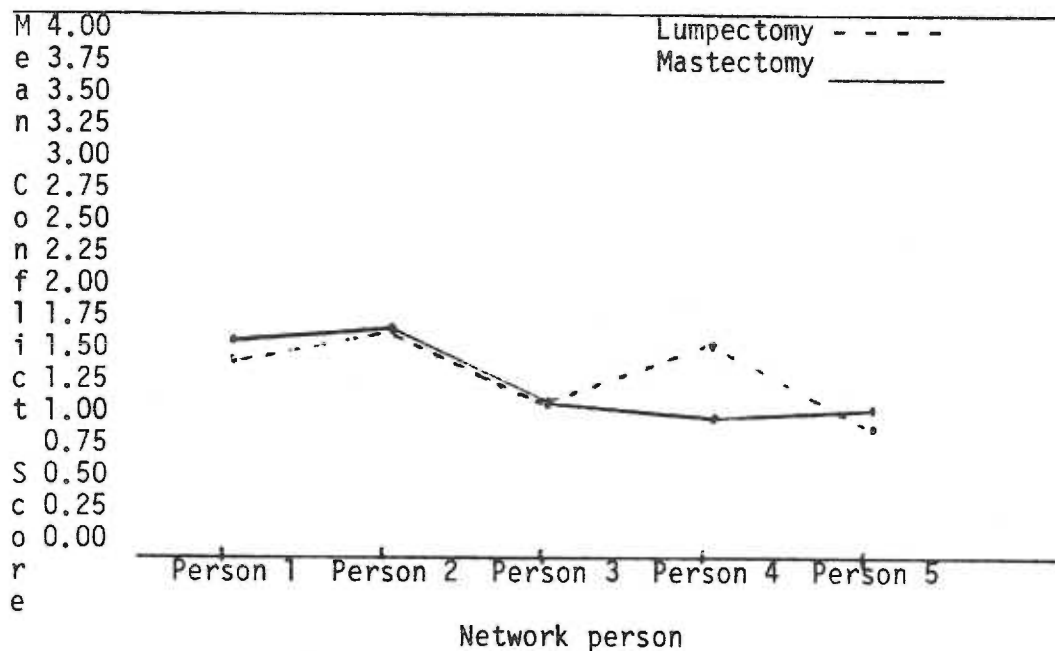


Figure 4. Comparison between the lumpectomy group and the mastectomy group of network person 1 through 5 mean CCARSS Conflict scores.

Research Question Four, Cost. Differences in group means of cost were not statistically significant (Table 3). However, trends in both groups suggested a gradual decrease in perceived cost across the five person network (Figure 5). It should be noted that this decrease in perceived cost was not paralleled by a corresponding decrease in perceived conflict as reported above. Thus, while cost of a relationship decreased moving across the network, from closest to more distant persons, perceived conflict remained concurrently low.

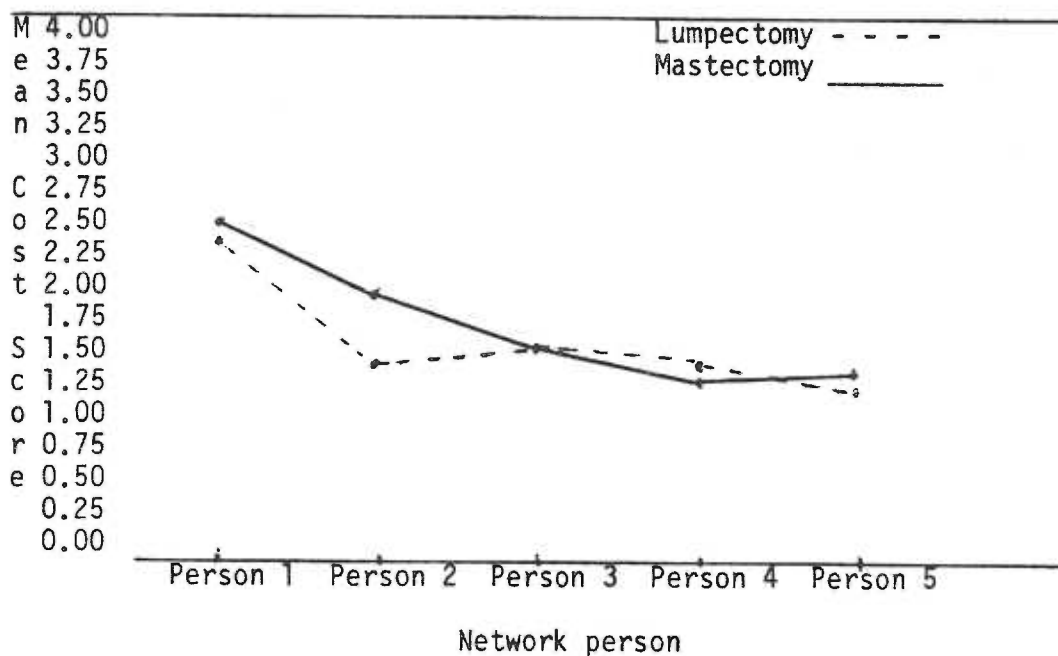


Figure 5. Comparison between the lumpectomy group and the mastectomy group of network person 1 through 5 mean CCARSS Cost scores.

Research Question Five, Reciprocity. Differences in group means of reciprocity were not significant, nor did any of the individual means for each of the five people named differ significantly. Thus, lumpectomy and mastectomy patients both reported the same level of reciprocity in relationships with significant network persons.

Research Question Six, Equity. Differences in group means of equity were not significant. However, a trend may be noted which suggests an inverse relationship between conflict and equity for the distant network person in the lumpectomy group (Figures 4 and 6). Moreover, perceptions of relationship equity are relatively high across the 5 person network in contrast to

low perceived relationship conflict. In addition, perceived relationship cost decreased (Figure 5) across the five person network while equity remained high.

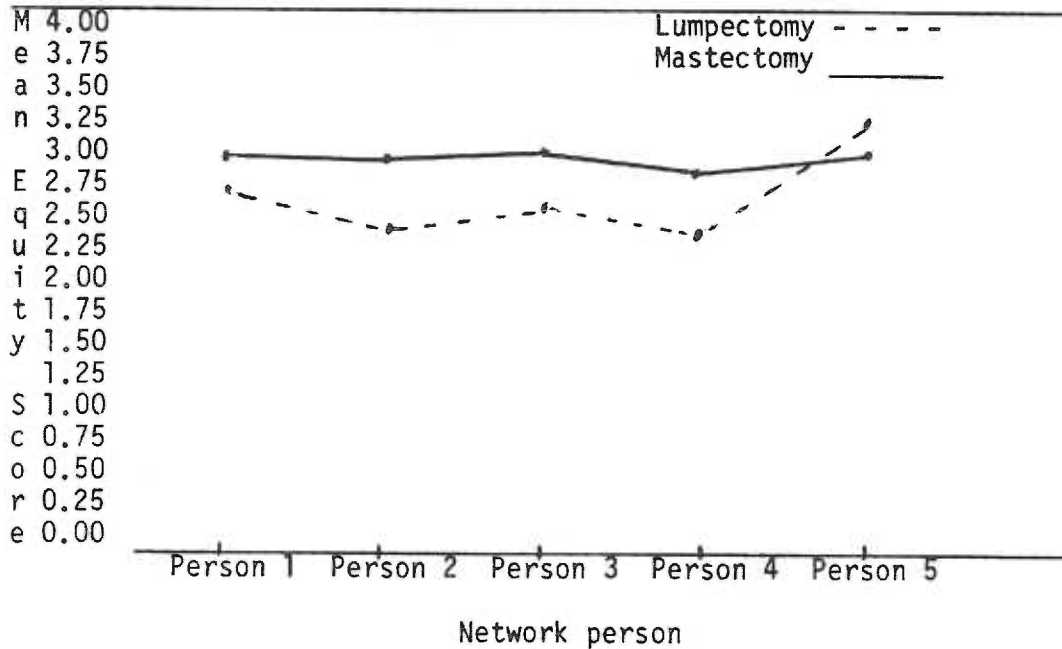


Figure 6. Comparison between the lumpectomy group and the mastectomy group of network person 1 through 5 mean CCARSS Equity scores.

Summary

In summary, quantitative analysis, using Students' t statistic, of main study findings indicated no significant differences between the two groups in any of the six research questions. Spouses and daughters were named as primary sources of support. Trends in reported cost suggested a gradual decrease in this variable across the five most important network persons. Perceived conflict remained low while relatively high levels of perceived reciprocity and equity were reported across the five most important network persons.

CHAPTER V

DISCUSSION

This chapter contains the interpretations of qualitative and quantitative findings; a discussion of the strengths and limitations of the pilot study and main study; implications for nursing practice; and suggestions for future research.

Interpretations of Qualitative and Quantitative Findings

These two data sets are compared; however, the methods used in the pilot study versus the main study for data collection may have assessed different dimensions of the subjects' responses to cancer and its treatment. Therefore, while comparisons are made between pilot study and main study groups, caution should be exercised to avoid possible over-interpretations of either similarities or differences.

Social Support Network Characteristics

Pilot study data on network characteristics yielded information on who subjects turned to during the course of treatment and how their networks changed. Similarly, in the main study, subjects identified their supportive relationships in order of importance. Both qualitative and quantitative data indicated that for married subjects in both treatment groups spouses were the most important support persons. Of the widowed and divorced subjects in both treatment groups, daughters were named as the most important support persons. In addition, both quantitative and qualitative data indicated that daughters were important sources of support for married subjects as well.

These findings may be interpreted through family developmental theory (McCullough, 1981). It has been posited that the family goes through developmental stages similar to individuals (Erikson, 1963; Terkelson, 1981; McCullough, 1981). Developmentally, the pilot study groups and main study groups could be described as middle-to-older generation parents (McCullough, 1981). During this time the couple may either reinvest in the marriage, or begin to meet relational needs outside the marriage. The increased independence of the children often leads women into more autonomous career or work roles. These changes can lead to increasing marital conflict. The developmental task is for the couple to examine and to change the basic tenets of the marital relationship. Relationships with adult children may also change. The importance of the mother-daughter relationship, in particular, has been noted (Baruch & Barnett, 1983). Because breast cancer is primarily a woman's illness, the support from an adult daughter may be especially important. However, as the data did not allow controlling for the proportion of daughters versus sons, further interpretation is unwarranted.

The support networks of both pilot study subjects and main study subjects consisted primarily of relatives. In his discussion of single parents, Weiss (1974) pointed out that relationships with family and spouses are based on an alliance. He posited that continuing close proximity may be one reason the marital relationship tends to provide more support. Relatives' support

has been shown to be an important factor in breast cancer patients' psychosocial adaptation (Wortman, 1984; Meyerowitz, 1983). The stigma associated with the cancer diagnosis may account for the few numbers of friends named as sources of support (Peters-Golden, 1982; Wortman & Dunkel-Schetter, 1979). Cancer patients' fears of rejection may make it difficult for them to tell friends of their diagnosis. The investigator would further speculate that relatives were named more often than friends as sources of support because family ties naturally tend to be stronger. Terkelson (1980) pointed out that family membership is different from other social systems in two distinct ways. First, there are generally no rules which govern termination, other than death, and even then, the deceased will continue on in the conversations and memories of surviving members. Secondly, while the family puts a high value on role competence, it places an even higher value on caring, personal loyalty, and attachment. Thus, while the cancer patient's role functioning may change and cause some organizational difficulties, membership will continue based on strong affectional ties.

It is noteworthy to point out that "God" was named as an important source of support for lumpectomy and mastectomy subjects in the pilot study. For those breast cancer patients, the support from God relieved much of the existential isolation created by the cancer diagnosis.

Perceptions of Social Support

In the pilot study, significant differences in age may have influenced the pilot study subjects' perceptions of social support. Lumpectomy subjects were an average of 17 years younger than the mastectomy subjects. Importance of the breast was described by both pilot study groups, however, only the lumpectomy group reported actively choosing their surgical treatment. This younger group of subjects may have experienced a stronger societal trend towards women being more active decision-makers and, therefore, become more informed and more likely to question authority figures such as physicians.

The main study lumpectomy group, who were also an average of 17 years older than the pilot study lumpectomy group, scored high in perceived social support. The difference in the social support of these two groups may be explained by sampling error. Because physicians sometimes selectively screened out subjects who were distressed, the main study lumpectomy group represents a biased sample. It is probable that main study lumpectomy subjects were indeed receiving high levels of social support. In addition, increased awareness of surgical alternatives may have influenced the main study lumpectomy group's perceptions of social support by making the lumpectomy somewhat less difficult to acquire. The main study lumpectomy group may not have had to aggressively seek out alternatives to treatment since the media had focused on lumpectomy as an acceptable form of treatment

(i.e., The Oregonian, Time magazine, Phil Donahue television talk show).

Qualitative data suggested that women treated with lumpectomy perceived low social support, particularly as time progressed and they were pressured by family to return to their routine roles. These women tended to associate their lack of support to the surgical treatment as well as to significant others' inability to discuss cancer concerns. In fact, in the metropolitan area in which the pilot study was conducted lumpectomy patients were not treated by the cancer society as if they needed support. In the pilot study, the mastectomy group also perceived low social support. However, the perceived low social support was reportedly related to increased symptomatology. Therefore, both groups in the pilot study reported low perceptions of social support. In contrast, quantitative data obtained in the main study suggested that both lumpectomy and mastectomy subjects perceived high social support.

One explanation for the difference between the two studies' findings may be that the perceptions of some of the subjects in the pilot study had changed since they retrospectively reported their social support. In addition, subjects in the pilot study were considerably sicker, with poorer prognosis, than the main study subjects. The literature indicated that a peak period of distress occurs approximately three months following the diagnosis of breast cancer (Weisman & Worden, 1977; Morris et al.,

1977). Most of the subjects in the main study were newly diagnosed; perhaps those subjects had not yet felt the expectation to return to previous roles and were actually receiving adequate social support.

Cost and Conflict of Social Support

While neither cost of nor conflict within supportive relationships was directly investigated in the pilot study, both lumpectomy and mastectomy subjects described what seemed to be an increase in cost and conflict within their support network. In retrospect, however, it is possible that the pilot study group was describing a specific type of cost and conflict related to dysfunctional communication patterns within the support network. Since the CCARSS does not measure dysfunctional communication, it may not have adequately measured the key constructs of interest, thus accounting for the fact that no differences between main study groups were found.

Locus of relationship conflict differed between the two pilot study groups. For the lumpectomy group, conflict increased as their needs for feedback continued and important persons in their support network expected them to return to normal. Social exchange theory would suggest that these lumpectomy patients are in a high distress/low support situation. Their overriding emotion regarding the conflict would be anger at the discrepancy between their continued need for support and the network's expectation that they return to normal. Pilot study mastectomy

subjects described an increased conflict within significant relationships that was related to their own inability to reciprocate social support, an increase in physical symptoms due to chemotherapy treatments, and decreased personal contact with their husbands during hospitalization.

In contrast, in the main study both groups reported low levels of conflict across the support network. Perceived cost for the most important person was moderately high, however, this gradually decreased across the identified five-person network. It makes theoretical sense that cost gradually decreased as the importance of network relationships also decreased. Those relationships considered most important would logically involve more exchanges of support such as time, effort, thought, material things, and services. This finding corroborates Tilden's (1983) pilot study of non-cancer women where cost gradually decreased across the network.

This investigator would further speculate that the relationship between subjects in the main study and their most important network person would be, in fact, characterized by high conflict as well as the reported high cost. With an increase in exchanges comes the increased possibility for conflict as well. Perceived low conflict, in the main study, may be due to the cancer patients' interpretation of "conflict." Conflict may be an inappropriate variable in this population, that is, while subjects are ill and in increased need for support, conflict may

have been viewed as a negative report of their most supportive relationships. Findings are similar when comparing the mean conflict scores of the main study subjects' most important relationship to Galyen's (1985) non-surgical cancer group. The non-surgical cancer group's report of conflict was comparable (lumpectomy: $\bar{X} = 1.6$; non-surgical cancer group: $\bar{X} = 1.4$). Further, in the pilot study, conflict was indirectly acknowledged. It may be that conflict within important supportive relationships is a variable best examined indirectly and in as non-threatening and non-perjorative a manner as possible when the subjects are being faced with a life threatening illness.

Reciprocity and Equity of Social Support

While neither reciprocity nor equity of social support was directly investigated in the pilot study, both groups described disruptions in the give-and-take process of support. The lumpectomy group described disruptions in relational exchanges Weiss (1974) would term intimacy, social integration, and reassurance of worth. These disruptions in the support network left lumpectomy subjects feeling angry and despairing. Likewise, for the mastectomy group in the pilot study, feelings of guilt were prominent when subjects could no longer contribute the support they had normally provided. In contrast, both groups in the main study reported high levels of reciprocity. In addition, their perceptions of equity within supportive relationships was also high.

The differences found between the pilot study group and the main study group may be related to the selection process. Subjects in the pilot study were not screened by physicians, whereas, the main study subjects were and, therefore, represent a select group of women likely to be less distressed. In addition, the cancer diagnosis and treatment (Wortman & Dunkel-Schetter, 1979) as well as the increased symptoms of the illness may account for the pilot study's descriptive report of disrupted exchanges of support. Although the main study group was newly diagnosed, it was expected that the cancer diagnosis would have disrupted the reciprocity and equity of supportive relationships in that group as well. It is possible that a certain amount of denial was operating, or it could be that the main study groups' relationships were, in fact, equitable at the time of participation.

In summary, while qualitative differences were found between the mastectomy and lumpectomy groups' social support in the pilot study, these findings were not born out in the main study. During this time of distress the marital relationship and relationships with children can be a primary source of support. A disruption in the reciprocity of those supportive ties may create less equitable relationships.

Strengths and Limitations

A limitation for both studies was the small, nonrandom samples. The lack of statistically significant findings in the

main study may have been related to the small number of participants. The results of both studies should be interpreted cautiously and only be used to describe these study groups. Findings should not be generalized to any other breast cancer population.

Another limitation related to the differences between the pilot study and main study groups' stage of diagnosis and treatment as well as social support. Comparisons were difficult to make because the pilot study sample's reports of social support were given at a variety of diagnostic stages and treatments, whereas the main study reports of social support were obtained in the early stages of diagnosis and treatment. In the pilot study, both groups had some subjects who were two to four years post diagnosis and treatment. Data collected in the pilot study were sometimes based on subject recall; therefore, a discrepancy may exist between what the actual nature of their social support was and what they retrospectively reported. In contrast, subjects in the main study were two days to four months post surgery. Moreover, subjects in the main study sample had a better prognosis, due to more rigorous criteria for selection of that group, while the pilot study group included some subjects in the terminal stages of cancer. Because social support is a dynamic concept, it is difficult to distinguish how social support was differentially affected by the surgical breast cancer treatment and/or life events.

Another limitation of the main study was associated with the necessity for the investigator to obtain treating physicians' permission before contacting potential subjects. This permission was sometimes denied, resulting in the main study sample representing a select group of women. Most often physicians' rationale for withholding permission was to protect a distressed patient from further stress. The investigator knows of 25 potential subjects who were not approached because permission was denied. Those 25 women were not demographically different from the main study groups. However, there may be differences in perceived social support between the main study sample and those women not approached.

Limitations of the main study also included questionable validity of parts of the instruments for the study sample. The PRQ's subscale of "opportunity for nurturance" was not applicable to the women in the main study because most of them no longer had children at home. The average age for women in the main study groups was 62 and the questions aimed at assessing that particular subscale were associated with the direct care of children. For the CCARSS tool, conflict may have been a contaminated variable due to the subjects' negative connotation of this concept.

Finally, the scope of the study is a limitation. The time frame was too short to collect the numbers of subjects needed to make an adequate comparison. Women undergoing diagnosis and

treatment of breast cancer are experiencing a tremendous amount of stress. Sensitive and careful consideration of their feelings needs to be considered when approaching them for clinical research. This consideration means having a sufficiently extended time frame to include an adequate sample for those women willing to participate who are representative of the breast cancer population.

A major strength of this study was in the recognition of lumpectomy patients as a potential vulnerable group. The literature to date does not adequately address breast cancer patients' experience with that form of treatment while mastectomy patients' experience has, in contrast, been widely documented.

Further, this study contributes to a growing body of knowledge related to breast cancer treatment and social support. The potentially stressful as well as beneficial aspects of social support were addressed. Cost, conflict, and reciprocity of social support were identified as particularly important when assessing the positive affects of cancer patients' socially supportive relationships.

Implications for Nursing Practice

The results of this study support previous findings that indicate women diagnosed with breast cancer undergoing surgical treatments are vulnerable to psychosocial distress. In particular, the study's results identify lumpectomy patients as a potentially vulnerable group whose psychosocial well-being may be

facilitated by psychiatric/mental health nurses.

The qualitative data indicated that women treated with lumpectomy and mastectomy perceived their primary support persons as unable to provide the support needed for them to discuss cancer concerns of death and recurrence. This finding implies the need for nurses practicing within the medical setting to attend to the psychosocial needs of breast cancer patients undergoing treatment.

Nurses have traditionally taken a holistic approach to patient care. Given the stigma and myths attached to the cancer diagnosis (Peters-Golden, 1982), nurses have an important direct role in assisting individuals to interact with their environment for the purpose of promoting and maintaining positive mental health. In the direct care role, professional nurses offer support through counseling or performing routine breast exams. The latter may be important to women who fear recurrence in the unaffected breast.

The increasing incidence of breast cancer among women suggests a concurrent increase in the need for social support; and yet, direct services cannot be adequately provided by the professional community (Gottlieb, 1982). Mental health nurses can contribute to the needs of this vulnerable group by acting as both consultants and liaisons. As consultants, professional nurses could play an integral part in developing volunteer visitation programs and self-help groups. As liaisons,

professional nurses could connect patients to existing support systems in the community.

The mental health nurse's role may be especially important for the lumpectomy patient, whose experience has not been adequately addressed in the literature to date. Disruptions in the exchange of support between the lumpectomy patient and her significant relationships could be minimized by the mental health nurse, through both direct and indirect care.

Suggestions for Further Study

Women's experience with lumpectomy has as yet, not been adequately explored. The purpose of this study was to gain further information about the relationship between two types of surgery for breast cancer (lumpectomy vs mastectomy) and social support. This investigator urges further studies examining the social support needs and experience of lumpectomy patients, in particular. Eliminating controls for nodal involvement and adjuvant chemotherapy may serve to increase the numbers of women eligible to participate. With larger numbers the influence of those variables may be statistically controlled.

The difficulty in the pilot study and main study comparison provides evidence that social support is a dynamic concept most accurately examined over time. A longitudinal investigation could provide valuable information on the nature of breast cancer patients' social support and how surgical treatments may influence that support. In addition to using an instrument, such

as the CCARSS, it would be useful to interview lumpectomy and mastectomy subjects at different points in time to indirectly assess the changes in cost, conflict, and reciprocity of their supportive relationships. More indepth interviews of lumpectomy patients' experience with that form of treatment would also be useful.

It is not known if personality differences influence whether a woman chooses lumpectomy over mastectomy, and how those differences may also influence their social support. An investigation examining lumpectomy and mastectomy patients' locus of control could be informative.

Finally, another focus of research may be to examine the nature of the mother-daughter relationship of women facing the diagnosis and treatment of breast cancer. It may be clinically important when assessing the breast cancer patients' support network.

Summary

This study sought to provide additional information on the relationship between two methods of surgical treatment for breast cancer (lumpectomy versus mastectomy) and social support. The pilot study and main study were based on prior research findings (Peters-Golden, 1982; Lierman, 1982; Dimond, 1979; Tilden, 1983). These studies found an association between socially supportive relationships and positive health outcomes in individuals faced with a variety of physical illnesses, including cancer.

Cancer patients in general, and breast cancer patients in particular, are in need of increased social support to facilitate psychosocial adaptation (Lierman, 1982; Quint, 1963). Fears and myths associated with the cancer patients and their significantly supportive relationships (Wortman & Dunkel Schetter, 1979; Peters-Golden, 1982). Mastectomy and lumpectomy patients have been found to have fairly high degrees of anxiety and depression related to their fears of death and recurrence (Schain et al., 1983). How the lumpectomy procedure in particular may influence women's social support has not, however, been documented in the literature.

The conceptual model for this study holds that people come together for the purpose of exchanging goods and commodities that may be material, non-material, or both (Ridley & Avery, 1979). In this exchange, efforts are aimed at minimizing losses and maximizing rewards. The exchange occurs within and between individuals' primary and secondary relationships and may include support in terms of intimacy, social integration, opportunity for nurturance, reassurance of worth, assistance, and the obtaining of guidance (Weiss, 1974). Interference in the exchange of social support when emotional distress is high may lead to a sense of anomie and to feelings of despair.

The pilot study was conducted for the purpose of identifying variables to be examined in the main study. The main study addressed six specific research questions for these two groups.

Summarized, they are as follows: Are there differences between post-surgery lumpectomy and mastectomy patients' social support network characteristics? Are there differences between post-surgery lumpectomy and mastectomy patients' perceptions of social support? Are there differences between post-surgery lumpectomy and mastectomy patients' perceptions of cost, conflict, reciprocity, and equity of social support?

To examine the questions, an ex post facto correlational field study was designed. The independent variable was type of surgical treatment and the dependent variable was the subjects' perceived social support. As a correlational study, the independent variable was not manipulated so that the findings cannot be interpreted in a cause and effect manner.

In the pilot study, a convenience sample of eight lumpectomy and seven mastectomy patients were drawn from women in treatment for breast cancer at one private medical center. Each subject was asked to participate in a semistructured interview conducted by the investigator. Following the interview, women's responses were recorded as verbatim as possible. Data were analyzed looking for potential similarities and differences within and between the two groups. Based on subjects' responses, three major content areas emerged. The qualitative data was then compared to the quantitative data obtained in the main study.

In the main study a convenience sample of eight lumpectomy and eleven mastectomy patients were drawn from women in treatment

at five private medical centers. Each subject in the main study was asked to complete two instruments: Part two of the Personal Resource Questionnaire (Brandt & Weinert, 1981) and the Cost, Conflict, and Reciprocity of Social Support (Tilden, 1984). Student's t statistic was chosen to test the data on each of the six research questions.

Both lumpectomy subjects and mastectomy subjects in the pilot study described losses and changes in available social support, which they associated with the cancer diagnosis and increased physical symptoms. In contrast, lumpectomy subjects associated their surgical treatment with low social support, whereas the mastectomy group associated low social support with their own inability to reciprocate support, and increase in physical symptoms from chemotherapy treatment, and their decreased personal contact with spouses while hospitalized. No significant differences were found between the lumpectomy group and mastectomy group in the main study in relation to the six research questions.

When the pilot study groups and main study groups were compared, data from both study groups indicated that spouses and children were the most important sources of support for the breast cancer patients. Main study subjects, who were approached during the first two to four months of treatment, reported that their supportive relationships were low in cost and conflict, and high in reciprocity and equity. In contrast, pilot study

subjects, who were approached at a variety of diagnostic and treatment stages, indirectly reported an increase in the cost of and conflict within their supportive relationships when they were expected to return to their roles. An increase in illness symptoms as well as the significant network members' expectations that the pilot study subjects not discuss fears of death and recurrence further disrupted the give-and-take process of exchange.

This study is important because it has identified lumpectomy patients as a potentially vulnerable group in need of psychosocial intervention. It provides a basis for future research, utilizing larger samples and a longitudinal design where differences between the social support of women for breast cancer treated with lumpectomy and mastectomy may be detected. This study has important clinical implications for professional mental health nurses involved in both direct and indirect care of breast cancer patients.

Appendix ASemi-structured Interview Schedule for Pilot Study

Demographic information: Age

Education level

Marital status

- 1) What has it been like for you to be a breast cancer patient?
- 2) Sometimes difficult situation arise. Have there been difficult situations for you that you could talk about? How were you helped? Who was there?
- 3) How has your social support been affected by your illness?
- 4) Who would you call if you needed help? In the middle of the night?
- 5) What are your primary concerns now?

APPENDIX B

Personal Resource Questionnaire, Part II

Q-10 Below are some statements with which some people agree and others disagree. Please read each statement and circle the response most appropriate for you. There is no right or wrong answer.

| STATEMENTS | STRONGLY AGREE | AGREE | SOMEWHAT AGREE | NEUTRAL | SOMEWHAT DISAGREE | DISAGREE | STRONGLY DISAGREE |
|---|----------------|-------|----------------|---------|-------------------|----------|-------------------|
| a. There is someone I feel close to who makes me feel secure..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| b. I belong to a group in which I feel important..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| c. People let me know that I do well at my work (job, homemaking)..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| d. Sometimes I can't count on my relatives and friends to help me with important problems..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| e. I have enough contact with the person who makes me feel special..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| f. I spend time with others who have the same interests that I do..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| g. There is little opportunity in my life to be giving and caring to a child or young person..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| h. Others let me know that they enjoy working with me (job, committees, projects)..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| i. There are people who are available if I needed help over an extended period of time.. | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| j. Often there is no one to talk to about how I am feeling..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| k. Among my group of friends, we do favors for each other..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| l. I have the opportunity to encourage others to grow and develop their interests and skills.. | 7 | 6 | 5 | 4 | 3 | 2 | 1 |

| STATEMENTS | STRONGLY AGREE | AGREE | SOMEWHAT AGREE | NEUTRAL | SOMEWHAT DISAGREE | DISAGREE | STRONGLY DISAGREE |
|---|---|-------|----------------|---------|-------------------|----------|-------------------|
| | m. My family lets me know that I am important for keeping the family running..... | 7 | 6 | 5 | 4 | 3 | 2 |
| n. I have relatives or friends that will help me out even if I can't pay them back..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| o. When I am upset there is someone I can be with who lets me be myself..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| p. I often feel no one has the same problems as I..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| q. I enjoy doing little "extra" things that make a child's or young person's life more pleasant..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| r. I know that others appreciate me as a person..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| s. There is someone who loves and cares about me..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| t. I have people to share social events and fun activities with..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| u. I am responsible for helping to provide for a child's or young person's needs..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| v. If I need advice there is someone who would assist me to work out a plan for dealing with the situation..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| w. I have a sense of being needed by a child or young person..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| x. Sometimes people think that I'm not as good a friend as I should be..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| y. If I got sick there is someone to give me advice about caring for myself..... | 7 | 6 | 5 | 4 | 3 | 2 | 1 |

APPENDIX C



Introduction

Every important relationship between two people has a bother side as well as a benefit side. Think of what support for and from others costs you in bother or trouble. The purpose of these questions is to measure the bother (trouble or cost) as well as benefits of important relationships.

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Permission for use of this
questionnaire may be obtained
by writing to Dr. Tilden,
Oregon Health Sciences University,
School of Nursing, Portland, OR 97201
6/15/84

CONTINUE...

(1)

In the spaces below, list all the people who provide personal support to you and who are important to you. Start with the MOST IMPORTANT person in your life. Use only first names or initials; this is only to help you remember who they are while you complete this questionnaire. For each person you list, state their RELATIONSHIP as shown in this example:

EXAMPLE:

| | | |
|----|----------|----------------|
| a. | (Person) | (Relationship) |
| b. | John | husband |
| | J.M. | father |

YOUR LIST:

| | | |
|------------------------|----------|----------------|
| MOST IMPORTANT 1. | (Person) | (Relationship) |
| NEXT MOST IMPORTANT 2. | _____ | _____ |
| NEXT... 3. | _____ | _____ |
| (etc.) 4. | _____ | _____ |
| 5. | _____ | _____ |
| 6. | _____ | _____ |
| 7. | _____ | _____ |
| 8. | _____ | _____ |
| 9. | _____ | _____ |
| 10. | _____ | _____ |
| 11. | _____ | _____ |
| 12. | _____ | _____ |
| 13. | _____ | _____ |
| 14. | _____ | _____ |
| 15. | _____ | _____ |
| 16. | _____ | _____ |
| 17. | _____ | _____ |
| 18. | _____ | _____ |
| 19. | _____ | _____ |
| 20. | _____ | _____ |

(2)

| | | | | |
|----------|----------|----------|----------|----------|
| PERSON 1 | PERSON 2 | PERSON 3 | PERSON 4 | PERSON 5 |
| | | | | |

NEXT, ENTER THE NAMES OR INITIALS OF THE FIRST FIVE PEOPLE FROM YOUR LIST IN THE SPACES PROVIDED DIRECTLY ABOVE.

On the pages that follow, you will be asked to answer questions about these five people from your list. Select the number from the rating scale that best answers each question, and write it in the corresponding space. For example:

EXAMPLE ANSWERS (using the numbers from the rating scale below)

| | | | | |
|----------|----------|----------|----------|----------|
| Person 1 | Person 2 | Person 3 | Person 4 | Person 5 |
| John | J.M. | Jill | Mom | Fred G. |
| 4 | 4 | 3 | 3 | 3 |

a. How important is this person to you?

| | | | | |
|---|---|---|---|---|
| 4 | 4 | 3 | 3 | 3 |
|---|---|---|---|---|

none or a moderate quite a great
not at all little amount a bit deal

| | | | | |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |
|---|---|---|---|---|

RATING SCALE

As you answer each question on the following pages, rate the overall COSTS and BENEFITS of each relationship you listed, even though they vary from time to time.

There are no right or wrong answers...just select the answer that is most like your HUNCH or GUT FEELING.

NOW, ANSWER THE QUESTIONS THAT BEGIN ON THE NEXT PAGE...

(3)

| | PERSON 1 | PERSON 2 | PERSON 3 | PERSON 4 | PERSON 5 |
|--|----------|----------|----------|----------|----------|
| | ▽ | ▽ | ▽ | ▽ | ▽ |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

QUESTIONS

1. How much time does this relationship cost you?
2. How much effort does this relationship cost you?
3. How much thought does this relationship cost you?
4. How much in the way of services (i.e. babysitting, giving rides, helping out by doing things) do you put into this relationship?
5. How much money or gifts or loans of material things does this relationship cost you?

RATING SCALE

| | | | | |
|-----------------------|----------|----------------------|----------------|-----------------|
| 0 | 1 | 2 | 3 | 4 |
| none or not at all | a little | a moderate amount | quite a bit | a great deal |

(4)

(5)

CONTINUE...

IN EACH RELATIONSHIP, SCORE HOW MUCH YOU GIVE BACK TO THAT PERSON:

| | PERSON 1 | PERSON 2 | PERSON 3 | PERSON 4 | PERSON 5 |
|---|----------|----------|----------|----------|----------|
| 13. Affection, love, or liking | ▽ | ▽ | ▽ | ▽ | ▽ |
| 14. Status, or worth | | | | | |
| 15. Helpful information or advice | | | | | |
| 16. Money (gifts or loans) | | | | | |
| 17. Goods (sharing or giving possessions) | | | | | |
| 18. Appreciation | | | | | |
| 19. Services or doing favors | | | | | |
| Are there any other things that were not mentioned that you give? (please specify & rate) | | | | | |

- 13. Affection, love, or liking
- 14. Status, or worth
- 15. Helpful information or advice
- 16. Money (gifts or loans)
- 17. Goods (sharing or giving possessions)
- 18. Appreciation
- 19. Services or doing favors

Are there any other things that were not mentioned that you give? (please specify & rate)

RATING SCALE

| | | | | | |
|--------------------|---|---|---|---|---|
| none or not at all | 0 | 1 | 2 | 3 | 4 |
| a little amount | | | | | |
| a moderate amount | | | | | |
| quite a bit | | | | | |
| a great deal | | | | | |

(8)

CONTINUE...

(9)

| | PERSON 1 | PERSON 2 | PERSON 3 | PERSON 4 | PERSON 5 |
|--|----------|----------|----------|----------|----------|
| | ▽ | ▽ | ▽ | ▽ | ▽ |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

- 20. How satisfied are you with the balance of receiving and giving back? ...
- 21. How much would you like to change the balance if you could?
- 22. Overall, how much stress for any reason does this person cause you?
- 23. How much trouble is this person to you?
- 24. How much concern or worry do you feel about this person?

RATING SCALE

| | | | | |
|-----------------------|-------------|----------------------|----------------|-----------------|
| 0 | 1 | 2 | 3 | 4 |
| none or not at all | a little | a moderate amount | quite a bit | a great deal |

FOR THE NEXT QUESTION, THE WORDING OF THE RATING SCALE IS A LITTLE DIFFERENT, SO LOOK AT THE NEW SCALE FIRST, THEN ANSWER THE QUESTION.

NEW RATING SCALE

| | | | | |
|-----------------|---------------------|---------------------|-----------------|---------------------|
| 0 | 1 | 2 | 3 | 4 |
| very unequal | somewhat unequal | moderately equal | almost equal | completely equal |

- 25. Overall, how equal is this relationship?

| | PERSON 1 | PERSON 2 | PERSON 3 | PERSON 4 | PERSON 5 |
|--|----------|----------|----------|----------|----------|
| | ▽ | ▽ | ▽ | ▽ | ▽ |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

CONTINUE....

FINAL QUESTIONS

Age at last birthday: _____ Sex: Male
 Female

Legal marital status: Single (never married)
 Married
 Divorced or Separated
 Widowed

Education level: Circle the highest grade of school that you completed.

| | | | | | | | | | | | | | | | | | | | |
|---------------------|---|---|---|--------------------|---|---|---|----------------|----|----|----|--------------------|---|---|---|---|---|---|---|
| <u>grade school</u> | | | | <u>high school</u> | | | | <u>college</u> | | | | <u>grad school</u> | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |

Race: Asian
 Black
 Hispanic
 White
 Other

Occupation: _____
 (fill in)

How many people live with you in your household? _____
 (total No.)

How many of your blood-relatives (i.e. children, brothers, sister, and parents) live within fifty miles of you? _____
 (total No.)

THANK YOU FOR YOUR PARTICIPATION.

APPENDIX D

Oregon Health Science University
Department of Mental Health Nursing

Informed Consent

I, _____

(First Name) (MI) (Last Name)
herewith agree to serve as a subject in the investigation named,
"Effects of surgical intervention on the social support system of
women diagnosed with breast cancer," conducted by Patty Osborne,
RN, BSN, under the supervision of Virginia Tilden, RN, DNSc.

The aim of this study is to explore the effects of
mastectomy and lumpectomy on women's social support. I
understand that I will be asked to complete two written
questionnaires requiring 10 to 15 minutes each. I understand
that the only risk to me may be the inconvenience of completing
the questionnaires and from an increased awareness of social
support deficits and conflicts. While my participation in this
study may not benefit me directly, it may help someone else
diagnosed with a similar illness. My participation in this study
will help nurses better understand social support.

The information obtained by the investigator will be kept
confidential. My name will not appear on the records and code
numbers will be used to protect my privacy. The information will
be destroyed after the project is completed and the results of

the study will be reported in ways that do not identify me with my specific answers. Patty Osborne, RN, has offered to answer any questions that I might have about my participation in this study.

"It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014."

I understand I may refuse to participate or withdraw from this study at any time without affecting my relationship with, or treatment at the

_____.

I have read the foregoing and agree to participate in this study.

(Date)

(Subject's signature)

(Date)

(Witness)

REFERENCES

- Adams, B.N. (1967). Interaction theory and the social network. Sociometry, 30, 64-78.
- American Cancer Society. (1983) Rehabilitation volunteer visitor program guidelines. Unpublished manuscript.
- American Cancer Society. (1985). Cancer facts and figures. New York: N.Y.
- Bard, M., & Sutherland, A.M. (1965). Psychological impact of cancer and its treatment: IV adaptation to radical mastectomy. Cancer, 8, 656-672.
- Baruch, G. & Barnett, K. (1983). Adult daughters relationships with their mothers. Journal of Marriage and the Family, 45, (3), 601-607.
- 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 (2), 186-204.
- Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. Social Science and Medicine, 16 (14), 1329-1338.
- Bluming, A. Z. (1982). Treatment of primary breast cancer without mastectomy. The American Journal of Medicine, 72, 820-827.
- Brandt, P., & Weinert, C. (1981). The PRQ--A social support measure. Nursing Research, 30 (5), 277-267.

- Broadhead, W. E., Kaplan, B. H., James, S. A., Wagner, E. H., Schoenbach, V. J., Grimson, R., Heyden, S., Tibblin, G., & Gehlbach, S. H. (1983). The epidemiological evidence for the relationship between social support and health. American Journal of Epidemiology, 117 (5), 521-537.
- Cassel, J. (1976). The contributions of the social environment to host resistance. American Journal of Epidemiology, 104, 107-123.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic medicine, 38 (5), 300-314.
- Cohen, C. I., & Sokolovsky, T. (1978). Schizophrenia and social networks: Ex-patients in the inner city. Schizophrenia Bulletin, 4 (4), 546-560.
- Dimond, M. (1979). Social support and adaptation to chronic illness: The case of maintenance hemodialysis. Research in Nursing and Health, 2 101-108.
- Erikson, E. (1963). The eight stages of man. Childhood and society. (Second ed., pp.247-269) New York: Norton.
- Funch, D. P., & Marshall, J. (1983). The role of stress, social support, and age in survival from breast cancer. Journal of Psychosomatic Research, 27 (1), 77-83.
- Funch, D. P., & Mettlin, C. (1982). The role of support in relation to recovery from breast surgery. Social Science and Medicine, 16 (1), 91-98.

- Gallo, F. (1982). The effects of social support networks on the health of the elderly. Social Work in Health Care, 8 (2), 65-74.
- Galyen, R. (1985). The confidant relationship and psychological adjustment among persons with lymphatic cancer or multiple myeloma. Unpublished master's thesis. Oregon Health Sciences University, Portland, OR.
- Gottlieb, B. H. (1982). Preventive interventions involving social networks and social support. In B. H. Gottlieb (ed.), Social network and social support, (pp. 201-222). Beverly Hills: Sage Publications, Inc.
- Jamison, K., Wellisch, D. K., & Pasnau, R. D. (1978). Psychological aspects of mastectomy: 1. The woman's perspective. American Journal of Psychiatry, 2, 117-132.
- Lee, E. C., & Maguire, G. P. (1975). Emotional distress in patients attending a breast clinic. British Journal of Surgery, 62 162.
- Lierman, L. M. (1982). Psychological preparation and supportive care for mastectomy patients. Western Journal of Nursing Research, 4 (3), 13-18.
- Margolis, G. J., Carabell, S. C., & Goodman, R. L. (1983). Psychological aspects of primary radiation therapy for breast carcinoma. American Journal of Clinical Oncology, 6 533-538.
- McCullough, C. (1981). Launching children and moving on. In E. A. Carter and M. McGoldrick (eds.), The family life cycle, (pp. 171-196). New York: Gardener Press, Inc.

- McDonald, G. W. (1981). Structural exchange and marital interaction. Journal of Marriage and the Family, 54, 825-839.
- Meyerowitz, B. E. (1983). Postmastectomy coping strategies and quality of life. Health Psychology, 2 (2), 117-132.
- Meyerowitz, B. E., Watkins, I. K., & sparks, F. C. (1983). Psychosocial implications of adjuvant chemotherapy: A two-year follow-up. Cancer, 52 1541-1545.
- Mitchell, R. E. (1982). Social networks and psychiatric clients: The personal and environmental context. American Journal of Community Psychology, 10 (4), 387-401.
- Morris, T., Greer, H., & White, P. (1977). Psychological and social adjustment to mastectomy. Cancer, 40, 2381-2387.
- National Cancer Institute (1979). Breast cancer digest, (pp. 26-31). Maryland: Office of Cancer Communications.
- Norbeck, J. S. (1982). The use of social support in clinical practice. JPNMHS, 20 (12), 22-29.
- Norbeck, J. S. (1981). Social support: A model for clinical research and application. Advances in Nursing Science, 3 (4) 43-59.
- Pattison, E. M., DeFrancisco, D., Wood, P., Fraxier, H., & Crowder, J. (1975). A psychosocial kinship model for family therapy. American Journal of Psychiatry, 132 (12), 1246-1251.
- Peck, A. (1972). Emotional reactions to having cancer. American Journal of Roentgenology, 114 591-599.

- Peters-Golden, H. (1982). Breast cancer: Jarred perceptions of social support in the illness experience. Social Science Medicine, 16, 483-491.
- Polit, D., & Hungler, B. (1983). Non-experimental research. In D. Polit & B. Hungler (eds.), Nursing research; principles and methods, (Second ed., pp. 188-218) Philadelphia: J. B. Lippincott Co.
- Quint, J. C. (1963). The impact of mastectomy. American Journal of Nursing, 63 (11), 82-92.
- Revenson, T., Wollman, B., & Felton, B. (1983). Social supports as stress buffers for adult cancer patients. Psychosomatic Medicine, 45 (4), 321-331.
- Ridley, C., & Avery, A. (1979). Social network on the dyadic relationship. In R. C. Burgess & T. L. Huston (eds.). Social exchange in developing relationships, pp. 223-246. New York: Academic Press. 223-246.
- Sanger, C. K., & Reznikoff, M. (1981). A comparison of the psychological effects of breast saving procedures with the modified radical mastectomy. Cancer, 48 2341-2346.
- Schain, W., Edwards, B. K., Gorrell, C. R., Moss, E. V., Lippman, M. E., Gerber, L. H., and Lichter, A. S. (1983). Psychosocial and physical outcomes of primary breast cancer therapy: Mastectomy versus excisional biopsy and irradiation. Breast Cancer Research and Treatment 3, 377-382.
- Sontag, S. (1979). Illness as a metaphore. New York: Vintage Books.

- Steinburg, M. D., Juliano, M. A., and Wise, L. (1985). Psychological outcome of lumpectomy versus mastectomy in the treatment of breast cancer. American Journal of Psychiatry, 142 (1), 34-39.
- Terkelson, R. (1981). Toward a theory of the family life cycle. In E. A. Carter and M. McGoldrick (eds.), The family life cycle, (pp. 21-52). New York: Gardener Press, Inc.
- Tilden, V. (1984). The development of an instrument to measure social support, cost, and reciprocity. Unpublished manuscript.
- Tilden, V. (1983). The relation of life stress and social support to emotional disequilibrium during pregnancy. Research in Nursing and Health, 6, 167-174.
- Tilden, V., & Galyen, R. (In press). Cost and conflict: the darker side of social support. Western Journal of Nursing Research.
- Thoits, P. A. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior, 23, 145-159.
- Weinert, C. (1982, October). Evaluation of the PRQ: A social support measure. Nursing roundtable conference on social support and families of vulnerable infants, 24-26.
- Weisman, A., & Worden, J. W. (1976). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry in Medicine, 7 (1), 1-15.

- Weiss, R. S. (1974). The provisions of social relationships. In Z. Rubin (ed.), Doing unto others (pp. 16-26). Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Wellman, B. (1982). Applying network analysis to the study of support. In B. H. Gottlieb (ed.), Social networks and social support, (pp. 171-201). Beverly Hills: Sage Publication.
- Wilcox, B. L. (1982). Social support in adjusting to marital disruption: A network analysis. In B. H. Gottlieb (ed.), Social networks and social support, (pp. 97-115). Beverly Hills: Sage Publications.
- Woods, N. F., & Earp, J. L. (1978). Women with cured breast cancer: A study of mastectomy patients in North Carolina. Nursing Research, 27 (5), 279-285.
- Wortman, C. B. (1984). Social support and the cancer patient: conceptual and methodologic issues. Cancer, 53, 2339-2362.
- Wortman, C., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer. Journal of Social Issues, 35 (1), 120-155.

AN ABSTRACT OF THE THESIS OF

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This ex post facto correlational field study sought to provide additional information on the relationship between social support and two methods of surgical treatments for breast cancer. The independent variable was type of surgical treatment (lumpectomy versus mastectomy) and the dependent variable was perceived social support. Fifteen women participated in a pilot study, 8 having been treated with lumpectomy and 7 having been treated with mastectomy. Nineteen women participated in the main study, 8 having been treated with lumpectomy and 11 having been treated with mastectomy. Main study subjects were newly diagnosed breast cancer patients. Mastectomy patients' treatment protocol only included surgery whereas the lumpectomy patients' treatment protocol included surgery and an irridium implant. Subjects were a convenience sample drawn from five private metropolitan medical centers. The pilot study was first conducted for the purpose of identifying variables to be examined in the main study. The main study examined six research questions. Summarized they are: Are there differences in post surgery lumpectomy patients' and mastectomy patients' social support network characteristics? Are there dirrences in post srugery lumpectomy patients' and mastecoly patients' perceptions of cost, conflict, reciprocity, and equity of social support? The Personal Resource Questionnaire (Brandt & Weinert, 1981) and the Cost, Conflict and Reciprocity of Social Support (Tilden, 1984) was used to assess these variables. Qualitative analysis of pilot study interviews showed both surgical groups to focus on fears of recurrence, mutilation, and death. Lumpectomy subjects reported low perceived social support was attributed to the limited extent of surgery. In contrast, mastectomy subjects attributed low perceived social support to their own inability to reciprocate social support, an increase in illness symptoms, and decreased personal contact with husbands during hospitalization. Quantitative analysis, using Students' t statistic, of main study findings indicated no significant differences between the two

groups in any of the six research questions. Spouses and daughters were named as primary sources of support. Trends in reported cost suggested a gradual decrease in this variable across the five most important network persons. Perceived conflict remained low while a relatively high level of perceived reciprocity and equity was reported across the five most important network persons. Generalizability of findings are limited due to small sample size and probable sample bias. However, this study may have important practice implications.