Breast cancer patients: depression and satisfaction with support systems.

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BREAST CANCER PATIENTS:
DEPRESSION AND SATISFACTION WITH SUPPORT SYSTEMS

A Thesis Presented
By
Therese P. Rumpf

Submitted to the Graduate School of the
University of Massachusetts in partial fulfillment
of the requirements for the degree of

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BREAST CANCER PATIENTS:
DEPRESSION AND SATISFACTION WITH SUPPORT SYSTEMS

A Thesis Presented
By
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"Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

Susan Sontag
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CHAPTER I
INTRODUCTION

Statistics on breast cancer tell a sobering tale. According to the American Cancer Society (1978), breast cancer is found in some 90,000 women in America each year: approximately one out of thirteen women. The majority of breast cancers are discovered by women themselves. It is currently the leading cause of death among women aged 40 to 44, and kills some 43,000 women annually. The risk of breast cancer increases with age; about 75% of all breast carcinoma occurs in women aged 50 or above.

Unfortunately, our understanding of many of the physical and emotional dimensions of cancer are still very limited. Yet understanding the psychological and emotional dynamics of serious illness can be considered one of the most important contributions that the behavioral sciences can make to medicine (Lipowski, 1969). The process of understanding the adjustments that a person makes to illness is difficult because of the large number of variables that need to be considered: e.g., the type of illness, the personality of the patient, the quality of available care, the attitudes of those nearby, the amount of physical discomfort, and the meaning of the illness to the individual (Lipowski, 1969; Hinton, 1977).

The crisis of a serious illness like breast cancer is a time when past and present experiences converge, and the response of the indivi-
dual is likely to be shaped by previous experiences which are called into play as well as by the nature of current events (Klein, 1971). Thus, understanding the way in which a person copes with cancer requires an understanding of the many real world factors which confront the individual, and at the same time requires an understanding of the subjective world of the individual, i.e., how s/he perceives and makes sense of what is happening.

Some aspects of the situation are likely to be felt as stressful by the vast majority of this population: finding a lump, waiting for an appointment with a physician, biopsy, surgery, recovery time in the hospital, pain and discomfort, a post-surgical convalescent period, loss of an important body part, threat of recurrence, threat to life and the quality of living. Other factors, such as reaction to the hospital environment, ways of responding to threat, ability to cope with stress, interpretation of illness, and the attribution given to the illness are largely determined by the intrapsychic makeup of the individual, as are levels of depression, anxiety, and hostility. In addition, the effect of breast cancer on such variables as self esteem, body image, and the ability to communicate is also determined by the unique psychic structure of the person involved. Therefore one would expect there to be significant differences in the above variables among women sharing this experience.

Other "external" factors, such as the amount of time involved in waiting while various procedures are scheduled, the quality of care available, the type of relationships that the patient has with doctors,
nurses, and other medical personnel, as well as the support received from family and friends, also play an important role in determining the nature of this experience. These too may vary widely from one individual to another.

In this study several assumptions underlie these considerations of adaptation and reaction to serious illness. The first of these assumptions concerns the nature of coping. As it is usually conceived clinically, the coping mechanisms utilized by an individual appear as products of the intrapsychic structure of that individual and are determined by intrapsychic functions. However, the social context can also be an important determinant of coping and adjustment responses (Appley, 1952; Cobb, 1976), one which can ameliorate and modify the stresses of serious illness.

A second assumption is that cancer is a disease which is interpersonal in nature; it is a disease which affects not only the person in whom it is diagnosed, but those who fall within the interpersonal nexus or support system of that individual as well. A large number of researchers have stressed the interpersonal nature of cancer (Abrams, 1966; Bard, 1952; Bard and Sutherland, 1955; Carey, 1974; Cobb, 1976; Dyk and Sutherland, 1956; Giacquinta, 1977; Harker, 1972; Hinton, 1977; Jamison et al, 1978; Klein, 1971; Lieber et al, 1976; Peck, 1972; Sutherland and Orbach, 1953; Wellisch et al, 1978; Winder and Elam, 1978; Wortman and Dunkel-Schetter, 1978, 1979), but only a few have made social support or interpersonal relationships the focus of their research.

A third assumption is that cancer is a disease which causes stress.
While initially this may seem a simplistic or redundant statement, it is made here to establish the idea that one does not have to be identified as neurotic or have any other sort of nosological label to have a strong emotional reaction to serious illness. While underlying pathology may influence the way in which one reacts to disease, and may influence the configuration of coping and defense mechanisms, cancer is stressful in a wide variety of ways in an objective sense.

All of these represent starting points: points from which to begin an investigation of this important area of so many unknowns. This study begins by exploring the following questions:

1. Is there a significant correlation among women who have had a mastectomy between perceiving interpersonal relationships as supportive and satisfactory, and lower levels of depression?

   1a. Are women who feel that they are able to communicate their needs and concerns satisfactorily less depressed than women who feel they cannot do so?

   1b. What do these women have to say about what makes a response from significant others satisfactory or unsatisfactory? What ways of responding do they find supportive? Not supportive?

2. Are women who need chemotherapy after surgery more depressed than women who need no further immediate treatment after surgery?

   Literature pertinent to these issues touches on a wide variety of topics: stress, coping, depression, social support, crisis, neoplastic disease, family systems, and interpersonal relationships. In order to organize these into a format relevant to this study, the fol-
The following literature review has been divided into three parts: psychosocial aspects of breast cancer, interpersonal aspects of cancer, and cancer and emotions.

**Psychosocial Aspects of Breast Cancer**

Psychological investigators of breast cancer and mastectomy can be divided into two groups: (a) those who have studied the experiences and ways of responding of individuals who have had a diagnosis of cancer, and (b) those researchers who have tried to find specific connections between cancer and certain personality traits or patterns of behavior.

A large number of studies have been done which basically support the notion that various forms of life stress may be significant factors in the subsequent development of neoplastic disease (Bahnson and Bahnson, 1966; Brown, 1966; Coppen and Metcalfe, 1963; Greene, 1966; Huggen, 1968; Kissen, 1966, 1967, 1969; Kissen and Eysenck, 1962; Kissen and Leshan, 1964; Kowal, 1955; Leshan, 1956, 1966; Schmale, 1958; Schmale and Howard, 1966; Schmale and Iker, 1966). Writing specifically about the connection between breast cancer and personality traits or behavior patterns are Bacon et al, 1952; Muslin et al, 1966; Renneker et al, 1963; and Reznikoff, 1954.

Personality types delineated by these studies point to the development of breast cancer in women who tend to be masochistic, excessively guilty, hopeless, or despairing; who are unable to express anger or who cover it with a pleasant exterior. Other studies stress life events
which are implicated in the development of neoplastic disease: separation experiences, lack of individuation from one's mother, and excessive responsibility in childhood are mentioned. Although there does not appear to be any agreement about just which stressful life experiences, or personality traits, may foster the development of neoplastic disease, the fact that so many epidemiological studies have been done in this area can hardly be ignored.

Perhaps at some future time, we may be able to say with some degree of certainty that certain stressful life experiences or personality traits play an important part in the etiology of cancer. What seems questionable is that the variables represented in these studies will be the ones implicated, because these variables represent a specific cultural context and represent what our society considers problems in living. Sontag makes this point in her recent book, Illness as Metaphor (1978), in which she compares cancer, the most dreaded disease of the 20th century, with tuberculosis, its analogue during the 19th century.

Before the discovery that a bacillus caused it, T.B. was commonly conceived of as a disease brought on by an excess of passion or passionate emotion. The studies mentioned above attempt to find connections between cancer and the repression of violent emotion or expression of despair, etc. In any case, the individual is held responsible for his/her own disease; a kind of "blaming the victim." Sontag writes that "the view of cancer as a disease of the failure of expressiveness condemns the cancer patient; expresses pity, but also conveys contempt"
(1978, p. 49). Wortman and Dunkel-Schetter (1978, 1979) have elaborated on the concept of the cancer patient as victim, and on the kind of mixed messages and approach-avoidance ways that victims are often treated.

If the notion that stressful events cause cancer is open to debate, the idea that cancer is a disease which is inherently stressful and disruptive in nature is beyond dispute. Bard (1952) says that the emotional reaction begins as soon as a lump is discovered. In the series of stressful events which begins with this discovery and ends with postsurgical convalescence, an individual's response is shaped by each of the previous events in the sequence, as well as by previous life experiences (Bard and Sutherland, 1955). Fears and anxieties generated during this sequence of events are numerous: fears of anesthesia; fears of surgery; concern for the preservation and continuity of one's existence; fear of disfigurement; fear that one will not be able to take up one's previous life activities; fear of inability to plan for the future; fears of disruption of sexual relationships; fears about interpersonal relationships; derogation of self worth; fears of isolation, alienation, and rejection; fear of physical pain; separation from one's family; loss of work; difficulties in communication; anticipation of loss of femininity and death constitute only a partial list mentioned in the literature (Asken, 1975; Bard, 1952; Bard and Sutherland, 1955; Goldsmith and Alday, 1971; Healy, 1971; Hinton, 1978; Jamison et al, 1978; Klein, 1971; Polivy, 1977; Wellisch et al, 1978).

The stressfulness of the life situation of the individual at the
time the cancer is discovered appears to be a significant influence on the series of events which follow. Bard and Sutherland (1955) state that a patient's response to hospitalization may be greatly influenced by the life problems she is experiencing at the time of surgery. Once the mastectomy is over, a process begins of repairing the physical and emotional upheaval. Some difficulties at this stage may result from the surgical experience: feeling that one's body has been damaged, that it has been mutilated or is no longer whole; feelings of increased vulnerability due to a weakened condition; fears of complications which may cause prolonged periods of convalescence; and feelings of weakness which may increase feelings of vulnerability.

Looking at women in their sample who judged themselves to be better adjusted after mastectomy, Jamison et al (1978) found that better adjusted women in their study had lower scores on the EPI Neuroticism Scale, had a more external locus of control, had been married longer, were older and perceived more support from spouses, nurses, physicians, and their children than women who had lower adjustment levels.

In an effort to assess the effects of mastectomy on self concept and body image, Polivy (1977) found that immediately after mastectomy there were no significant changes reported in either body image or total self image scores (total self image = body image + self concept + satisfaction with relationships score on the Berscheid, Walster, and Bohrnstedt Body Image Scale), but that on the second follow up several months after surgery, scores indicated a loss of self-esteem for mastectomy patients. In contrast, women with benign breast disease indi-
cated lower self image scores immediately after biopsy, but reported no significant change on the second testing.

Age does appear to be a significant factor in post-mastectomy adjustment (Jamison et al, 1978; Kushner, 1975). Both these researchers found that younger women, i.e., women under 45, rated their adjustments as significantly more difficult than women over 45. One might hypothesize that younger women feel more threatened by the loss of a body part which is so intimately connected to our cultural standards of physical attractiveness and sexuality.

The role of mourning and grief in relation to the loss of an important body part is stressed by Harker (1972) and Klein (1971), who consider that mourning one's loss is an integral part of the healing process. Grief must be expressed, and the loss must be dealt with in order for a patient to begin to reintegrate a sense of wholeness, self worth, and self esteem. While the nature of mourning and grief may take on many different forms, Klein stresses that it may include coming to terms with fears of recurrence and death as well as loss of a breast.

**Interpersonal Aspects of Cancer**

As stated earlier, this writer shares the opinion that cancer is a disease which causes stress and is stressful not only to the individual who has received the diagnosis, but to those other individuals who care for and support him/her as well. Likewise, the role played by individuals in the social environment is seen as crucial in deter-
mining the kind of experience a person with cancer can have. At a time when so many things seem ambiguous, the need to feel supported and cared for is critical (Wortman and Dunkel-Schetter, 1979). The role played by the social network is considered significant in its potential for relieving stress, offering emotional support, and being able to help in more pragmatic, instrumental ways. Social support is defined by Cobb (1976) as information which provides the individual with a "sense of being cared for and loved, valued and esteemed, and which offers the individual membership in a network which can share and support him/her" (p. 300).

While there can be little doubt that an individual with a serious illness has need of emotional and instrumental support, difficulties in communicating the need for support and in receiving support appear to be considerable. Wortman and Dunkel-Schetter (1979) find that cancer patients need to "clarify what is happening to them and to be supported and reassured by others" (p. 8). Clarification is often difficult, since answers to any number of questions concerning the status of the disease may not be possible, or may involve periods of waiting. In addition, while others may want to offer support and reassurance to the patient, they may not feel very reassured, given the amount of ambiguity inherent in the situation, and may find themselves in the difficult position of wanting to express something they do not feel. To further complicate the situation, many people feel that "being cheerful" is the proper way to act in the presence of someone who is ill. Often, the effect of this is to stress both parties.
Family relationships often constitute the first line of support in a crisis, and the support (or lack of it) from family members is believed to have a definite influence on the outcome of an illness (Cobb, 1976; Dyk and Sutherland, 1955; Giacquinta, 1977). Illness may either pull a family together or push members apart, increasing alienation and feelings of isolation. Klein (1971) says that the family has the ability either to help or to hinder the individual who is trying to cope with cancer. Individuals within a family system often have shared or agreed-on patterns of communication. While these may work well in normal situations, the person with cancer may suddenly find she has the need to communicate ideas or emotions which fall outside the accepted patterns of the family. When such "unacceptable" feelings arise, communication becomes difficult, if not impossible. Personal accounts by Harker (1972) and Rollins (1975) bear this out.

Harker (1972) feels that it must be the patient herself who sets the tone of communication with others; she must lead and give others cues as to what she feels is acceptable and desirable to communicate. However, the fact that the subject of discussion is cancer complicates the situation. In addition, while others may find it difficult to express their feelings, the presence of anxiety and depression in the patient can make things even more difficult. According to Harker, "it often happens, that the patient becomes depressed and uncommunicative, and others, taking their cue from him [sic] leave him [sic] alone, reduce conversation or become visibly anxious or even irritated. An interpersonal stalemate is reached" (p. 166).
The end result may be a conflicting series of emotions about what to do, what to say, and how to act, both on the part of the patient and on the part of others close to the patient. Patients may be put in the difficult position of being forced to choose between expressing their true feelings at the risk of alienating those on whom they are most dependent, or faking cheerfulness and risking their own increased sense of isolation and alienation. Or, rather than choose one way or the other, the patient may oscillate between the two (Worthman and Dunkel-Schetter, 1979).

Lieber et al. (1976) studied patients who were deprived of normal interpersonal relationships because they were undergoing a type of chemotherapy which necessitated that they be kept in a special germ-free unit. All physical contact was prohibited. Thirty-eight men and women with cancer and their respective spouses took part in the study (N = 76). Results showed that feelings of affection increased among 28% of the participants, decreased among 13%, and 59% reported no change. All groups except men patients (women patients, husbands, wives) reported some increased frequency of positive feelings. Of the participants, 49.3% reported an increased desire for physical closeness since the onset of illness, but less than 6% reported an increased desire for sexual intercourse. Also reported were depression scores for each of the four subgroups. Women patients were reported as the most depressed, while their husbands reported the lowest level of depression among the subgroups. The study concludes that, for the majority of these couples, the stresses of living with cancer and chemotherapy did not
produce circumstances of alienation and withdrawal. Feelings of affection either increased or remained the same. The major change in relationships once illness was diagnosed was the increased desire for physical closeness and a decreased desire for sexual intercourse.

Encouraging as the previous study may appear, Jamison et al. (1978) found that little or no time was spent talking about the emotional concomitants of mastectomy with either spouse or a significant other. Among the 41 women they studied, 89% had little or no discussion of feelings prior to surgery; 87% had little or no discussion of feelings while in the hospital; and only 50% discussed their feelings after returning home. In a companion study, Wellisch et al. (1978) interviewed spouses of women with breast cancer and reported that of 31 men, 56.6% saw themselves as having been considerably involved in the decision-making process before surgery. Men who rated their involvement as high also perceived more sexual satisfaction in their relationships than men who were less involved.

Concerning the influence of mastectomy on sexual relationships, 14.3% of the spouses reported a "bad" effect, 21.4% reported a "somewhat bad" effect, and 57.1% reported that surgery had no influence on their sexual relationship at all. However, although the majority did not report a significant disturbance in their sex life, 42.8% of the spouses reported that their ability to work had been adversely affected by their experience, 40% reported sleep disorders and nightmares, and 26.7% reported disturbances in their eating habits.

Finally, when speaking of interpersonal relationships and cancer,
one cannot underestimate the importance of relationships with those in the medical environment: the physicians first and foremost, because so much depends on their judgement, but also important are contacts with nurses, social workers, X-ray technicians, etc. (Abrams, 1966; Asken, 1975; Bard and Sutherland, 1955; Giacquinta, 1977; Goldsmith and Alday, 1971; Harker, 1972; Hinton, 1978; Jamison et al., 1978; Mitchell and Glicksman, 1977; Peck, 1972; Sutherland and Orbach, 19753; Winder and Elam, 1978; Wortman and Dunkel-Schetter, 1979).

Jamison et al. (1978) reported better psychological adjustment after mastectomy among those women who perceived more support from doctors and nurses. Abrams (1966), Peck (1972), and Hinton (1978) discuss feelings of dependence on the physician through various stages of illness when the doctor-patient relationship may be loaded with conflicting emotions and ambivalent feelings. Both Harker (1972) and Wortman and Dunkel-Schetter (1979) mention ambivalent feelings of physicians when discussing the nature of the disease with cancer patients. Peck (1972) stresses that it is of the utmost importance that physicians be in touch with their own feelings about cancer in order to work effectively with cancer patients, since excessive anxiety can lead to difficulties in communicating important information to the patient. Likewise, the physician should be prepared to spend time with the patient, particularly in the pre-surgical period, and should encourage her to express her feelings and ask questions so that any distortions can be corrected and some of the stressfulness of this period perhaps mitigated (Bard and Sutherland, 1955). The importance of the doctor-
patient relationship as a factor which can decrease anxiety is also
discussed by Sutherland and Orbach (1953) who report that an anxious
patient is less likely to relate to medical personnel, risking an in-
crease in isolation which could escalate to the point of total break-
down.

Patients may have many conflicting and ambivalent feelings toward
their physicians since the role played by the doctor is so crucial.
Anger, which may actually be a positive sign, may be misunderstood by
hospital personnel, as may expressions of dependence. Anger may be
expressed by a patient, even when a physician has been particularly
supportive, and can be interpreted as an indication that the patient
feels secure enough in the relationship to express this emotion (Bard
and Sutherland, 1955).

The positive effects of intervention by professionals are discussed
by Winder and Elam (1978) and Wortman and Dunkel-Schetter (1979). A
number of health care professionals (e.g., nurses, social workers, and
psychologists) who are familiar with the situation of the cancer patient
can intervene to decrease the emotional tension of both the patient
and family members.

**Cancer and Emotions**

Emotional responses to cancer have been an important area of in-
vestigation (Bard and Sutherland, 1955; Craig and Abeloff, 1974; Harker,
1972; Jamison et al., 1978; Lieber et al., 1976; Peck, 1972; Plumb and
Holland, 1977; Sutherland and Orbach, 1953). While depression appears
to be the most frequently studied response, anxiety, anger, guilt, denial, and bitterness are also cited as emotions which significantly affect the course of adaptation and interpersonal relationships.

While the literature on depression is too extensive to be covered in this review, a useful perspective on depression is one formulated by Coyne (1976) who proposes that depression in one individual significantly affects the affective states of members of the individual's environment. Included in this is the idea that depressed persons provoke hostility and depression in members of their social environments, although these others may attempt to respond to the depressed person with the kind of non-genuine reassurance and support mentioned earlier by Wortman and Dunkel-Schetter (1979).

Depression as an immediate response to mastectomy is discussed by Bard and Sutherland (1955) and Harker (1972). Using the Beck Depression Inventory, Plumb and Holland (1977) found that patients with advanced cancer were no more significantly depressed than were their immediate family members, and appeared to be significantly less depressed than patients who had been hospitalized after suicide attempts. A further finding of this study was that the self esteem of both cancer patients and family members appeared to remain intact. The authors suggest, therefore, that it was the situation that the person was in, as opposed to factors intrinsic to the individual, which appeared to be distressing.

Sutherland and Orbach (1953) state that post-surgical depression may be related to a sense of injury to the self, but that it is more
likely to be a reflection of the changes that surgery is apt to bring about in the patient's life and life style. Depression is likely to persist, they report, until the individual is able to resume presurgical activities which are deemed important. In the case that the individual is not able to do so, because of the limitations imposed by surgery, s/he is apt to maintain a level of depression. Other reasons for an extended depression are feelings of physical frailty and the diminished role, rather than the role of caretaker that one had previously identified with.

Peck (1972) found anxiety to be the most common response in the patients he studied. Depression appeared as the second most common response: 37 out of the 50 patients interviewed were rated depressed (5 severely depressed, 16 moderately depressed, and 16 mildly depressed). Other prevalent emotions reported were guilt (in 18 of the 50 patients) and anger (in 22). An interesting note is that the 14 most angry patients in Peck's study included the 10 who appeared to be the most anxious.

Findings of Craig and Abeloff (1974) disagree to some extent with those of Peck (1972). In a study of 30 hospitalized cancer patients, more than 50% reported moderate to high levels of depression and only 30% had elevated anxiety scores.

Plumb and Holland (1977) reported that of the cancer patients in their sample, 77% had Beck Depression Inventory scores which indicated that they were not depressed, 19% had moderate levels of depression, and only 4% were severely depressed.
The discrepancies in levels of depression reported by these studies raise some questions about the amount and quality of depression one might expect to find in this population. Unfortunately, few studies have utilized the same measurement instruments, although both Lieber et al. (1976) and Plumb and Holland (1977) used the Beck Depression Inventory. In addition, there are inherent difficulties in studying cancer patients; e.g., difficulties in comparing patients with different types of cancer and different prognoses, difficulties in finding patients who have had about the same amount of time pass since diagnosis or surgery, variation in age, socio-economic status, education, and other demographic variables all complicate the study of emotion in this population.

Cancer and Social Support

In any crisis situation, the quality of social support can have an influence on the way in which the crisis is resolved (Cobb, 1976; Walker et al., 1977). Factors which influence the quality of the support are (a) the needs of the individual and (b) the ability of individuals within the network to respond and to extend the appropriate kind of support. In essence, there must be a positive match between what the individual needs from others and what those others are able to give to the individual. The person with cancer who asks friends and relatives for support and caring must receive this kind of emotional support in order for the network to be helpful. Instrumental support may also be welcomed, but will not act as a substitute.
Since not all members of a network are apt to have equal ability to respond to the needs of a person with cancer, it seems reasonable to suggest that one or two close family members ought not to be put in the position of trying to cope with the variety of stressful situations and needs that arise. While the actual size of an individual's network is not necessarily a relevant factor, one hypothesis is that a network which is sufficiently large and diverse (i.e., composed of different types of people) will be able to accommodate a greater diversity of needs.

Underlying the willingness to communicate needs for support, affection, caring, etc., one needs to maintain the belief that there is a network composed of individuals who have the potential to respond to these needs. While a crisis such as cancer may call forth stresses which have not been encountered before, an individual who is convinced at the onset that no one will respond to him (or her) is not likely to even ask for support, and is likely to be more alienated and depressed than the person who feels cared for and supported.

Hypotheses

Based on the research presented in the literature review, the following hypotheses were generated:

1. Scores on the Beck Depression Inventory will not be significantly different for the sample of women (N = 10) undergoing chemotherapy and/or radiation and those (N = 10) who require no treatment after surgery.
2. Scores on the Multiple Affect Adjective Checklist will not be significantly different for the sample of women undergoing chemotherapy and/or radiation and those who require no treatment after surgery.

3. Scores on the satisfaction with communication scale of the Social Support Questionnaire will not be significantly different for the two groups of women.

4. Scores on the satisfaction with response scale of the Social Support Questionnaire will not be significantly different for the two groups of women.

5. Women in both groups who have higher scores on the satisfaction with communication scale will score lower on the Beck Depression Inventory than women whose scores on this scale indicate less satisfaction with their ability to communicate.

6. Women in both groups who have higher scores on the satisfaction with response scale will have lower scores on the Beck Depression Inventory than women whose scores on this scale indicate that they are less satisfied with the responses they receive from close friends and family members.
Chapter II
Method
Participants

Twenty-two women completed questionnaires and were interviewed for this study. Questionnaire data from two women could not be used: in one case the woman had had her mastectomy prior to the two-year time limit, and in the other the woman had made a decision not to have a mastectomy. (The latter had simply had the tumor excised, followed by radiation therapy.) The remaining twenty women are divided into two groups: those who received chemotherapy and/or radiation after their surgery and those who had no follow-up treatment.

Ages of the 22 women interviewed ranged from 29 to 67. The mean age of women who had (or were having) chemotherapy or radiation was 43 (the range was 29-59). The mean age of women who had no follow-up treatment was 49.6 (the range was 30 to 62).

Level of education varied widely among the women. The mean number of years spent in school was approximately 14.7. One woman had only completed the 9th grade, while one had an M.D. from a foreign medical school and another had completed a Ph.D. Of the 22 women interviewed, 14 were involved in some kind of work at the time they were interviewed, three had retired (two of the three had done so following surgery; one of these had given up her job because of the difficulty of working and undergoing chemotherapy simultaneously), and five were
housewives. One woman, a nurse, who had been having both chemotherapy and radiation treatments, gave up her job shortly after she was interviewed.

All of the women interviewed were Caucasian. Their geographic distribution was diverse: urban areas, suburbs, and small towns were represented in the sample. In general, this was a well-diversified group of women, who did not appear to have much in common as a group other than the fact that they all had breast cancer. To provide some sense of the variety of women in the sample, a very brief description of some life circumstances of each of the participants follows.

Group A. 1. A 30-year-old married woman with one six-year-old daughter who had been born and brought up in England but was married to an American and had lived in Massachusetts for some years. She worked as a nurse, had taken several months off following surgery, but had returned to work at the time the interview took place. No further treatment had been necessary following surgery.

2. A 36-year-old married woman with two sons, aged seven and nine, who had had fifteen years of education and was currently at home with her children. Chemotherapy had been initially recommended to her, but after consulting several physicians she had decided against it and had had no further treatment at the time she was interviewed.

3. A 56-year-old married woman with 14 years of education and four living children, aged 22-33. A fifth child had died at age ten. This woman worked as a secretary in a local hospital where she had the opportunity to come into contact with many seriously ill patients.
She had had no further treatment following her surgery, when interviewed.

4. A 40-year-old married woman with a six-year-old son and 17 years of education who produced and directed plays in an urban area. This woman had undergone two mastectomies and had had breast reconstruction. She felt very strongly in favor of reconstruction and felt that women were not being adequately informed about the potential for this procedure. She had had no follow-up treatment after her second mastectomy.

5. A 62-year-old married woman with 14 years of education and a 38-year-old son and who was a part-time antique dealer. As in the second case mentioned above, chemotherapy had been suggested but she had decided against it and had had no further treatment after surgery.

6. A 58-year-old woman with 16 years of education and a 23-year-old daughter and who was a housewife. This woman felt her disease had been treated at a very early stage and had had no follow-up treatment after surgery.

7. A 57-year-old married woman with three children aged 22-28 and 14 years of education and who was a bookkeeper in an insurance agency and whose husband had also been treated for cancer. This woman had had no further treatment after surgery.

8. A 46-year-old teacher with a B.S. and some additional graduate credits who had three sons, 15-19 years old. This woman had been widowed and was recently remarried at the time her cancer was discovered. She had made a major move when she remarried. She had had no further treatment.
9. A 60-year-old widow who had one 28-year-old son, who had been a clerk with the postal service, but who had retired after her mastectomy. This woman had no further treatment although she had been told that a number of lymph nodes were positive.

10. A 50-year-old woman who had been divorced twice and was currently married to her third husband, this woman was the mother of twin daughters, aged 25. She had earned a M.D. degree in her native country (Scotland) and had come to the U.S. to do an internship. She had not practiced medicine, although she had completed the internship, and was otherwise employed at the time she was interviewed. She had not been treated following her mastectomy.

Group B. 11. A 42-year-old married woman with a high school education and three children aged 12-18, this woman was employed at a local state institution for the retarded. She was undergoing chemotherapy at the time she was interviewed and had recently been told that the disease had metastisized.

12. A 29-year-old mother of two children, aged one and five, this woman had never been married. Her tumor had been discovered at the six-week check-up following the birth of her second child. From a large family, she had completed only the 9th grade and was on welfare when interviewed. She was in the middle of a course of chemotherapy and had managed to take care of her two young children in spite of the side effects she sometimes suffered.

13. A 39-year-old married woman with three children aged 10-15,
this woman had 11 years of education and was employed in her family's grocery store in the center of a small town. She had finished eight months of chemotherapy when the interview was done and was glad that the chemotherapy was over.

14. A 49-year-old married woman who was a registered nurse, this woman had five children aged 15-24 and was married to a commercial airline pilot. She had been active in the formation of support groups for cancer patients in her area and was undergoing both radiation and chemotherapy.

15. A 32-year-old married woman with two children aged four and five, this woman was the wife of a minister in a very small town. The entire community had pitched in to help pay the medical bills, as the couple was without medical coverage when the cancer was diagnosed. This woman was currently at home with her children, but had a college degree and talked about activities outside the home in the future. When interviewed, she was undergoing chemotherapy treatments.

16. A 48-year-old married woman with a college degree and who was a homemaker, this woman had four sons aged 12-22 and had been treated with radiation after her mastectomy.

17. A 45-year-old married woman with 12 years of education, this woman had worked (and enjoyed her work) as a clerk until she began having chemotherapy treatments, at which time she had had to quit her job because of the time and energy taken by the treatments. She had three children aged 15-23. Although she said that the treatments made her feel "sluggish" she had joined a local "Y" and had begun swimming and
participating in group sessions with other women who had had mastectomies only three weeks after her surgery.

18. A 41-year-old married teacher with 12- and 14-year-old sons, this woman had a B.S. in mathematics and had done some additional graduate work. She was part way through a course of chemotherapy when interviewed and was very fond of sailing.

19. A 46-year-old woman with a college degree and some additional course work, this woman had three children aged 22-25 and was in the midst of a course of chemotherapy treatments when interviewed. She worked in the welfare department of a large urban area.

20. A 59-year-old woman, married with two children aged 33 and 35 and with 12 years of education, this woman worked as an administrator in a local hospital. She had just begun chemotherapy treatments when the interview took place.

In addition, the two women who were interviewed and considered part of the sample, but whose scores on the BDI, MAACL, and Social Support Questionnaire have not been included, are:

1. A 53-year-old woman with a Ph.D. in one of the health areas who was both a professor and an administrator at a university. This woman had never been married and had made many major life changes in the year preceding her diagnosis. She had decided not to have a mastectomy but had had the tumor excised and had subsequent radiation treatments.

2. A 67-year-old woman who was a widow with a 32-year-old daughter, this woman had been a teacher before her marriage and was retired
at the time she was interviewed. Her disease had been caught at a very early stage, and she had had no treatment and no recurrence since her surgery three years previously.

Interviews with these women are of interest since they add valuable insight to what might be termed a "minority" perspective among the women in the sample in that they were not married. Of the 22 women interviewed, only a total of four were not married at the time of the interview. While the number is too small to draw conclusions, an interesting follow-up study would be one in which differences between married and single women coping with the same experience would be explored.

**Procedures**

Participants for this project were contacted in a variety of ways: through personal referrals, through letters sent out by local Reach to Recovery coordinators, and through the ENCORE program sponsored nationally by the YMCA. Reach to Recovery coordinators in several local counties sent out letters describing the project to all the women on their lists who fit the project qualifications (that the diagnosis and surgery for breast cancer had taken place within approximately two years of the interview date and not less than two months after the surgery had been done). A copy of the letter sent to the participants appears in Appendix A. Letters had postcards attached which were returned if the woman was interested in obtaining more information about the project or had decided that she was interested in participating.
When a postcard was returned, the woman received a follow-up phone call within several days. More information about the project was exchanged at this time, and a time and place for a meeting was also arranged. A woman who chose to participate was offered the choice of having the interview conducted at the University of Massachusetts (neutral territory), her own home, or her place of work. Of the 22 interviews, eleven were done in the participants' own homes, seven were done at the University, two were done at the woman's place of work, and the rest were done at other meeting places, such as a YMCA near the participant's home or a meeting room in another local college.

In addition, a Personal Data Sheet (see Appendix B) was completed at this time. Participants were asked basic demographic information, the date of their mastectomy, and whether follow-up treatment had been indicated. They were also asked whether they were in any particular discomfort at that time. If the phone call was within one week prior to the interview, participants were also asked whether or not anything particularly disturbing or upsetting had occurred within the last week and whether any other major life changes (divorce, death of a parent, spouse, etc.) had occurred within the preceding year.

The interviews were expected to take between one and three hours, and only one was not completed in that time range. That interview was still unfinished after three and a half hours, but the woman thoughtfully typed out her answers to the remaining questions and returned them by mail. There were no differences in duration for groups A and B.

Two standardized instruments, the Beck Depression Inventory and
the Multiple Affect Adjective Checklist (Appendices C and D) were given at the beginning of each interview. These instruments are described in the following section. The MAACL was administered first because it was considered a simpler, less structured inventory. Both the MAACL and the BDI are short questionnaires which together generally took no more than 15-20 minutes to administer.

The remainder of the interview was then divided into three parts (see Appendix E). Each participant was asked to answer a set of questions aimed at putting her experience in some sort of context. The questions briefly asked her to describe what her experience had been, what she had been told about her disease, what the experience of having surgery had been like, and what changes, if any, took place among the important relationships in her life during the course of her experience.

The second part of the interview, called the Social Support Questionnaire, focused more specifically on important interpersonal relationships, concentrating on feelings about how the experience was shared and how it was responded to by the individuals who were most important to each participant. Each woman was asked to make a mental list of the people she considered most important in her life, the people who constituted the "innermost circle" if she were to think of relationships in terms of a series of concentric circles. Once the list had been generated, the participant was asked to determine whether this was a person she had been able to turn to for support, advice, or information, or with whom she had been able to discuss her feelings.
Further questions in this section asked about the general nature of the discussions with each of these important people, and who had initiated the discussions.

Finally, each participant was asked to rate each of the people on the list as to: a) how satisfied she was with what she had been able to communicate to this person; b) how satisfied she felt about that individual's response to the situation. Both of these were rated on a 1-5 scale (1 = low; 5 = high).

The third part of each interview then began formally by asking each woman why she had decided to participate in the study. In addition, questions were asked specifically about what constituted a satisfactory or unsatisfactory response and what each woman found most and least helpful. The women were also asked about which aspects of their experience seemed easiest and most difficult to talk about with other people, and whether they felt it was easier to talk with someone who had undergone a similar experience.

The interviews ended by asking each woman whether she felt that there was anything else of significance that should be included in this kind of research, based on what she had learned through her own personal experience. Each participant was also told that she should feel free to contact the interviewer if anything (problematic or otherwise) further presented itself after the end of the interview, and in several cases the women were assured that if anything troublesome developed it was all right to call. To date, no one has. Several women were also told about the support groups sponsored by the Cancer
Cooperative, a local organization whose purpose is to increase the range of services offered to cancer patients.

**Instruments**

**Beck Depression Inventory (1967).** The Beck Depression Inventory (BDI) was developed as an inventory which would measure levels of depression. The author's intent was to "provide a standardized, consistent measure that would not be sensitive to the theoretical orientation, the idiosyncracies, or the inconsistencies of the individual administering it" (Beck, 1967, p. 187). The inventory is divided into 21 categories of symptoms and attitudes related to depression (see Appendix C). Within each category, the statements are graded in intensity, ranging from minimal or neutral to maximum severity (Beck, 1967, p. 188).

In theory, as the intensity of depression increases the number of categories responded to in other than a neutral way increases, and the score reported moves toward the more severe end of each category.

Split half reliability of the inventory, using a Pearson $r$ between odd and even categories, yielded a coefficient of .86; using a Spearman-Brown correction, it yielded a coefficient of .93 (Beck, 1967).

Concurrent validity showed the BDI correlated at higher levels of significance with the Depression Scale of the MMPI and with the Multiple Affective Adjective Checklist than those two tests did with each other (Beck, 1967, p. 201).

As concerns construct validity, Beck postulated that "patients scoring high on the depression inventory have had life experiences
during the developmental period that predispose them to react to stress later by the appearance of, or exacerbation of, depressive symptomatology" (1967, p. 202). Beck further predicted that 1) dreams of depressives were likely to have a masochistic content, 2) depressives were likely to have a negative self concept, 3) they were likely to identify with failure rather than success, 4) they were likely to have a history of childhood deprivation, so that they were predisposed to depression as adults, and 5) they were likely to respond to feelings of failure with what the researcher considered "disproportionate" decreases in self-esteem and increased feelings of hopelessness; Beck's research largely supported these hypotheses (1967, pp. 202-203).

Multiple Affect Adjective Checklist (1965). Developed by Zuckerman and Lubin, the Multiple Affect Adjective Checklist (MAACL) measures levels of anxiety, depression, and hostility. It is a measure designed to assess affect states at a particular moment and does not attempt to reflect stable personality traits (Zuckerman et al., 1964). Accordingly, participants are asked to check adjectives which apply to their feeling state at the moment the test is given.

Split half reliabilities, using the Spearman-Brown coefficient, yielded coefficients of .79 (p < .01), .92 (p < .01), and .90 (p < .01) for the Anxiety, Depression, and Hostility Scales (Zuckerman et al., 1964). Test-retest reliabilities were relatively low (Zuckerman et al., 1964, 1965), as would be expected with an instrument whose function is to measure affective states at a particular moment.

Normative data on the MAACL was drawn from samples of job appli-
cants, college students, and V.A. patients (Zuckerman and Lubin, 1965) and therefore was not applicable to the present population except in the broadest sense. Means on the Anxiety, Depression, and Hostility Scales for female job applicants (mean age = 28) were 6.7, 11.1, and 6.7, respectively (Zuckerman and Lubin, 1965).

Zuckerman and Lubin (1965) discussed the correlations between the three scales, a factor of some concern since the intercorrelations all appeared to be high and significant at $p < .01$. The authors felt that "since the scales are intended to measure change rather than static traits the high correlations between them do not necessarily invalidate their use as separate scales" (Zuckerman and Lubin, 1965, pp. 20-21).

As used in this study, the MAACL was intended as an additional measure of depression, to give a score which could be correlated with a participant's score on the BDI and which would therefore increase validity. It was also used to give additional qualitative information, information about the ways that the women in this sample chose to describe themselves.
CHAPTER III

RESULTS

The results have been divided into three parts. In the first part data from the Beck Depression Inventory and the Multiple Affect Adjective Checklist are presented. Data in the second part come from the Social Support Questionnaire. The data in the third part consist of answers to interview questions about relationships with family and friends.

Results of the Beck Depression Inventory and the Multiple Affect Adjective Checklist. Results of the BDI and the MAACL showed that there were no significant differences on these scales between women in the group that had not had further treatment following surgery (N = 10) and women in the group that had had or were having either chemotherapy or radiation (N = 10). According to the BDI data, women in one group were not more depressed than women in the other; according to the MAACL, there were no significant differences between the groups in terms of levels of depression, anxiety, or hostility.

BDI scores for women in the no-treatment group ranged from 0 to 13, with a mean of 4.8, s.d. = 5.03. BDI scores for women in the chemotherapy-radiation group ranged from 0 to 11, with a mean of 5.5, s.d. = 3.78. A t test on the difference between the group means showed no significant differences (t = .35; see Table 1). The mean depression score on the BDI for women when the groups were combined (N = 20) was 5.15.

MAACL scores on the Depression Scale for the no-treatment group
Table 1

Comparison of the No-Treatment and Chemotherapy-Radiation Groups:

Means and Standard Deviations on the Beck Depression Inventory

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>0-13</td>
<td>4.8</td>
<td>5.03</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>0-11</td>
<td>5.5</td>
<td>3.78</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ranged from 1 to 21, with a mean of 8.5, s.d. = 5.79. Women in the
chemotherapy-radiation group also had a mean score of 8.5, with a range
of 0 to 11, s.d. = 4.54. A t test showed no significant differences be-
tween the groups (see Table 2). A Pearson correlation between the de-
pression scales of the BDI and the MAACL was .481, which was significant
at the .05 level (p < .05; see Tables 1 and 2).

MAACL scores on the Anxiety Scale ranged from 2 to 11 for the group
which had had no further treatment, with a mean of 4.9, s.d. = 3.4. For
the women in the chemotherapy-radiation group, scores on the Anxiety
Scale ranged from 1 to 10, with a mean of 5.4, s.d. = 3.68. A t test
on the difference between the means of the two groups was not signifi-
cant (t = -.33; see Table 3).

Scores on the Hostility Scale of the MAACL ranged from 0 to 12 among
the women who had had no further treatment, with a mean of 4.8, s.d. =
3.68. For the women in the chemotherapy-radiation group scores ranged
from 1 to 12, with a mean of 5.4, s.d. = 3.53. A t test on the difference
between the two means was not significant (t = -.39; see Table 4).

Results of the Social Support Questionnaire. When asked to consider the
people they felt closest to and make a list of the people they thought
of as their closest relationships, women in the no-treatment group list-
ed from 3 to 17 relationships. Women in the chemotherapy-radiation
group listed from 5 to 17 intimate relationships. The mean number of
intimate relationships for women with no further treatment was 8.3, s.d.
= 4.87. The mean number of intimate relationships for women in the che-
motherapy-radiation group was 10.22, s.d. = 3.49 (see Table 5). The hy-
Table 2  
Comparison of the No-Treatment and Chemotherapy-Radiation Groups: Means and Standard Deviations on the Depression Scale of the Multiple Affect Adjective Checklist

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>1-21</td>
<td>8.5</td>
<td>5.79</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>0-11</td>
<td>8.5</td>
<td>4.54</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
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</tbody>
</table>
Table 3
Comparison of the No-Treatment and Chemotherapy-Radiation Groups:
Means and Standard Deviations on the Anxiety Scale
of the Multiple Affect Adjective Checklist

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>2-11</td>
<td>4.9</td>
<td>3.4</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>1-10</td>
<td>5.4</td>
<td>3.68</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Table 4

Comparison of the No-Treatment and Chemotherapy-Radiation Groups:
Means and Standard Deviations on the Hostility Scale of the Multiple Affect Adjective Checklist

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>0-12</td>
<td>4.8</td>
<td>3.68</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>1-12</td>
<td>5.4</td>
<td>3.53</td>
</tr>
<tr>
<td>(N = 10)</td>
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</tbody>
</table>
Table 5
Comparison of the No-Treatment and Chemotherapy-Radiation Groups:
Means and Standard Deviations of Number of Intimate Relationships
from the Social Support Questionnaire

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>3-17</td>
<td>8.3</td>
<td>4.87</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>5-17</td>
<td>10.22</td>
<td>3.49</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
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</tbody>
</table>
hypothesis that there would be no significant differences between the two groups of women in terms of their ability to communicate their thoughts and feelings about cancer to the people who constituted their most intimate personal relationships was tested. The question whether there would be significant differences between the groups in terms of how satisfied the women were with their responses from these intimates was also tested.

A mean score was calculated for each of the scales of the Social Support Questionnaire, satisfaction with communication (SC) and satisfaction with response (SR). Each scale was a 5-point scale, with 1 equal to the lowest level of satisfaction and 5 equal to the highest. The mean score on the SC scale for women who had had no further treatment was 3.67, \( s.d. = .68 \). For women in the chemotherapy-radiation group, the mean score was 3.8, \( s.d. = .61 \). A \( t \) test on the difference between the group means was not significant (\( t = -.10 \); see Table 6).

An average score was calculated for each individual participant, where average score equals the sum of the ratings for each intimate relationship, divided by the number of intimates listed by that individual. For women in the no-treatment group, the average scores ranged from 2.6 to 5. For women in the chemotherapy-radiation group, the average SC scores ranged from 2.7 to 4.6.

On the satisfaction with response scale, the mean score for women in the no-treatment group was 3.86, \( s.d. = .61 \). The average scores for individual participants in the group varied from 2.8 to 4.6. In the chemotherapy-radiation group, the mean score was 3.7, \( s.d. = .55 \). The average scores ranged from 3 to 4.5. A \( t \) test on the difference between
Table 6

Comparison of the No-Treatment and Chemotherapy-Radiation Groups:

Means and Standard Deviations on the Satisfaction with Communication Scale of the Social Support Questionnaire

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>2.6-5</td>
<td>3.67</td>
<td>.68</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>2.7-4.6</td>
<td>3.8</td>
<td>.61</td>
</tr>
<tr>
<td>(N = 10)</td>
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</table>
the group means was not significant (t = .59; see Table 7).

In summary, the null hypotheses 3 and 4, that the scores on the SC and SR scales would not be significantly different as a function of membership in one group or the other, could not be rejected.

It was hypothesized (Hypothesis 5) that women in the sample who had higher scores on the SC scale, i.e., who were satisfied with their own ability to convey whatever thoughts and feelings they had concerning their disease, would have lower levels of depression as indicated by scores on the Beck Depression Inventory. Conversely, women whose scores indicated that they were less satisfied with their ability to communicate would have higher scores on the BDI. It was also hypothesized (Hypothesis 6) that women who had higher scores on the satisfaction with response scale, i.e., who were satisfied with the responses they received from close friends and family members, would have lower scores on the BDI than women who indicated that they were less satisfied with the responses they received.

Correlation of the satisfaction with communication (SC) scale and satisfaction with response (SR) scale with the Beck Depression Inventory scores (see Table 8) revealed a significant negative correlation (r = -.72, p < .05) between levels of depression and satisfaction with communication for the women in the no-treatment group. A somewhat lower, but still significant, correlation between depression and satisfaction with communication (r = -.52, p < .10) was found for women in the chemotherapy-radiation group. When the BDI scores of all 20 women in the sample were correlated with their satisfaction with communication scores, a
Table 7
Comparison of the No-Treatment and Chemotherapy-Radiation Groups:
Means and Standard Deviations on the Satisfaction
with Response Scale of the Social Support Questionnaire

<table>
<thead>
<tr>
<th>Group</th>
<th>Range</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>2.8-4.6</td>
<td>3.86</td>
<td>.61</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>3-4.5</td>
<td>3.7</td>
<td>.55</td>
</tr>
<tr>
<td>(N = 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 8
Correlation of the Satisfaction with Communication (SC) and Satisfaction with Response (SR) Scales with Participants' Scores on the Beck Depression Inventory

<table>
<thead>
<tr>
<th>Group</th>
<th>SC:BDI correlation</th>
<th>SR:BDI correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment</td>
<td>$r = -0.72$</td>
<td>$r = 0.15$</td>
</tr>
<tr>
<td>($N = 10$)</td>
<td>($p &lt; 0.10$)</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy-radiation</td>
<td>$r = -0.52$</td>
<td>$r = -0.37$</td>
</tr>
<tr>
<td>($N = 10$)</td>
<td>($p &lt; 0.10$)</td>
<td></td>
</tr>
<tr>
<td>Combined</td>
<td>$r = -0.64$</td>
<td>$r = -0.07$</td>
</tr>
<tr>
<td>($N = 20$)</td>
<td>($p &lt; 0.01$)</td>
<td></td>
</tr>
</tbody>
</table>
highly significant negative correlation ($r = -.64, p < .01$) was obtained.

However, the same pattern of results was not observed when scores on the BDI were correlated with scores on the satisfaction with response scale. Scores of women in the no further treatment group shared a correlation of .15; scores of the women in the chemotherapy-radiation group shared a correlation of -.37, a correlation in the expected direction, although not significant. When the groups were combined, there was essentially no correlation ($r = -.07$) between the two scales.

Thus women who felt they were not able to communicate their thoughts and feelings about their disease to their own satisfaction did tend to have higher levels of depression than women who felt satisfied with their ability to communicate, while the same pattern was not observed relative to the responses they received.

In summary, Hypothesis 5, which predicted an inverse relationship between level of depression and ability to communicate to one's own satisfaction, could not be rejected. Hypothesis 6, which predicted an inverse relationship between level of depression and satisfaction with the responses received from close family and friends was not supported by these data.

When BDI scores were correlated with the SC scores using only the first three people listed on the Social Support Questionnaire (assuming these to be the three most important relationships for each participant), results were quite significant ($p < .10$) for both the no-treatment ($r = -.59$) and the chemotherapy-radiation ($r = -.55$) groups. The correlation was highly significant ($r = -.55, p < .02$)
when the groups were combined.

When scores on the BDI were correlated with SC scores above 3 (scores which indicated that the participant was very satisfied with what she could say to that particular person), there was a negative correlation ($r = -0.43$, $r = -0.50$) for the no-treatment and the chemotherapy-radiation groups, respectively. When the groups were combined, $r = -0.41$ ($p < .10$).

However, when an attempt was made to see whether the women in this sample found it preferable to have a few close relationships or many (i.e., whether the number of individuals in a support network could influence levels of depression), the results were negative. As can be seen in Table 9, the correlations were low enough to indicate that the actual number of people did not seem to be a factor which influenced depression. This is in contrast to the results described above, where there did appear to be a relationship between levels of depression and the way in which the participant felt she could communicate with the people she felt closest to. As Table 9 indicates, there appears to be a significant relationship between level of depression and satisfactory communication with those people deemed most important (the first three people listed), and a relationship between level of depression and the number of people with whom the participant felt she had very satisfactory communication.

The Multiple Affect Adjective Checklist asked the women in this sample to describe themselves as they felt at the time they were interviewed. The results showed which characteristics these women as-
Table 9
The Relationship between Levels of Depression and Satisfaction with Communication: Additional Correlations of the BDI and SC Scale Scores

<table>
<thead>
<tr>
<th>Group</th>
<th>BDI scores: SC scores of the first three people listed on the Social Support Questionnaire</th>
<th>BDI scores: SC scores above &quot;3&quot; (very satisfactory communication scores)</th>
<th>BDI scores: number of people listed on the Social Support Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment (N = 10)</td>
<td>$r = -0.59$</td>
<td>$r = -0.43$</td>
<td>$r = 0.21$</td>
</tr>
<tr>
<td></td>
<td>($p &lt; 10$)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy radiation (N = 10)</td>
<td>$r = -0.56$</td>
<td>$r = -0.50$</td>
<td>$r = -0.10$</td>
</tr>
<tr>
<td></td>
<td>($p &lt; 0.10$)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Combined (N = 20)</td>
<td>$r = -0.55$</td>
<td>$r = -0.41$</td>
<td>$r = 0.12$</td>
</tr>
<tr>
<td></td>
<td>($p &lt; 0.02$)</td>
<td>($p &lt; 0.10$)</td>
<td></td>
</tr>
</tbody>
</table>
cribed to themselves and which they saw as alien. The MAACL is a list of 132 adjectives (see Table 10). Each woman was told that she could check as many or as few words as she liked; what was important was that she check all those that described her accurately. For the women in the no-treatment group the mean number of adjectives checked was 37.6. For the women in the chemotherapy-radiation group the mean number of adjectives was 33.9. For all 20 women the mean number of adjectives was 35.75.

Table 10 is a frequency count of the words that were checked and the number of women who used each of the adjectives to describe herself. Table 11 is a list of the adjectives not checked by any of the women in this sample.

The most frequently checked adjectives (words used by 15 or more women to describe themselves) are: active, friendly, affectionate, happy, alive, clean, interested, fine, good-natured, understanding, cheerful, agreeable, cooperative, fit, and healthy. Words which were not used by any of the women included: angry, bitter, gloomy, grim, hopeless, hostile, incensed, lost, mad, outraged, panicky, sad, shaky, suffering, terrified, and unhappy. Given the way that the women in this sample described themselves, one might infer that this was a group of women who were leading contented, healthy lives in a relatively stable situation. Their descriptions of themselves gave no indication that they are a group of women all of whom had had breast cancer within (approximately) the past two years, and half of whom were undergoing or had undergone chemotherapy or radiation treatments for their dis-
Table 10
A Comparison of the MAACL Descriptors Chosen by Women in the No-Treatment and Chemotherapy-Radiation Groups

<table>
<thead>
<tr>
<th>Adjective</th>
<th>No treatment group</th>
<th>Chemotherapy-radiation group</th>
</tr>
</thead>
<tbody>
<tr>
<td>active</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>adventurous</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>affectionate</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
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<td>2</td>
</tr>
<tr>
<td>agitated</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>agreeable</td>
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<td>7</td>
</tr>
<tr>
<td>aggressive</td>
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<tr>
<td>alive</td>
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<td>9</td>
</tr>
<tr>
<td>alone</td>
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<td>0</td>
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<tr>
<td>amiable</td>
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<td>6</td>
</tr>
<tr>
<td>amused</td>
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<td>2</td>
</tr>
<tr>
<td>annoyed</td>
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<td>1</td>
</tr>
<tr>
<td>bashful</td>
<td>0</td>
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<td>blue</td>
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<td>0</td>
</tr>
<tr>
<td>calm</td>
<td>3</td>
<td>5</td>
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<tr>
<td>cautious</td>
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<td>2</td>
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<tr>
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<td>6</td>
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<tr>
<td>understanding</td>
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<td>8</td>
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<td>unsociable</td>
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<td>whole</td>
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<td>4</td>
</tr>
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<td>willful</td>
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<td>1</td>
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<tr>
<td>wilted</td>
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<td>0</td>
</tr>
<tr>
<td>worrying</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>young</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 11
MAACL Adjectives Not Used as Descriptors by Any of the Women
in the No-Treatment and Chemotherapy-Radiation Groups

<table>
<thead>
<tr>
<th>Angry</th>
<th>Gloomy</th>
<th>Rough</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awful</td>
<td>Grim</td>
<td>Sad</td>
</tr>
<tr>
<td>Bitter</td>
<td>Hopeless</td>
<td>Shaky</td>
</tr>
<tr>
<td>Bored</td>
<td>Hostile</td>
<td>Suffering</td>
</tr>
<tr>
<td>Contrary</td>
<td>Incensed</td>
<td>Sullen</td>
</tr>
<tr>
<td>Cruel</td>
<td>Indignant</td>
<td>Sunk</td>
</tr>
<tr>
<td>Desperate</td>
<td>Jealous</td>
<td>Terrible</td>
</tr>
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<td>Destroyed</td>
<td>Lost</td>
<td>Terrified</td>
</tr>
<tr>
<td>Disagreeable</td>
<td>Mad</td>
<td>Tormented</td>
</tr>
<tr>
<td>Disgusted</td>
<td>Mean</td>
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<td>Vexed</td>
</tr>
<tr>
<td>Enraged</td>
<td>Panicky</td>
<td>Wild</td>
</tr>
<tr>
<td>Forlorn</td>
<td>Reckless</td>
<td></td>
</tr>
<tr>
<td>Furious</td>
<td>Rejected</td>
<td></td>
</tr>
</tbody>
</table>
ease. This will be discussed further.

Further analysis of the BDI scores was undertaken to try to assess what it was that the 20 women in this sample did find disturbing. In two previous studies with cancer patients (Lieber et al., 1976; Plumb and Holland, 1977), the BDI had been divided into items which measured the physical and non-physical components of depression. The non-physical component was assessed by items A-M. The physical component was measured by items N-U (see Appendix C).

For women in this sample, an item analysis of the BDI scores of the 20 women showed that item Q, a measure of fatigue, was the most frequently responded to \((N = 13)\). Other items which received frequent responses were T \((N = 10)\), J \((N = 8)\), and H \((N = 7)\). These items measured somatic preoccupation, crying, and self-accusation, respectively, and gave some indication that at least a significant number of the women interviewed were reacting to the stress of the disease.

For the items in the N-U group (somatic component of depression), there was a total of 19 responses from the women who had no further treatment and a total of 22 responses from the women who had chemotherapy or radiation. The mean score on the N-U items was 2.4 for women in the first group and 2.7 for women in the second. A \(t\) test was not significant \((t = .459)\). For the A-M (non-physical) items, the mean score for women in the first group was 2.3 and for women in the second it was 2.9. A \(t\) test was again not significant \((t = .92)\).

As another part of the Social Support Questionnaire, the women in the sample were asked to consider the conversations they had had
about this experience with the people they had listed as being their most intimate relationships. They were asked to recall their impression of who had usually been the initiator of those conversations. They were each asked to answer the question in one of four ways: "me," if they had a clear sense that they had initiated the majority of conversations with that particular person; "other," if it was clear that the other person had been the person to bring up the subject; "mutual," if it was their sense that the conversations had been spontaneous, with the desire to talk about the situation shared between the participants; and "don't recall," if they did not have a clear impression one way or the other.

In the group that had had no further treatment, the total number of intimate relationships listed by the ten women was 83. The number of communications that were considered mutual was 35 (42% of the total); the number that the women felt they themselves had initiated was 34 (41% of the total); and the number that had been initiated by others was only 7 (8.4% of the total). Also in this group a total of five intimate relationships were listed with whom there had been no discussion of the cancer (6% of the total), either because the relationship was between the woman and her child or grandchild who was too young to understand the situation or because it was a close relationship but one in which this difficult subject simply could not be discussed. In only two cases (2.4%) the participants did not have a clear sense of who had begun the communication.

In the chemotherapy-radiation group, the ten women listed a total
of 99 intimate relationships. Of these, 40 (40%) were considered to have been mutually initiated; 19 (19%) had been initiated by the women themselves; and 31 (31%) were thought of as having been initiated by the other person. A total of 8 (8%) of the intimates had had no discussion of the cancer, and only one case existed when the participant did not have a clear recollection of who had initiated the conversation.

As can be seen in Table 12, there appears to be a difference in the pattern of communication between the two groups with regard to the conversations that the women recall as having been initiated by themselves and the conversations initiated by close friends and family. In the no-treatment group, the participants recall that they were the initiators of 41% of the conversations about their illness, while only 8.4% of the conversations are recalled as having been initiated by others. In the chemotherapy-radiation group, a smaller percentage of conversations (19%) were recalled as having been self-initiated, while a larger number (31%) were recalled as having been initiated by the other person.

When tested with a chi square, the results were significant at both the .05 and .01 levels ($\chi^2 = 18.26$, d.f. = 1) for self- and other-initiated, respectively, indicating that the recalled pattern of conversations was significantly different between the groups. It appears that the women in the chemotherapy-radiation group recalled many more conversations initiated by their friends and family, and the women in the no-treatment group recalled themselves as the initiators of the majority of conversations.
Table 12
Discussions of Cancer with Close Family and Friends

<table>
<thead>
<tr>
<th>Initiator</th>
<th>Groups</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No treatment group</td>
<td>Chemotherapy-radiation group</td>
<td></td>
</tr>
<tr>
<td>Mutually initiated</td>
<td>35 (42%)</td>
<td>40 (40%)</td>
<td></td>
</tr>
<tr>
<td>Self-initiated</td>
<td>34 (41%)</td>
<td>19 (19%)</td>
<td></td>
</tr>
<tr>
<td>Other-initiated</td>
<td>7 (8.4%)</td>
<td>31 (31%)</td>
<td></td>
</tr>
<tr>
<td>No discussion</td>
<td>5 (6%)</td>
<td>8 (8%)</td>
<td></td>
</tr>
<tr>
<td>Not recalled</td>
<td>2 (2.4%)</td>
<td>1 (1%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>83</td>
<td>99</td>
<td></td>
</tr>
</tbody>
</table>
With regard to the other categories listed in Table 12, the number of conversations initiated mutually appeared to be approximately the same for both groups, as did the number of cases where the participant could not distinctly recall who had been the initiator of the conversation. Neither did there appear to be a significant difference between the groups with regard to the number of intimates with whom there was no discussion of cancer.

Results of the interviews. What kinds of responses did the women in this sample consider helpful to them during this experience? What responses were not helpful? Each participant was first asked to define the response she considered most satisfactory. In essence, she was asked to clarify what someone had said or done that had made her feel better during her experience with breast cancer. She was then asked to consider the least satisfactory response. Answers to what constituted the most satisfactory response (see Appendix F) fell into five categories. The majority of women \((N = 15)\) felt that what was most satisfactory was to have someone address the emotional aspects of their experience, to be able to share feelings openly and have those feelings accepted, and to feel loved and cared for. Other categories of response that were most satisfying to some women were when others told them that they looked good \((N = 2)\), when people said they were offering their prayers \((N = 1)\), when other people opened up and shared their own problems \((N = 1)\), and when people reacted calmly and were not overwhelmed \((N = 1)\).

The following quotes give a sense of the kind of responses that
the women in this sample found most satisfactory. As in all the quotes in this section, the candor and the willingness of the participants to share their experience with others is apparent.

More than a [verbal] response, it was just the fact that my husband would sit and listen, and let me talk about anything. He didn't even have to answer me. Just that he would sit and let me talk to him about what was going to happen if I should die. How [my daughter] would cope, what he would do. He could sit and listen to me saying these things.

--30-year-old woman, no treatment

That I hadn't changed, that I was really the same person... Just because I only had one breast, that that was a physical thing... That people love me, that I'm cared for, and that they let me know that.

--36-year-old woman, no treatment

I guess [my husband] responded in such a way that I realized he really did love me, cared about me. And I guess my father did, too. When I came home from the hospital after the [biopsy], [my husband] couldn't even talk about it... Then the day before the surgery, I always get up at 6 and make his coffee and we sit and have coffee, and I just looked at him and he was crying, but wouldn't say anything to me. I said to him, well, everything's going to be all right, and he just went out the door. But... that evening, before I went in [to the hospital], he had a conversation with a friend who was dying of cancer, and after that his attitude was completely different. He was there when I came out of surgery and didn't leave me, and when I came home he didn't reject me, and made me realize that he really did care... I thought he would reject me, I really did.

--39-year-old woman, chemotherapy

The best was their concern, the offers of help... That was the best thing, the very active concern that people actually did something about.

--32-year-old woman, chemotherapy

...From my family, that I was still the same person, that they were all on my side, that they knew there was a problem, and they were always there to help me get through it.

--45-year-old woman, chemotherapy
One woman described her most satisfactory response as one in which she could find relief at being able to communicate openly with someone and have that openness shared and reciprocated:

The most satisfactory response was the openness and encompassing communication between my brother and myself. I think it was the most satisfactory because it was the first time post-mastectomy that I could express my feelings with anyone... He initiated our talk, and it just felt like a giant load had been lifted from me after that, because everything sort of tumbled out, and I could relate my cancer experience and some of my anger, etc., to things from way back to our childhood or toward some characteristics of relatives. This was four and a half months after my mastectomy, when to all outward appearances, everyone who knows me seemed to think I looked "super" and was able to react in a social sense just like nothing ever happened, but I was actually still so obsessed with my fears, and wondered if I would ever not thinking of anything else again. Now I can recall quite vividly everything we talked about and how I was actually talking around some words at first, like metastasis, probable recurrence, etc., but then realized that I could actually verbalize the real honest things I had dammed up inside. It was a very important time.

--49-year-old woman, chemotherapy and radiation

For responses that the women in this sample considered least satisfactory, there was much more variety and the responses did not easily lend themselves to categorization. Three of the women said that everyone's response had been satisfactory, that no one of their close relationships had responded in a way other than they would have wished for.

One woman said that the least satisfactory response she received had come from her husband, who told her that she looked terrific when she knew she didn't. Another expressed her dissatisfaction with a co-worker who was concerned only with clothes and appearance and did not consider other aspects of the experience which she considered more im-
portant. Another was disappointed when she tried to talk about dying, and received a response to the effect that it was also perfectly possible to be hit by a car, a response which invalidated the life-threatening aspect of her experience. One woman was annoyed at those people who tried to give her advice, who "played doctor," and another was upset by those who told her that chemotherapy wouldn't work.

A number of women (N = 3) expressed their least satisfactory response as one which had come from children or other close family members who could not express emotion or share their concern. One mother was upset when a teenaged son said that he thought he could accept her death, but could not accept the thought that his father would die.

Other women in this sample talked of abandonment, of friends who were no longer friends. One woman spoke of a relationship with a man she had been planning to marry, who had left her shortly after her mastectomy. Although he said that was not the reason, in her opinion he simply could not accept what had happened to her. Another woman said that her least satisfactory response was a letter from a friend who tried to joke about the situation, saying that her husband had always been a "leg man" and not a "boob man" and that it was stylish to be flat-chested.

Two of the women said that their least satisfactory responses had come from their physicians; one felt that her doctor did not adequately prepare her for the problems that she had to cope with after the mastectomy, and another tried to ask her surgeon a serious question (concerning the number of mastectomies he had performed) and re-
ceived the flippant answer of "one."

One woman found that her least satisfactory response came from people who needed her to take care of them, rather than being able to offer her support and care. Another said that for her the least satisfactory response had been the look of fear and horror on an older woman's face when she learned that this woman had cancer.

When asked how their cancer had affected relationships with family and friends, the women in this sample answered in a variety of ways (see Appendix F). Nine women felt that the experience had created no changes in their relationships with their closest family and friends, although they offered some very different reasons for this lack of change. One woman, whose daughter had returned home from California because she had to "see for herself" how her mother was, expressed her feelings this way:

I will have to say they're all concerned, my husband and children. We always were close anyway, everybody has respect and love for the other one... I think mostly it's that I've tried to be super strong... to show them that I'm still able to get up and do things the way I did... There would be days, when I was on chemotherapy, that I would be thoroughly disgusted because I couldn't do the things I wanted to do... and I'd start to cry and come out with things like "I just can't be an invalid, I just want to keep going the way I was," and my little son [15] would say, "Ma, you're going to be fine." That's when you know that the concern comes in and you know that they're all there with you.

--45-year-old woman, chemotherapy

Another woman said that she had noticed no changes because

I didn't tell my family, except for my husband and my children, because there has been a lot of cancer in my family. My family doesn't live in [this city]. They've never found out about it, and they never will. My neighbors know about it, and even they wouldn't have known except that a couple of them are volunteers at the hospital.
When this woman was asked why she had decided not to tell her family, she replied:

Oh, because it would kill my mother. My father has cancer, and of the five children in her own particular group, she's the only one alive and she's the oldest... The last thing I'm going to do is tell her. My mother is 78 years old, and therefore I couldn't tell anyone else in the family. But since they don't live in [this city] and since I go to see my mother every three weeks, I was able to get there and there's no reason for her to know.

--46-year-old woman, chemotherapy

This response contrasts strongly with that of another woman who had recently begun chemotherapy treatments. When asked whether she had noticed any changes in relationships since her mastectomy she replied:

No, because we've been very outgoing about this whole thing. Everybody knew what was going to be done to me; there was nothing kept secret. The children, our grandchildren knew it, even the little eight-year-old, our son explained it to him. There has been no embarrassment, no embarrassment since my coming back to work... Everybody has been so glad to see me up and about and well. I think if I had tried to hide it, it would have been an embarrassment. People would have been talking... Well, they would have known. Everybody's talked about it.

--59-year-old woman, chemotherapy

Ten of the women said that they found themselves feeling closer to their family and close friends in general or closer to some intimates, but more distant from others. Of the women who only expressed feelings of increased closeness since their mastectomies, one summarized her situation:

We'd been married for eight years, and we were starting to get involved in careers. [My husband] was tending to get very involved in his work and [my daughter] had just started school all day, and I was getting involved in my work, and we didn't have a lot of things together any more. I suppose that's a normal
part of anybody's married life after a few years, but this really brought us back. Really brought us close together... Now we do a lot of things together, even if one of us isn't particularly interested, just to be together as a family. We try very hard to do that.

--30-year-old woman, no treatment

For another woman in this sample, having cancer had created drastic changes in her family:

It's made my life better... I might have stayed married the rest of my life and never realized what we meant to each other. He was always so busy, and I was always so busy thinking that he wasn't thinking about me, and it wasn't true. He realized after this happened how much he really cared, and my husband isn't the one to tell you. He's not that type of person, and he's never stopped telling me ever since... Just little things he does, and we appreciate each other. In a way, I'm glad it happened. It sounds crazy, it just affected my life so much, it's made it so much better. It really has. It's too bad something traumatic has to happen, but my life is great with him [now].

When asked if the cancer had created changes in her relationship to any other members of her family, this same woman responded:

In my father... When I grew up, I never felt my father cared for me, I just never did... But since I found out I had cancer, I see my father at least twice a week. I talk to him at least twice a day. My father never kissed me [before], but he was right outside the operating room when I came out, and he never left the hospital for almost the whole time I was there. He never leaves without kissing me goodbye. I never knew I had a father all those years. I knew I had him, but I just thought he didn't care about me.

In terms of changes in her relationships with her children, she said:

Some [changes] with the children, although kids tend to forget that you're sick, once they see you doing dishes and making supper. I don't consider myself sick now, but I think they forget. Sometimes they'll bring it up and say, "Ma, is there something else you're not telling us?" If I don't feel good, if I'm kind of quiet, if I've gone to the doctor, I'll come home and they'll say, "Are you sure? Is there something you're not telling us?" I think we talk more than we used to, but then again, they're at that age now, teenagers, where they need more than they used to.

And in summarizing all the changes, this woman said:
I feel that if I died tomorrow, that at least I have had this year of fulfillment with my husband, and life itself. I wouldn't feel that I had been gypped out of life, that at least I saw it, I guess. I feel contented. If it wasn't for the pain... Everything else is fine.

--39-year-old woman, chemotherapy

Another woman described her experience equally vividly:

I think this has made us [my family] closer. I think life has suddenly become more important to them. I think they've begun to realize that their parents aren't going to be with them always, and it just made them aware of the possibility that Mom and Dad could be gone before they realized. I think we are a lot closer. [But] within myself, I feel there's one particular area [where] I feel apart. Maybe it's being aware of myself as an individual. I guess I've always put myself into my children, into my home, into my family. This is a very personal, very real thing, just for me. Deep inside, I feel a very remote spot. Generally, I think we've become a closer family, [but it's] a private feeling. I can't quite share it with anyone. It's taken me a long time to reach that point, because I've always given of myself, my whole being to my family... That's one area they can't really be part of.

And, in describing changes in relationships with friends, she said:

I still enjoy their company, their friendship. There again, I feel a wall, a curtain. Since they haven't experienced this illness, perhaps they can't quite understand how I feel. They sympathize, they care, but they can't quite reach that little space. I don't know how else to put it.

--59-year-old woman, no treatment

Several women felt that their experiences with breast cancer had caused them to rearrange relationships with friends and family members.

One woman described her experience:

I lost most of my friends... Everybody in that city sent me a plant... There was one couple that we were closer to than anybody else, and she didn't come to see me in the hospital until the last day. I was very angry at her, but by the time she got to see me in the hospital my anger had dissipated, and I felt sorry for her because I realized that what she was terrified of was cancer... There are many women who do not call me any more.
There are many women who never called me after I got out of the hospital. Occasionally their husbands will call, to talk to my husband, to go fishing or something. They no longer ask for me... I have not grown away from those women. The phone just doesn't ring with those ladies any more... On the other hand, I've picked up a few friends.

--40-year-old woman with a bilateral mastectomy, no further treatment

Another woman described her experience of having someone close to her react in a way other than she had anticipated, and echoed this theme:

People that you think would be sympathetic, they ignored it. I have two friends that didn't, but I have a sister-in-law that I'm close to that ignored it. She was helpful, but she ignored it. I felt some of the men I know had more understanding. I am the only one of the people that I know that has had this, so I wonder if these women looked at me and were afraid.

--58-year-old woman, no treatment

Two women responded to the question in such a way as to describe changes in themselves in relation to their families. One woman described a decrease in sexual feelings towards her husband:

I feel extremely close to my husband, even though I feel I don't know if I really am more tired than I was. I don't want not to have sex with him, but I don't feel the way I did before. I feel less libido, or whatever you call it... People don't tell you, or talk to you about these things.

And in another part of the interview this woman continued, saying:

I haven't talked directly with my husband about my loss of interest in sex. I'm afraid he'd think it is some permanent thing that would decrease his sexual feeling for me. At present I think I can go along, probably the way my grandmothers did.

--49-year-old woman, chemotherapy and radiation

Another woman described the changes in her attitudes towards attending family gatherings and parties that had taken place since her
mastectomy:

I did decide that if I really didn't want to go to something, I didn't feel that I was obligated to go just because it was a family thing... I do go if I want to go, but that was the one thing I did decide.

--50-year-old woman, no treatment

When asked to describe what parts of their experience with breast cancer they could talk about most easily (see Appendix F), six of the 20 women said they could talk about all parts of it, without exception. One woman said she didn't really talk about any of it, and one was evasive. Of the remaining twelve women, one said it was easiest to talk about having had a mastectomy, as differentiated from having cancer, so that the two could be separated, and about how it didn't make any difference in the kind of things she could do or the kind of clothes she wore.

A number of other women ($N = 5$) echoed this theme and said that it was easiest to discuss the physical aspect of having had surgery, e.g., occasional difficulties in the use of their arms, the prosthesis, and how one could still look good after a mastectomy. A woman who had had breast reconstruction said that that was the easiest aspect of the experience to discuss, while another found it easiest to discuss the quick return to a normal, active life after her surgery. One woman said that it was easiest to discuss the fact that she had had no node involvement, that her cancer had not spread. In contrast, a woman who had had lymph node involvement said that she found it easiest to talk about people who had recovered from cancer or who had had good success with chemotherapy.
What was the most difficult aspect to discuss? Seven of the 20 women answered that nothing was too difficult, that all parts of the experience could be talked about. Two women said that it was difficult to use the word cancer, that in their discussions they used the word mastectomy instead. One said:

The word cancer, I don't think you mention it that much, but when you do, people have very strong feelings and dread. So basically, I dealt with the term mastectomy... I had a very short time to introduce the idea, and it depended on the person. I had to make personal judgments about how much they could deal with.

--46-year-old woman, no treatment

One woman said that it was difficult to discuss having sexual relations with only one breast, while another woman said that she found it difficult to talk about the loss of such an important body part, that she felt it was "like an amputation." Another woman found it difficult to discuss the physical pain she had experienced with anyone.

A number of the women (N = 6) said that it was most difficult to discuss the emotional aspects of the experience: the psychic pain, the fears, their anxiety. One woman said that she found it most difficult to talk about whether she would have a recurrence, and whether she would die of the disease. Another woman expressed concern for her daughters, whether she would live to see them grow up, married and settled. She also said that it was difficult for her to explain the tests she was undergoing to friends and co-workers, and how difficult it was to answer their questions about the results of the tests, since she had recently been told that the cancer had metastized.

A woman who was in the course of chemotherapy treatments expressed
her fears for the future and wondered if she would ever feel "whole" again. One young woman said that death was the most difficult thing to talk about, and that the second most difficult thing was the physical appearance, and the fact that she didn't feel any different inside. Another woman who described her reactions to talking about the future and her fears as the most difficult part of her experience said:

Talking about the future and my fears is difficult. When I "celebrated" taking my last chemo, my friends would say, "You mean this is IT, the last one you'll ever have to take?" My answer was either that I sure hoped so, or that there would be just check-ups from now on. A few months before completing my chemo, I did ask my oncologist if I couldn't be a guinea pig for another year, because I tolerated it well, and I actually dreaded not having the drugs in my system, like good little soldiers. She told me the current thinking was to shorten, not lengthen, the therapy, etc.... Even though I feel that I've talked quite a bit with my oncologist, she doesn't realize, I don't think, that I still have some pretty deep fears about my disease. I really think that my way of coping well is to sublimate. I think I hold back because I know that she [the oncologist] is vulnerable too, and I know that if she has some doubts about my prognosis or pathology, she would not want me to demand certain information in detail. I've asked her, and we've discussed as much as I want to know, but there are also some nagging questions that I don't really care to put to her.

--49-year-old woman, chemotherapy and radiation

One woman who said that she could basically talk about all aspects of the experience summarized her feelings both about her physician and the difficulty she had initially in talking about her cancer:

Well, now I can talk about the whole thing. I just think the whole experience was so overwhelming: the cancer. You come out, and the surgeon sends you home, and you have no one to talk to... I had no one that had had the same experience. A doctor simply cannot do it. It's not his fault, he simply can't.

--58-year-old woman, no treatment
CHAPTER IV
DISCUSSION

The results of both the Beck Depression Inventory and the Multiple Affect Adjective Checklist showed that none of the women in this sample described themselves as seriously depressed. According to the categories derived by Beck (1976, p. 196), most of the participants showed either no significant depression or else had mild to moderate depressive symptomatology.

The BDI was chosen for this study because it had previously been used in studies of cancer patients by Lieber et al. (1976) and Plumb and Holland (1977). Lieber et al. interviewed 38 patients who were receiving chemotherapy, and interviewed their spouses to "assess changes since illness in the desire for affection (sexual, physical, and verbal)." In that study, the mean score on the BDI for the women patients was 12.94 and for the men patients, 8.37. Husbands of women patients in the Lieber et al. study had a mean score of 4.67 on the BDI and wives of men patients averaged 8.14. In the present study, women in the no-treatment and chemotherapy-radiation groups had means of 4.8 and 5.5 respectively.

Plumb and Holland (1977) used the BDI to compare levels of depression among cancer patients, their next-of-kin, and a group of physically healthy individuals who had either made a recent suicide attempt or were considered at risk for such an attempt. The mean score for
the cancer patients (N = 97) was 9.6; for their next-of-kin (N = 66) the mean score was 6.8; and for the suicide group (N = 99) it was 16.3.

Both the Lieber et al. and the Plumb and Holland studies calculated sub-group scores for the physical and non-physical items of the BDI. Once again their results were higher than the results obtained for the women in this sample. The mean score on the physical items for cancer patients in the Plumb and Holland (1977) study was 5.9; the mean score on the non-physical items was 3.7. In the Lieber et al. (1976) study, the mean score on the physical items was 6.5 for women patients and 5.09 for men patients. The mean score on the non-physical items was 6.44 for women patients and 3.18 for men patients. In this study, the mean score on the physical items was 2.4 for women in the no-treatment group and 2.7 for women in the chemotherapy radiation group. The mean score on the non-physical items was 2.3 for women in the no-treatment group, and 2.9 for women in the chemotherapy-radiation group.

Several factors may have contributed to the discrepancy of scores between this study and the two cited above. Given the method of self-selection, it was hypothesized that no one who was seriously depressed would participate, and it appears that none did, so that the scores were in general lower. Second, it is likely that many of the patients studied in the two previous studies had cancer more advanced than the women in this sample. As Plumb and Holland (1977) are careful to point out, while certain symptoms may be representative of the somatic components of depression, they may also be symptomatic of cancer in the
more advanced stages.

The results of the MAACL further corroborate the evidence that this was a well-adjusted sample of women who appear to have adjusted to having cancer and who appear to be coping with the emotional consequences of the disease. However, a recent article by Derogatis, Abeloff, and Melisaratos (1979) questioned whether this "adjustment" is conducive to survival for women with this disease. In a study of 35 women with metastatic breast cancer, these researchers found that women who survived for more than a year (considered long-term survivors) showed higher levels of anxiety, alienation, and depression than women who survived for less than one year (short-term survivors).

They found that the women who lived longer were "more capable of externalizing their negative feelings and aspects of the underlying conflicts that give rise to them, and did not appear to suffer any self-image loss as a result of communicating in this fashion" (Derogatis, obeloff, and Melisaratos, 1979, p. 1507). On the other hand, the short-term survivors were less able to communicate their feelings of anger or hostility.

This finding seems particularly important in light of the fact that none of the women in this sample was willing to describe herself as angry, bitter, gloomy, mad, or grim, although a few expressed anger and disappointment at friends or relatives who had not been able to offer them emotional support or who had not been willing to talk about what was happening to them. Perhaps the key here is the discrepancy between being able to express anger appropriately and describing one-
self as an angry person. Another possible explanation is that although the statements made during the course of the interviews did appear to reflect anger on the part of some of the women, these feelings may not have been recognized as anger by the women themselves, and may instead have been interpreted as feelings of disappointment, regret, depression, etc.

Still another possible explanation, although not one favored by this researcher, is that the women in this sample do fit the stereotype delineated in the earlier studies mentioned in the literature review (Bacon et al., 1952; Muslin et al., 1966; Renneker, Cutler, et al., 1963; Resnikoff, 1954). Present in these studies is a tendency to describe women with breast cancer as unable to express anger, as well as hopeless, despairing, excessively guilty, etc.

One must also consider, given that there is a real need for the support of one's closest friends and family during this stressful period, how much anger and depression can actually be expressed by the cancer patient before there are interpersonal consequences which affect the relationships with the very individuals who are needed for emotional support. Friends and family members, sharing the situation and the experiences of the person with cancer, may find themselves in the difficult position of wanting to provide support and nurturance, but being all too aware of the uncertainty and the stressful nature of the situation. (See Wortman and Dunkel-Schetter, 1979, for an excellent discussion of the "mixed" responses to the cancer patient by close friends and family members.)
In addition to emotional stress shared by members of the patient's support system, cancer causes physical and financial resources to be severely strained. When the situation is prolonged, as in the case when chemotherapy or radiation is necessary, the prolonged stress may cause aversive or angry reactions on the part of the people close to the patient, people whose lives are also being extremely disrupted by this disease. These negative feelings may be difficult to express, since the person may feel guilty for having them. They may therefore go unstated, but sensed by the cancer patient, who may in turn feel the need to keep her emotions under control so as not to create any additional tension. Alternatively, she may oscillate between expressing her feelings and hiding them (Wortman and Dunkel-Schetter, 1979).

In addition, friends and family members may have difficulty dealing with strong emotional reactions of the cancer patient because they know that they too are vulnerable, and this vulnerability creates a sense of anxiety about unleashing strong affects.

Finally, the possibility must be considered that the women in this sample did not express as many of the unpleasant affects associated with cancer as they might have, and described themselves in average "healthy" terms because to say that one feels bitter, grim, distraught, etc., lacks social acceptability, whereas describing oneself as contented, interested, etc., demonstrates a sense of self that is socially desirable and acceptable.

In addition, since in general these were women who saw themselves as coping effectively with the disease, there may have been the desire
to appear as role models for other women which would preclude describing oneself in a less positive way. Anecdotal data supports this since, in a number of cases, participants said that while they thought they were able to cope effectively, they were aware of other women who were not doing as well. The desire to serve as a role model was also manifest when the participants were asked why they were willing to participate in the study. A large number replied that they had done so out of a desire to be helpful to other women. Comparison data of how normal middle-aged women describe themselves on the MAACL would provide useful information on how the women in this sample compare to a sample of women without breast cancer.

For the most part, the women in this sample seemed satisfied with their ability to say the things they wanted to say to the people they cared about, and were satisfied with the responses they received. As the data showed, there was a definite relationship between depression and the ability to communicate thoughts and feelings satisfactorily. As shown in Table 8, depression seemed to increase when the most important people could not be communicated with in a satisfactory manner. In addition, there appeared to be a relationship between lower levels of depression and greater numbers of people with whom communication was at a very satisfactory level. Although the correlations for these two indicators \( r = -0.43 \) and \( r = -0.50 \) for the no-treatment and chemotherapy-radiation groups, respectively) were not significant, they were substantial enough to suggest that this kind of a relationship should be considered.
Because communicating about cancer is apt to be difficult, Wortman and Dunkel-Schetter (1979) have suggested that support groups can provide a forum which can increase the possibilities of open communication for the cancer patient. This researcher strongly supports this idea, and would add that groups of this kind can provide a valuable opportunity for the person with cancer to escape the social isolation (with its concomitant loneliness and potential for depression) experienced by cancer patients, by bringing together persons sharing a common experience.

In addition, support groups can also provide a valuable opportunity for the person with cancer to express angry, bitter, fearful, or depressed feelings in a supportive context. Although one can only speculate about why the women in this sample used so few adjectives of this type to describe the way they felt, evidence indicates they may be doing themselves a disservice by not acknowledging the existence of these feelings (Derogatis, Abeloff, and Meslisartos, 1979).

In the context of a support group, feelings which could not be previously acknowledged can be expressed and shared openly. In addition to ending the social isolation of the cancer patient, experiences of this kind may also do much to mitigate the emotional isolation, which is often more difficult to overcome. In the context of the group, new ways of expressing feelings and behaviors can be tried out, and the patient who has not expressed anger or depression, and who may be very afraid of doing so, can have an opportunity to do so in the context of the group. Subsequently, the experience may be less fear-
some, and those feelings easier to express outside the group.

Winder and Elam (1978) have suggested family counseling as a way that communication within the immediate family can be facilitated, and family functioning can be improved while the family is coping with cancer. As shown in this study, being able to communicate with the most important people can do much to alleviate feelings of isolation and depression for the cancer patient. While the field is relatively new, some practitioners and organizations (such as the Cancer Cooperative in western Massachusetts) are beginning to organize these support systems for cancer patients and their families.

In 1972 Harker stated that she felt it was up to the person with cancer to lead the way in discussions of the disease. While the women in this sample felt that they had initiated a substantial number of the conversations about cancer, in both groups the largest number of conversations were recalled as having been mutually initiated. Perhaps this difference is an indication that there has been some change within the last eight years, that the stigma of having cancer has been somewhat lessened, and that, at least with people one is close to, it is something that can be discussed.

However, with regard to the number of conversations that were recalled as having been self-initiated and having been initiated by the other person, the difference between the no-treatment and chemotherapy-radiation groups is significant. The women in the no-treatment group recalled a much greater number of conversations that were self-initiated, while in the chemotherapy-radiation group other-initiated
conversations were recalled with greater frequency. Perhaps there is more of a reluctance on the part of women in the chemotherapy-radiation group to initiate a discussion, since they may not feel as optimistic about their situation as women in the no-treatment group. Another possibility is that women in the chemotherapy-radiation group are remembering a higher proportion of other-initiated conversations as a way of saying that others care enough about their situation to initiate a discussion.

While the strong negative correlation between the ability to express feelings and thoughts to one’s own satisfaction and level of depression is one that is not difficult to understand, the weak negative correlation between feelings of depression and satisfaction with the responses received from others is somewhat more difficult to explain. One possible explanation is that all of the women in this sample had at least one person whose response was very satisfactory to them (at least a 4 on a 5-point scale), and most had several people at this level or higher, so that the presence of some very satisfactory responses may have mitigated the ones which were less satisfactory.

Another possibility is that unsatisfactory responses from some people could be more easily tolerated than others, i.e., a lack of support from a sister-in-law or a mother-in-law (even one who had been close before) was somehow more easily tolerated than an unsatisfactory response from a husband or child. Another related possibility is that while the responses which were considered less than satisfactory were perceived as disappointing, the women in this sample had sufficient
support from other sources, and were sufficiently secure and stable so that they did not interpret an unsatisfactory response as cause for self-derogation and did not become depressed as a result.

All of the married women mentioned that their husband's response was of extreme importance to them. For some it made the difference between coping and not being able to cope with the experience. Not all the responses were positive, however. One woman said that her husband had never seen the scar, and she had no intention of showing it to him. Most said that their husbands had seen the scar right away, and that they felt strengthened by the knowledge that they were still loved and cared for and could still have satisfactory sexual relationships.

Only four of the 22 women interviewed were not married at the time their cancer was diagnosed. While within the context of a marriage breast cancer creates a life crisis, for the women who were not married there seemed to be a different slant to the situation. For the unmarried woman, the idea of beginning a sexual relationship with a man after a mastectomy posed a situation which was not encountered by the married woman.

In this sample, one of the unmarried women, a widow, specifically addressed the issue of beginning a relationship with a man: how she wanted to develop new relationships, but how anxious she was about telling a man that she had had a mastectomy. One of the other unmarried women, whose lover had left her after her surgery, said that she too thought this might be a problem, but had not yet had the opportunity
to deal with the situation. The two other unmarried women in the sample did not raise the issue of new relationships with men.

Answers to specific interview questions asked during the second part of the interview provided a great deal of information about what the experience of having a mastectomy was like within the interpersonal nexus of each participant.

In general, the women in this sample seemed to be saying that what was helpful was an instance in which someone provided empathic listening, understanding, and support; where they felt cared for and valued; and where someone was able to put aside their own anxiety in order to listen to fears, thoughts of death, etc. While there was no one specific response that was cited as the most satisfactory, frequently stated as the most satisfactory response was the idea that there was someone who was willing to listen and show they cared.

Conversely, to expect some display of support, recognition, and caring from a close friend or family member and not receive it seemed to cause the greatest amount of dissatisfaction for the women in this study. In addition, someone who dealt with the situation by making light of it, by not recognizing the life-threatening nature of the crisis, was high on the list of unsatisfactory responses. Similarly, friends who dealt with the situation by no longer being available, who perhaps could not face their own feelings of vulnerability, or who were not able to accept a relationship that was suddenly different in terms of what each individual was able to contribute to the relationship were also high on the list of unsatisfactory responses.
The fact that half the women in the study found some positive changes in relationships as a by-product of their experience with cancer seemed somewhat surprising, but was clearly an indication of the ability of social support to mitigate life crisis. In many of the cases the changes that the women mentioned brought new candor and openness to important relationships and increased the affection and esteem of the individuals involved. Cobb defined social support as "information leading the subject to believe that he is esteemed and valued; information leading the subject to believe that he belongs to a network of communication and mutual obligation" (1976, p. 300).

On the basis of the data generated by this study, this author would suggest another factor to be added to the above criteria for defining social support: the knowledge that there are people with whom one can share one's most intimate thoughts and feelings, knowing that there are people who are willing to listen, and knowing that there are people with whom one can share one's deepest thoughts and feelings.

Although many of the women discussed positive aspects of the experience, the less pleasant aspects were by no means avoided. Fear of death was present in some way or another for many of these women. Having cancer made it necessary for them to look more seriously at the prospect of dying. Several of the women spoke of wanting to live long enough to see their children in college or settled, and two mothers of young children expressed their concern for their children's ability to cope if they were no longer there to care for them. Other themes common to women in this sample were feelings of depression and
anxiety, changes in feelings towards their bodies, and feelings about sex.

Finally, it is necessary to mention a discussion of the methodological problems inherent in this kind of research. First and foremost is the problem of getting a sample which is truly representative of this population of women. The women interviewed in this study, although relatively few in number, represented a wide variety of ages and socioeconomic backgrounds. Most had finished high school and had some college, one had only finished the 9th grade, and two had earned terminal degrees, one Ph.D. and one M.D. Most were in their forties, although the youngest was 29 and the oldest in her sixties. Most were married and had children. Some were from rural areas, some from towns, and a few lived in urban or suburban areas. Some were upper middle class, most were middle middle class, and a few were in the lower economic bracket. What they had in common was that all had had breast cancer and all were willing to talk about it.

Nevertheless, all were self-selected. Since this study was considered exploratory in nature, the method of obtaining participants through a variety of sources and from a diversity of backgrounds was considered an adequate, if not optimal, way to proceed. If replicated or extended at some point in the future, this study could be carried on through a large medical center. It would then be possible to obtain demographic data, and perhaps some of the depression measures, on women who were not willing to discuss their experiences, so that differences between women willing to talk about having breast cancer
and women who were not willing to talk might be better understood.

One of the researcher's fears was that the nature of the questions would prove stressful and anxiety-provoking for the participants. However, since all the women were self-selected and were informed in advance that the study would ask questions related to breast cancer and interpersonal relationships, it was felt that the method of selection would serve as a protective screening device and that women who considered the topic too anxiety-provoking would select not to participate. This appears to have been the case, since all of the women were told they could contact the interviewer if anything upsetting or disturbing occurred as a result of the interview, and none of them felt the need for a follow-up contact.

Each participant was asked, in an informal part of the interview, why she had volunteered. While several of the women said they did so because they knew it was hard to get volunteers for psychological research or because they wanted to know whether their reactions were similar to those of other women, the majority said that they had wanted to participate because they knew their reactions were different from those of other women they knew, and they thought it was important to let other women know that there was a range of ways to react to the experience.

Conducting this kind of research is not easy. As a woman researcher, it was difficult to maintain a sense of detachment (my own chances of undergoing such an experience are estimated as better than 1 in 13), and I could not help wondering, given a similar situation, what
my own reactions would be. As a final point, I would like to say that
the women in this sample were willing to share what had happened to
them in a way which was more open than had been anticipated. As I
listened to these women, I could not help being greatly impressed by
their courage and their dignity.
CHAPTER V
SUMMARY AND CONCLUSIONS

Twenty-two women were interviewed using a structured interview schedule and were given the Beck Depression Inventory, the Multiple Affect Adjective Checklist, and a Social Support Questionnaire. Data from two women were not used because one had not had a mastectomy (she had had the tumor excised and was treated with radiation implants and radiation treatments) and the other had had a mastectomy prior to the two-year time limit decided upon before the study began. The women were divided into two groups: women whose conditions indicated the need for no further treatment after mastectomy and those who had been treated or were being treated with chemotherapy, radiation, or both. The participants were self-selected; they were recruited through referrals or by means of letters sent out by the Reach to Recovery coordinators and coordinators of the ENCORE program in several counties surrounding the Amherst area.

Women were interviewed either in their homes, offices, or at the Psychology Department of the University of Massachusetts in Amherst. One interview took place at another area college close to the participant's home. Interviews generally lasted between one and three hours.

Results of the BDI data showed that women who were in a more advanced stage of the disease, i.e., whose cancer had spread to the lymph nodes and who had to undergo chemotherapy or radiation treatments, des-
cribed themselves as being no more depressed than women whose cancer had not spread. Similarly, there were no significant differences between the two groups in terms of levels of measured hostility or anxiety. None of the women scored as seriously depressed, and the most frequently responded to items of the BDI were those which measured fatigue, somatic preoccupation, crying, and self-accusation.

Results of the Multiple Affect Adjective Checklist showed no significant differences on any of the three dimensions (i.e., depression, anxiety, and hostility) between the two groups. The words most frequently used by the women in this sample to describe themselves were words that might be applied to any group of middle-aged women: active, friendly, affectionate, alive, clean, agreeable, etc. It is interesting to note that fit and healthy were two of the most frequently used adjectives. None of the women described herself as angry, bitter, gloomy, grim, or panicky.

A significant negative correlation was found between level of depression (as measured by the BDI) and the ability of the participant to communicate her thoughts and feelings about cancer to her own satisfaction (as measured by the SC scale of the Social Support Questionnaire) for both groups.

An additional significant negative correlation for both groups was found when SC scores for the first three (and presumably most important) people listed on the Social Support Questionnaire were correlated with BDI scores. Correlation of level of depression and the number of people listed in the Social Support Questionnaire did not
reach statistical significance, while the correlation of level of depression and the number of satisfaction with communication (SC) scores which were above 3 (on a 5-point scale) did not reach statistical significance for either of the groups alone, but did appear to be significant when the groups were combined.

With regard to the relationship between level of depression and satisfaction with the responses received from close friends and family members, the data failed to show any particular relationship. However, a significant difference was found with regard to the pattern of initiating conversations between the two groups. Women in the no-treatment group recalled conversations primarily as either mutually initiated or initiated by themselves, while women in the chemotherapy-radiation group recalled conversations about their illness as being primarily mutually or other-initiated.

Open-ended questions during the interviews asked the participants to consider what kinds of responses they found most and least satisfactory, whether they had noticed any changes in relationships with family and friends as a result of having cancer, and about the parts of the experience that were easiest and most difficult to discuss. Although the qualitative data make apparent the diversity of experience within this sample, a majority of the participants \( N = 15 \) felt that a most satisfactory response was another person's willingness to address the emotional aspects of their experience. The data showed more diversity with regard to what constituted a least satisfactory response. Abandonment, lack of regard for the seriousness of the situation, and
concern with unimportant aspects of the experience, i.e., how one would look in clothes, were examples of responses deemed unsatisfactory.

Nine women said that having breast cancer had created no significant changes in their relationships with family and friends, but ten women felt that the experience had made them feel closer to at least some of the important people in their lives.

While six women said that they could discuss all parts of their experience easily, an equal number said that it was most difficult to discuss the affective components of the experience: the stresses, fears, and anxiety. Dying, changes in physical appearance, and uncertainty about the future were discussed by the participants.

Many authors reviewed earlier have presented evidence that social support can do much to mitigate the deleterious effects of a life crisis such as breast cancer. The qualitative data generated by the women in this sample strongly supported such evidence.

While it must be emphasized that the way in which a person copes with cancer is dependent on many factors, the support and affection received from the people who are most important to the patient must be considered an important factor which can aid or hinder coping with the entire experience. In some cases, friends and family may not be able to offer all of, or the kind of, support the patient needs; they may feel too stressed or vulnerable to offer what the situation demands. In such cases, outside support from groups made up of other people with cancer or members of cancer patients' families may provide valuable additional empathy and care.
This study, considered exploratory in nature, generated questions about the women who, for whatever reasons, did not choose to participate. Are they more seriously depressed? Are they more isolated? Do they have less support than the women who felt able to discuss their experiences? These questions could be answered by replicating the study at a teaching hospital where the quantitative data (i.e., the depression scores and the social support measures) could be collected from a larger number of women. It would then be possible to differentiate those women who were willing to discuss their experiences from those who were not able to do so.
REFERENCES


____. (1970). Physical illness, the individual, and the coping process. Psychiatry in Medicine, 1, 91-102.


APPENDICES
Dear Madam,

This letter is to tell you about a research project on reactions to illness and interpersonal relationships that I am conducting at the Psychology Department, University of Massachusetts. The project will interview 30 women from the Amherst-Springfield-Greenfield area who have undergone surgery for breast cancer within the last two years. Each participant will be asked to complete two short questionnaires and a series of interview questions on emotional reactions to cancer and relationships with family and friends.

Interviews are expected to take from one to two hours, and will be conducted either at Tobin Hall, University of Massachusetts, Amherst, or at the participant’s home, if that is preferable. The project is being supervised by Dr. Dee Appley, a licensed clinical psychologist and a professor in the Psychology Department.

If you are interested in knowing more about the project, please complete the attached form and return to Ms. ______________________. I will contact you by phone within a few days and will be happy to answer any questions you may have. Although I personally feel that this is a tremendously important area of investigation, returning the attached form in no way obliges you to participate. If you decide to do so, an interview time will be scheduled at your convenience.

Sincerely,

Teri Rumpf
Psychologist-in-Training
TR/gs
Breast Cancer Study

I would like more information about this research project.

I would be interested in participating in this project.

Name __________________________

Address __________________________

Phone __________________________
APPENDIX B
PERSONAL DATA SHEET

Name ___________________________ Date of birth ________________
Address _______________________________________________________
Phone ___________________________ Date of surgery ________________
Further treatment required? _______________________________________
Type of treatment _______________________________________________
Date started _________________ Termination date (if known) _________
Marital status ______ Length of time married (if applicable) _________
Height _________ Weight _________ Level of education _____________
Children: Name(s) ___________________________ Ages

Are you currently in any physical discomfort?

Has anything occurred within the last week which was upsetting or dis-
turbing to you?

Have any major life changes (divorce, widowed, loss of a parent, etc.)
occurred within the last year?
APPENDIX C

DEPRESSION INVENTORY

A. (SADNESS)

0 I do not feel sad
1 I feel blue or sad
2a I am blue or sad all the time and I can't snap out of it
2b I am so sad or unhappy that it is quite painful
3 I am so sad or unhappy that I can't stand it

B. (PESSIMISM)

0 I am not particularly pessimistic or discouraged about the future
1 I feel discouraged about the future
2a I feel I have nothing to look forward to
2b I feel that I won't ever get over my troubles
3 I feel that the future is hopeless and that things cannot improve

C. (SENSE OF FAILURE)

0 I do not feel like a failure
1 I feel I have failed more than the average person
2a I feel I have accomplished very little that is worthwhile or that means anything
2b As I look back on my life all I can see is a lot of failures
3 I feel I am a complete failure as a person (parent, husband, wife)

D. (DISSATISFACTION)

0 I am not particularly dissatisfied
la I feel bored most of the time
lb I don't enjoy things the way I used to
2 I don't get satisfaction out of anything any more
3 I am dissatisfied with everything

E. (GUILT)

0 I don't feel particularly guilty
1 I feel bad or unworthy a good part of the time
2a I feel quite guilty
2b I feel bad or unworthy practically all the time now
3 I feel as though I am very bad or worthless
F. (EXPECTATION OF PUNISHMENT)
   0 I don't feel I am being punished
   1 I have a feeling that something bad may happen to me
   2 I feel I am being punished or will be punished
   3a I feel I deserve to be punished
   3b I want to be punished

G. (SELF-DISLIKE)
   0 I don't feel disappointed in myself
   1a I am disappointed in myself
   1b I don't like myself
   2 I am disgusted with myself
   3 I hate myself

H. (SELF-ACCUSATIONS)
   0 I don't feel I am any worse than anybody else
   1 I am critical of myself for my weaknesses or mistakes
   2 I blame myself for my faults
   3 I blame myself for everything bad that happens

I. (SUICIDAL IDEAS)
   0 I don't have any thoughts of harming myself
   1 I have thoughts of harming myself but I would not carry them out
   2a I feel I would be better off dead
   2b I feel my family would be better off if I were dead
   3a I have definite plans for committing suicide
   3b I would kill myself if I could

J. (CRYING)
   0 I don't cry more than usual
   1 I cry more now than I used to
   2 I cry all the time now. I can't stop it
   3 I used to be able to cry but now I can't cry at all even though I want to

K. (IRRITABILITY)
   0 I am no more irritated now than I ever am
   1 I get annoyed or irritated more easily than I used to
   2 I feel irritated all the time
   3 I don't get irritated at all at the things that used to irritate me
L. (SOCIAL WITHDRAWAL)

0 I have not lost interest in other people
1 I am less interested in other people now and have little feeling for them
2 I have lost most of my interest in other people and have little feeling for them
3 I have lost all my interest in other people and don't care about them at all

M. (INDECISIVENESS)

0 I make decisions about as well as ever
1 I try to put off making decisions
2 I have great difficulty in making decisions
3 I can't make any decisions at all any more

N. (BODY IMAGE CHANGE)

0 I don't feel I look any worse than I used to
1 I am worried that I am looking old or unattractive
2 I feel that there are permanent changes in my appearance and they make me look unattractive
3 I feel that I am ugly or repulsive looking

O. (WORK RETARDATION)

0 I can work about as well as before
1a It takes extra effort to get started at doing something
1b I don't work as well as I used to
2 I have to push myself very hard to do anything
3 I can't do any work at all

P. (INSOMNIA)

0 I can sleep as well as usual
1 I wake up more tired in the morning than I used to
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
3 I wake up early every day and can't get more than 5 hours sleep

Q. (FATIGABILITY)

0 I don't get any more tired than usual
1 I get tired more easily than I used to
2 I get tired from doing anything
3 I get too tired to do anything
R. (ANOREXIA)

0 My appetite is no worse than usual
1 My appetite is not as good as it used to be
2 My appetite is much worse now
3 I have no appetite at all any more

S. (WEIGHT LOSS)

0 I haven't lost much weight, if any, lately
1 I have lost more than 5 pounds
2 I have lost more than 10 pounds
3 I have lost more than 15 pounds

T. (SOMATIC PREOCCUPATION)

0 I am no more concerned about my health than usual
1 I am concerned about aches and pains or upset stomach or constipation
2 I am so concerned with how I feel or what I feel that it's hard to think of much else
3 I am completely absorbed in what I feel

U. (LOSS OF LIBIDO)

0 I have not noticed any recent change in my interest in sex
1 I am less interested in sex than I used to be
2 I am much less interested in sex now
3 I have lost interest in sex completely
APPENDIX D

MULTIPLE AFFECT ADJECTIVE CHECK LIST

Below you will find words which describe different kinds of moods and feelings. For each word, decide whether or not it describes how you feel now. If it does, make a mark in the first column on the IBM sheet for the number which corresponds to the word. If a word does not describe your present feeling, then do NOT mark that item at all on the IBM sheet. Because you will only place marks on the IBM sheet for those items which describe how you feel, you will be leaving some items blank. Therefore, please check frequently to make sure that you are marking the correctly numbered item. Some of the words may sound alike, but we want you to mark all the words that describe your feelings. Work rapidly.

1. active 16. bitter 31. daring
2. adventurous 17. blue 32. desperate
3. affectionate 18. bored 33. destroyed
4. afraid 19. calm 34. devoted
5. agitated 20. cautious 35. disagreeable
6. agreeable 21. cheerful 36. discontented
7. aggressive 22. clean 37. discouraged
8. alive 23. complaining 38. disgusted
9. alone 24. contented 39. displeased
10. amiable 25. contrary 40. energetic
11. amused 26. cool 41. enraged
12. angry 27. cooperative 42. enthusiastic
13. annoyed 28. critical 43. fearful
14. awful 29. cross 44. fine
15. bashful 30. cruel 45. fit
| 46.    | forlorn    | 71.  | kindly    | 96.  | rejected  |
| 47.    | frank      | 72.  | lonely    | 97.  | rough     |
| 48.    | free       | 73.  | lost      | 98.  | sad       |
| 49.    | friendly    | 74.  | loving    | 99.  | safe      |
| 50.    | frightened  | 75.  | low       | 100. | satisfied |
| 51.    | furious     | 76.  | lucky     | 101. | secure    |
| 52.    | gay         | 77.  | mad       | 102. | shaky     |
| 53.    | gentle      | 78.  | mean      | 103. | shy       |
| 54.    | glad        | 79.  | meek      | 104. | soothed   |
| 55.    | gloomy      | 80.  | merry     | 105. | steady    |
| 56.    | good        | 81.  | mild      | 106. | stubborn |
| 57.    | good-natured| 82.  | miserable | 107. | stormy    |
| 58.    | grim        | 83.  | nervous   | 108. | strong    |
| 59.    | happy       | 84.  | obliging  | 109. | suffering |
| 60.    | healthy     | 85.  | offended  | 110. | sullen    |
| 61.    | hopeless     | 86.  | outraged  | 111. | sunk      |
| 62.    | hostile      | 87.  | panicky   | 112. | sympathetic |
| 63.    | impatient    | 88.  | patient   | 113. | tame      |
| 64.    | incensed     | 89.  | peaceful  | 114. | tender    |
| 65.    | indignant    | 90.  | pleased   | 115. | tense     |
| 66.    | inspired     | 91.  | pleasant  | 116. | terrible |
| 67.    | interested   | 92.  | polite     | 117. | terrified |
| 68.    | irritated    | 93.  | powerful  | 118. | thoughtful |
| 69.    | jealous      | 94.  | quiet     | 119. | timid     |
| 70.    | joyful       | 95.  | reckless  | 120. | tormented |
121. understanding 125. vexed 129. willful
122. unhappy 126. warm 130. wilted
123. unsociable 127. whole 131. worrying
124. upset 128. wild 132. young
APPENDIX E

INTERVIEW: BREAST CANCER AND PERSONAL RELATIONSHIPS

A. 1. Please briefly describe your experience with breast cancer.

2. What did your M.D. tell you after surgery?

3. What problems are particularly troublesome to you right now?

4. Who do you talk with about them?

5. How does the cancer affect your life now?

6. Have you noticed any changes in relationships with members of your family, friends, or other relationships (changes which may be related to the cancer/surgery)?

7. How do you feel most of the time now?

8. Do you think having breast cancer has brought you closer or pushed you away from members of your family/close friends/casual relationships?

B. The next part of this interview will ask you about important relationships. In the first column, please make a list of all the people you think of as important to you. Sometimes, in making this kind of a list, it is helpful to think of people in clusters: friends, relatives, etc.

Next, in column 2A, place a check next to the person's name if this is someone to whom you have been able to turn for support, advice, information, or if it is just someone with whom you can talk about feelings. Otherwise, check column 2B.

In column 3, briefly describe the kinds of communication you have had with this person. Be as specific or as general as you like.

In column 4, indicate how this communication started. Did you start it, did the other person, or did it just seem to happen?

Column 5 asks you to indicate how well you feel you were able to say the things you wanted to say during communication with this person. Could you express your feelings, or ask for advice, etc., to your own satisfaction? Pick the statement which best expresses how you felt:
1. Thought it was better just to discuss ordinary, everyday things with this person; did not try to talk about more important things

2. Tried, but could not seem to say what I wanted to

3. Could discuss some important things, but not everything, with this person

4. Was satisfied with what I could communicate to this person; could say what I felt needed to be said

5. Was very satisfied with the way in which I could communicate with this person, could say whatever was on my mind

Finally, consider which of the following best expresses how well you feel the person was able to respond to you:

1. Person was able to respond in the way I would have liked them to

2. Received a somewhat satisfactory response from this person

3. The person's response was satisfactory

4. The person's way of responding was very satisfactory

5. The person's response could hardly have been better

C. 1. Please consider the responses you received which were both the most and the least satisfactory. What was the most satisfactory. What was the most satisfactory like? What was the least satisfactory like?

2. When you consider all the aspects of your experiences with cancer, which seem the easiest to talk about with other people?

3. Which seem the most difficult?

4. Are there things that you have not talked about at all, but that you would like to discuss?

5. In general, how do you feel about talking about cancer to others?

6. Do you think it is easier to talk with someone who has undergone an experience like yours?

7. Is there anything else that you think a person conducting this study ought to know, based on your experience?
<table>
<thead>
<tr>
<th>1. Person: Name and relationship to you</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. Support, advice, information, feelings, etc.</td>
</tr>
<tr>
<td>2b. Was in contact with person but did not talk about information, feelings, ask for support, etc.</td>
</tr>
<tr>
<td>3. Type of communication</td>
</tr>
<tr>
<td>4. How did it start? (You/other/just happened/don't recall)</td>
</tr>
<tr>
<td>5. How satisfactory was:</td>
</tr>
<tr>
<td>a. Your communication</td>
</tr>
<tr>
<td>(1, 2, 3, 4, 5)</td>
</tr>
</tbody>
</table>
APPENDIX F

PARTICIPANTS' RESPONSES TO INTERVIEW QUESTIONS

Q: Do you think that having had breast cancer has made you closer or more distant from members of your family?

A: Closer. We'd been married for 8 years and we were starting to get involved in careers and [my husband] was tending to get very involved in his work and [my child] had just started school all day, and I was getting involved in my work, and we didn't have a lot of things together any more. But I suppose that's a normal part of anybody's married life after a few years, and this really brought us back... Really brought us close together... And now we do a lot of things together, even if one of us isn't particularly interested... Just to be together as a family, we try very hard to do that.

Q: If you consider the responses that were both most satisfactory and least satisfactory, how would you describe...?

A: [The most satisfactory] ...More than a [verbal] response, it was just the fact that my husband would sit and listen and let me talk about anything. He didn't have to even answer me, just that he would sit and let me talk to him about what was going to happen if I should die... Was I going to cope? What would he do? He could listen to me saying these things.

[The least satisfactory] Again it was with [my husband]... He would always tell me I looked terrific even when I wasn't feeling particularly terrific, and I sometimes wished he would say, well, you don't look so terrific... And I used to want to shake him and say, I don't.

Q: When you consider all the aspects of your experiences with cancer, which seem the easiest to talk about?

A: It was always easier to talk about having a mastectomy, rather than having cancer, because you could kind of separate the two... It was always easier to talk about how it didn't make any difference and you could do everything.

Q: What was the most difficult?

A: Talking about whether the cancer would spread, whether I would have a recurrence, whether I would die.
Q: Of the responses that you got from various people, what was the most satisfactory and what was the least satisfactory?

A: That I hadn't changed, that I was really the same person. Just because I only had one breast, that that was physical, and that myself as a person that they knew before and got to know even better after.

Q: Is there a specific statement or something someone did that you can characterize this by?

A: Just that we love you, that's all I can think of, you know, that people love me, and that maybe they'll miss me a little bit. I don't know, I just put that in, but that I'm cared for, that they let me know that. I really can't think of anything else.

Q: What would be the least?

A: When I talked about fear of dying, and when they said to me, well, you could go out driving and get killed in an accident. And I can understand that, and I don't know what I wanted to hear from them. I feel like I didn't really need help there and that's my own problem... You know, I've always had this fear of dying of this kind of thing, but it feels like it's tomorrow now rather than 50 years from now. It brings it closer. It makes life, well, like you've got a little less time on your hands, a little dearer. As far as helping me, no one can really help me with that, not even [my husband].

Q: When you consider all the aspects of your experience with cancer, which seem the easiest to talk about?

A: It's easy to talk about how I went through it and everything, you know... and I- and the operation, that's probably the easiest really... Just that it doesn't bother me now, only having one breast, and I joke about it. I feel very easy talking about it really.

Q: What seemed the hardest?

A: ...The hardest... I guess I find it hard, not talking to [my husband] about it, but to my friends, about sexual relations and only having one breast... Expressing how I really feel about it, I find that hard. With [my husband] I can talk about it, but I really don't know if he can understand what I'm trying to say. That's the hardest.

Q: Have you noticed any changes in your relationships with members
of your family?

A: No changes. I don't feel they've changed towards me, I don't feel I've changed towards them either, except that I feel closer through all this, that they've stuck by me.

Q: What was the most satisfactory response and the least satisfactory...?

A: I think of my husband's response. I knew I had to get better and recover. I could now, I had a reason. I knew he was there and I could talk to him, I knew he'd understand... [Of the least satisfactory response] One of the girls that I worked with, one of the young girls. She was concerned with how I looked, my appearance. Really at that point, I didn't care. It was the least of my worries. She was a very clothes conscious person, and I think this is how she related to it... how I would find wearing a prosthesis, how I would find wearing clothes. That was not my interest in life, at that point it was the least of my worries.

Q: When you consider all the aspects of your experience with cancer, which seems the easiest to talk about?

A: I guess knowing that the cancer was not a metastatic type, that I did have a future. And that I did not have to undergo any kind of therapy, that was a major relief when the doctor told me that. And that I would get back to my usual routine.

Q: I want to focus on which seemed easiest to you, or were those all ones that seemed easiest for you to talk to other people about?

A: Just being able to know that there was a future, that I was able to express that. That was one of the questions that people asked me about most, do you need therapy, radiation, cobalt, whatever? And I was very happy to talk about that, to tell them, no, I didn't need that.

Q: What was the hardest part for you to talk about?

A: I guess it's the loss of an important body part. I'm not a vain person, but it's like an amputation.

Q: Do you think your illness has tended to pull you away or pull you closer to members of your family, or no change?
A: It's hard to think about it. I think it's made us closer. I think life has suddenly become more important to them. I think they've begun to realize that their parents aren't going to be with them always and it just made them aware that much sooner, the possibility that Mom and Dad could be gone before they realized it, you know. I think we are a lot closer. Within myself I feel there's one particular area I feel apart. Maybe it's just being aware of myself as an individual. I guess I've always put myself into my children, into my home, and into my family. This is a very personal, very real thing just for me, deep inside; in that way I feel a very remote spot. Generally I think we've become a closer family. A private feeling, I can't quite share it with anyone. It's taken me a long time to reach that point, because I've always given of myself, my whole being, to my family, so that's one area they can't really be part of.

Q: How about your friends, your close friends?

A: I still enjoy their company, their friendship. There again I feel a wall, a curtain. Since they haven't experienced this illness, perhaps they can't quite understand how I feel. They sympathize, they care, but they can't quite reach that little space. I don't know how else to put it.

Q: You put it very well. Have you noticed any changes in your relationships, in terms of being closer or farther away?

A: Many times I feel separated from them. I know they are there and always support me, but there again I feel as if I'm on an island. I know it's naive of me, I know there are many other people that have had this disease, but I still feel very alone when it comes down to the basic feeling and relationships.

Q: Do you relate it to the disease?

A: Not necessarily. I don't know. I haven't thought about it that deeply, but it's possible... I'm just becoming aware of myself as a person, a very private person. I've never really taken the time to stop to think about me, I guess is what it boils down to. I guess everyone gets that feeling.

Q: What do you think about the different responses you've received from people about this whole experience? I want you to think about the ones that were most satisfactory to you and the ones that were least satisfactory to you.

A: ...When people tell me that I look good, they tell me, gosh, you look good. At the [clinic] they have a wide medical staff and I
have contact with a lot of doctors and nurses. I share my progress with them, especially with one of the doctors. She'll inspire me, she'll tell me good things and it makes me happy... But it's mostly that people tell me that I look good or [say] you're working all the time? Things like this make me feel good.

The opposite is, that chemotherapy doesn't do much good. All it does is add a couple of years, statements like that.

Q: When you consider all aspects of your experience, which seems easiest to talk about?

A: It seemed easy to talk with people that I knew would be understanding. Because when I talk to them, they seem to appreciate the fact that I was not down in the dumps, miserable, and I was not crying or depressed. So in turn they always gave me inspiration, they always had someone they could tell me about. A relative or a friend who had had cancer years ago and was fully recovered, or [who] had been taking chemotherapy for three years and still is feeling great.

Q: So the easy things to talk and hear are that other people were successfully treated or something.

A: Right, and all the support. And the cards, they kept coming for months. And the calls... And my husband's company [which let him take time off to go for chemotherapy with me]. They told him not to worry about a thing. If he needs to take me to the doctor, there's no problem, and there's not a word to be said about it. That good support that makes you know people really care.

Q: What aspects seem the hardest?

A: When people ask me about the test. When I'm out of work and people might say, what did you have done yesterday? And I might say, I had to have a bone scan. And their immediate response to that is, what is that? What will it show?...

...Also hard to talk about is the concern for my daughters. I hope to be with them to see what I had planned on seeing with them. I want to be a grandmother, I want to see them go to college. Those are things that I find hard to talk about.

Q: Have you noticed any changes in your family since the surgery?

A: Not my husband, he doesn't pay any more attention to me, he doesn't pay any less... My children, no. That's why I said earlier, in our house it's like it never happened.
Q: Have you noticed any changes in members of your family or friends since you have had breast cancer?

A: ...There was this girl—we had our babies at the same time, we're good friends now—I never thought it would happen, but it did. After I had cancer, she came over... I'd known her for five years to say hi, now we're as close as can be... It's funny how things change, just because a disaster happens... My family is closer to me than they were.

Q: What was the most satisfactory response?

A: [My sister] was more understanding, she knew more about cancer. She was always right there. My mother was more upset, asking why this happened and blaming everybody for it. A lot of [my family] mostly felt that there was a reason. [My sister] was more like me, that there was no reason, that it just happened. Even to this day they ask questions, why, how come, this and that... They feel that especially because of the kids [who are illegitimate] that I'm being punished, that this is a horrible life for me...

Q: What was the least satisfactory response like?

A: [My fiance's], I'd have to say [my fiance's] was... Like I said, he cannot accept it. He says he can, but I can tell that he cannot.

Q: Did it break up your relationship?

A: He says no, but I say yes it did- We were supposed to get married ... A couple of months after the surgery, he said that he didn't care enough like he thought he did. When they said that I had cancer and I had to go through the surgery, I expected this. I expected him to drop it all.

Q: When you consider all the aspects of this experience, which seem the easiest to talk with other people about? Which seem the most difficult?

A: The surgery. A lot of people ask about the surgery. Nobody asks about what the scar looks like.

Q: What seem the hardest [aspects] to talk about?

A: Nothing.

Q: Do you think you've noticed any changes in relationships with family or friends since the surgery?
A: Yes, very definitely... I have lost most of my friends... Everybody in that city sent me a plant... There was one couple that we were closer to than anybody else, and she didn't come to see me in the hospital until the last day... I was very angry at her, but by the time she got to see me in the hospital my anger had dissipated. And I felt sorry for her, because I realized that what she was terrified of was cancer... There are many women who do not call me any more. There are many women who never called me after I got out of the hospital. Occasionally their husbands will call, to talk to my husband, to go fishing or something. They no longer ask for me... I have not grown away from those women. The phone just doesn't ring with those ladies any more... On the other hand, I've picked up a few friends.

Q: In the other cases do you think it was fright too?
A: No, I think they just got plain tired of hearing that [I] was sick.

Q: Any positive changes in your family?
A: No.

Q: When you consider all the responses that you got, which seem the most satisfactory? Which seem the least satisfactory?

A: [The most satisfactory] would be some place between my son [aged 6] and my neighbor up the street. Both had very positive attitudes. Son being very very funny all the time, and saying, don't worry, Mother, everything's going to be fine. My friend up the street being very very willing to listen, and also to laugh.

I would say [the least satisfactory] was from the other women that I had known, in town.

Q: When you consider all the aspects of having cancer, which seem the easiest to talk with other people about and which seem the most difficult?

A: Easiest... I found it all very easy to talk about.

The most difficult... I had a lot of pain from the first operation, I don't suppose I talked to anybody about the pain... It's very difficult to tell somebody pains you're having, or the anxiety of the moment, and I was very careful with whom I spoke, for fear that if they ever came up with a lump, they were going to remember what I said, so that it was important to let on with only those feelings and emotions and actual medical facts that I thought would make them a more intelligent person.

The easiest to talk about was the breast reconstruction.
Q: What was the least satisfactory response like?

A: Probably my son, 'cause we were having a conversation a week before all this happened, before I even knew I had cancer. And he said to me, I guess I couldn't ever accept Daddy's death, but I think I could accept yours. And I guess I didn't forget him saying that... And he didn't say anything when I told him it was cancer, he didn't react one way or the other, at all. I thought he would get closer to me, but he didn't. I guess I was disappointed in that.

Q: When you consider all the aspects of this experience, which seem the easiest to talk about? Which seem the most difficult?

A: I don't know. I can talk easy about anything, it doesn't bother me. I can't think of anything that I have a hard time talking about.

Q: Do you think this whole thing has pushed you closer or further away from people in your family?

A: I think we're closer now...

[But, in another part of the interview:]

The things that bother me are that I just know with this disease that there aren't any guarantees... But I just sit and wonder--I know that I'm done with my chemotherapy--which tense I'm in. Do I say, I have had cancer, I do have cancer, I might have cancer, or... I couldn't be too stupid and say I've been cured. Maybe something will come down the pike two years from now and I will, but I don't feel cured.

I like my life a whole lot the way it is now, if I could-- I feel kind of impatient to get my kids squared away and have them turn out the way I want 'em... I feel extremely close to my husband, even though I feel I don't know if I really am tireder than I was, and I don't want to have sex with him, but I don't feel the way I did before. I feel less libido or whatever you call it... People don't tell you, or talk to you about these things.

Q: When you consider all the responses that you got, which seem the most satisfactory? Which seem the least satisfactory?
A: The most satisfactory response was the openness and most encompassing communication between my brother and myself. I think it was perhaps the most satisfactory because it really was the first time post-mastectomy that I could express my feelings with anyone... Except while in the hospital with my surgeon. He and I were very candid and he understood my "vibes" quite well, but that was during a different stage. Even though my brother and I don't correspond regularly and live far apart we have a strong bond which I have always felt, and I'm sure he has, too. He is ten years my junior, and I can remember times such as when he was eleven and I twenty-one, when I found him devouring my nursing obstetrics-gynecology textbook. He sort of acted like he had been "caught" by our mother for a moment, but instead we looked through all the pictures of deliveries, anatomy, etc., and I believe this is when he received his pre-puberty introduction to sex, and we both freely exchanged questions and answers, etc. He is very perceptive--would have made a great oncologist... Anyway, he initiated our talking-out, and it just felt like a giant load had been lifted from me after that, because everything sort of tumbled out, and I could relate my cancer experience and some of my anger, etc., to things from way back to our childhood, or toward some characteristics of relatives, etc., which he and I both related to. This was four and one half months after my mastectomy, when to all outward appearances, everyone who knows me seemed to think I looked "super" and was able to react in a social scene, just like nothing ever happened. But I was actually still so obsessed with my fears, and wondered if I would ever not think of anything else ever again. Now I can recall quite vividly everything we talked about and how I was talking "around" some words at first--like "metastasis," "probable recurrence," etc--but then realized I could actually verbalize the real honest things I had dammed up inside. It was a very important time. And of course I didn't realize it until I could feel later the relief of anxiety, and I haven't even communicated this to my brother.

The least satisfactory response I received was just a letter that a friend wrote me. It almost made me gag, and I immediately threw it away--the antithesis of all the other letters which I have kept and have reread several times. She and I used to be very close before she moved away, even though we were poles apart in most every way. A few weeks after my surgery her letter came, and I'm sure she figured she'd cheer me up. But all she said in several paragraphs was how my husband was a "leg man" and not a "boob man," and I wouldn't have to carry all that extra pound or so around any more, and all the clothes were made for flat-chested women, and European women were binding themselves with Saran Wrap and she uses up a roll every week, etc. There was never a word about her being sorry, and it was just devastating to me. When we saw each other a couple months later, she was full of questions about
my treatment, etc., because she was worried about her own estrogen level, and articles she'd read. So much for that unsatisfactory response. But another very concerned friend—between my biopsy and surgery—remarked about, well, I must say, your chest has never been your greatest asset, or something like those words, and— I don't quite remember how I reacted, but when she left, I felt angry about that, and wished I would have said something like, It's a good thing I'm not losing my leg.

Q: When you consider all the aspects of your experience with cancer, which seems the easiest to talk about?

A: I would say the easiest aspect of my cancer experience to talk about is the physical part. They can ask about the chemotherapy and radiation reaction, or if my arm hurts after a tennis match, and I can complain if I feel like it, or tell how the chemotherapy does or doesn't seem to affect me at all, and how I almost wish it would make me throw up because it would seem more aggressive in its action then.

Q: What seems the hardest [aspect] to talk about?

A: Talking about the future and my fears is difficult. When I "celebrated" taking my last chemo, my friends would say, You mean this is it, the last one you'll ever have to take? My husband and family haven't said this, but several others have. My answer has either been that I sure hope so, or, This is it, just check-ups from now on. A few months before I completed my chemo, I did ask my oncologist if I couldn't be a guinea-pig for another year because I tolerated it well, and I actually dreaded not having the drugs in my system like good little soldiers. She told me how the current thinking was to shorten, not lengthen, the therapy, etc. Anyway, I don't feel that way now, and in general feel very hopeful.

Q: Are there things that you have not talked about at all, but that you would like to discuss?

A: Even though I feel that I've talked quite a bit with my oncologist, she doesn't really realize, I don't think, that I still have some pretty deep fears about my disease. I really think that my way of coping well is to sublimate. I think I hold back because I know that [my oncologist] is vulnerable, too, and I know that if she has some doubts about my prognosis or pathology, etc., she would not want me to demand certain information in detail. I've asked her and we've discussed as much as I want to know, but there are some nagging questions that I don't really care to put to her.

I also haven't directly talked with my husband about my loss of interest in sex. I'm afraid he'd think it is some permanent thing
that would decrease his sexual feeling for me, and at present I think I can go along, probably the way my grandmothers did.

Q: In general, how do you feel about talking about cancer to others?

A: In general, I can talk pretty easily about cancer to others--other than my immediate family, and that is improving. But there are reservations, because the precedent was sort of set early on, and now it's hard to open up with friends whom I didn't talk freely with before.

Q: Do you think it is easier to talk with someone who has undergone an experience like yours?

A: Yes, definitely. At first, I was anxious to get together with an old friend who had a mastectomy two years before me. I called her for lunch after not seeing her for over a year. But I had more questions about how long it took for her arm to feel decent, and about chemo, etc. Now I can talk to women about to undergo mastectomy [at the request of my oncologist several times]. But I would never open up a conversation in the waiting-room or with someone I didn't know, just because we had a mastectomy and Chemo in common. This past winter I did stop to see an old family friend I haven't seen in several years while on a visit to the state where she lives. She is in a later stage of breast cancer and doesn't get out except for her Chemo, etc., but she seemed genuinely glad to see me, and we talked about the treatment she is having and how different it was nine years ago when she was diagnosed. She told me about the type of metastasis, etc., whereas her family and my mother see each other frequently, and they had never divulged to my mother anything about her condition and treatment.

Q: Is there anything else that you think a person conducting this study ought to know, based on your experience?

A: The only thing I would be curious about is if, other than through Reach to Recovery, these women have been offered--actively invited--to share or turn to a specific support resource person or a group by their physician--surgeon or oncologist--or oncology staff nurses or personnel. If the woman did experience a severe anxiety reaction or depression which incapacitated her, what service and/or therapy was made available, and how did it help her?

Q: Do you think that having had breast cancer has either pushed you away or brought you closer to members of your family and friends?

A: No, I'd say we had good relationships before, and we still have good relationships. Nothing really has altered.
Q: I'd like you to think about the responses you received from other people. What was the most satisfactory response like? The least satisfactory?

A: [The most satisfactory] was a genuine interest in my emotional state, without coming out [and saying anything]. I mean, they understand me, but there was complete trying to help me in any way, physically or emotionally. They did many kind things, but it was the inner part that I like best. There just wasn't a day that went by that [my grandchildren] didn't call, or come by, or try and make me laugh, or say, boy, you're great...

[The least satisfactory] was my son... My daughter-in-law--his present wife--to this day... never has called, never would say, how are you? And she'd call me and it would be a bad day, and she'd say, you sound in a bad mood today. I'd say, well, I don't feel too great today, I'm tired or something... But to this day, I have never been asked, or there was never one thing done to make my life a little easier. In the hospital my son showered me with flowers and he came, but when I got home and he saw I was doing for myself, that was the very end. I know he loves me, but let's say... it has never been vocal. That I think has been the worst part of the cancer, because if it hadn't been for the cancer I wouldn't feel a little different towards my son.

...You feel that some place along the line you had to fail, because in a tragedy of any kind you separate the strong from the weak, and you find the friends that you knew were your friends remain your friends. If you could no longer go out, or entertain them, or go to their house, but they were just the same as they were the day before. But then, a lot of them, they wanted to do things, and you weren't quite that important... At least it made me see that everybody I really like really would have said I'd put my life on the line... But you accept things like that. My son, he's the only one who really bothers me.

Q: When you consider all the aspects of this experience with cancer, which seem the easiest to talk with other people about? Which seem the hardest?

A: Just the operation [was easiest]. Most difficult... the emotions. The prosthesis, etc., that's easy, but to bear your soul, to say how I really thought, that's a little harder. Because sometimes in these depressions with my son, you'd think, Oh, I wish the hell it'd gone through and that it was all over with, instead of working like a nut for what? The inner... those are the defeating things.
Q: Have you noticed changes in your relationships with either close family members or friends?

A: Not really, it's just about the same... People that you think would be sympathetic, they ignored it. I have two friends that didn't, but I have a sister-in-law that I'm close to that ignored it. She was helpful, but she ignored it. I felt men, some of the men I know, had more understanding. I am the only one of the people that I know that has had this, and so I wonder if the women looked at me and were afraid...

Q: What responses were the most satisfactory? The least satisfactory?

A: I talk about my husband and my daughter here. I thought they were just wonderful. Then my best friend,... her being a nurse,... I could discuss more with her and get more response. And another good friend, and then down to my sister-in-law, in whom I'm kind of disappointed.

For the most part, I think people don't care to talk about it, and I also think they avoid looking at you, and it hurts. The two good friends that I mention here I didn't feel that way at all. I thought they were primarily interested in me. I also felt that way with my husband and daughter. And the other I mention here, she can't help it, that's the way she is. Some people that want to talk about it, I feel they're curious, that they really aren't interested... that they just want to go and tell someone else...

The most uncomfortable reaction was with my in-laws. They didn't even mention it to my husband, and they work together. I felt there could have been some compassion for my husband anyway.

Q: Of all the aspects of your experience with cancer, which seem the easiest to talk about, and which seem the most difficult?

A: Well, now, I can talk about the whole thing. I think just the whole experience was so overwhelming, the cancer. You come out, and the surgeon sends you home, and you have no one to talk to. ...I had no one that had had the same experience. A doctor simply cannot do it, it's not his fault, he simply can't.

Q: You have had a long relationship [with your husband]. Has this changed it in any way?

A: Oh, yes, as bad as it was with him, I don't think we started to live until three years ago [when my husband was diagnosed with cancer], to see how valuable things are.
Q: Have you noticed changes other than that with members of your family and friends:

A: I know my children have realized, the same as we do, that you have to live each day. I don't think they did before... Money is nothing really, it doesn't buy you happiness, it buys you necessities, nothing more, really. Friends- I am finding there are friends and there are friends... [Speaking of my husband's cancer,] there are people who want nothing to do with him. These kind of people we don't need.

Q: To what do you attribute these changes?

A: I think this is something... Cancer is no worse than heart, diabetes, or any other disease... My husband- we learned with him. He can talk on his own, but it's really a loud whisper. Do you know, there are people that are interested enough in us that will sit and have a conversation, and they will even forget! There are other people that turn their immediately, I'm sorry, I don't hear him, I don't understand him. They don't want to. Those are the kind of people that we, unfortunately, have had to sort out.

...My neighbor next door, her husband died of cancer a few months ago. She has had the same thing as I have. She told one of the other neighbors, don't tell her I have had this, I don't want her to know, and she will not say a word to me.

Q: In general would you say that having had this has brought you closer or further away from members of your family and friends?

A: I think it brought us closer. I think we can communicate with people much better than we did before... I think possibly both of us felt inferior to other people because they seemed to be doing so much more and were so much more alive, but after having had this we have the feeling that we are alive, and we're so happy that we're alive... Things like [clothes] are not important. People are important to me, but not these other things.

Q: If you were to think about the responses that you got from other people, which would you consider the most satisfactory, and which would you consider the least satisfactory?

A: [The most satisfactory] I think [was] that so many of the people I have talked with have brought out misfortunes that they have had, or people that they know that have had this, their experiences and just being able to talk about it with someone else, that you normally wouldn't. I think we have been made aware that other people have as many problems as we do, and that other things can be very very much worse.
[The least satisfactory was] being ignored and pushed away, that their things were so much more important than yours. They wanted to hear about you, but their things were so much more important. It turned me off.

Q: When you consider all the aspects of your experiences with cancer, which seem the easiest to talk about? Which seem the most difficult?

A: [The easiest] I think probably [was] the recovery, how fast [cancer patients] were able to get back into social life, and the method of how they did it.

Most difficult... Nothing really.

Q: Have you noticed any changes in relationships with members of your family or friends? Has this brought you closer or further away?

A: No real changes... I felt that there were a lot of people you could contact, and that was even more supportive. Different women, like even in the hospital, women that had already had mastectomies who sort of came out of the woodwork to talk to you... like nurses or aides on the staff.

Q: When you consider all the responses that you received during that whole experience, what was the most satisfactory response? What was the least satisfactory?

A: [The most satisfactory was] probably the non-verbal, supportive type, that people are there, and they they're willing to do anything.

[The least was] probably in the doctor's office during the first visit, and I thought I'd better be informed about this since I don't know too much about it, and I asked him how many mastectomies he'd ever done, and he said one. I didn't think that a lot of the things he joked about [were funny]... Or things he didn't think I should be asking questions about, but I wanted to know.

Q: In considering all the aspects of this experience with breast cancer, which seem the easiest to talk about? Which seem the most difficult?

A: The word cancer, I don't think you mention it that much, but when you do people have very strong feelings and dread, and so basically I dealt with the term mastectomy... I had a very short time to introduce the idea, and it depended on the person. I had to
make personal judgments about how much they could deal with. My father I didn't tell because he was on his deathbed; my mother I finally told a day or so before the operation how serious it was. But other members of the family, it wasn't that difficult. It was fact and you had to deal with it. It might have shocked... It wasn't that difficult.

Q: To what do you ascribe your sense of well being about [cancer]?

A: I think my whole family being supportive. My husband--I think some men could become very upset by it--he hasn't let it change our life at all. Family- of course, my mother's gone through it [many years ago] and my mother-in-law's been very helpful.

Q: When you consider the responses that were both most satisfactory and least satisfactory, how would you describe the most and least satisfactory responses?

A: Everybody has been super. I've had nobody that's given me a hard time. Everybody at school has been overwhelmingly in support of me, and very concerned, even people that you don't speak to that often. My kids [at school] were super. I had kids that would just hug me, and with teen-age kids you usually don't get this kind of a response... I was back about two weeks at school and I had to go and start my treatments. I can remember that I told them I had to leave, that somebody else was going to come in the next day and take my class, that I had to go into the doctor's for a doctor's appointment. And one of my 9th grade algebra students said, Mrs. T, you're coming back, aren't you? ...I said, of course. She said, the last time [meaning the operation] you didn't. I practically cried in class.

Q: When you consider all the aspects of this whole thing, which seem the easiest to talk about? Which seem the most difficult?

A: Surgery didn't bother me. I think the treatments bother me more because they're longer.

I feel that I can talk about any part of it. It doesn't bother me.

Q: Are there relationships that you find have changed as a result of this, either closer or more distant?

A: When I first went back to work a lot of people came up to me and said how sorry they were that I went through it.
Q: Out of all the responses that you received, which did you find the most satisfactory? The least satisfactory?

A: They prayed for me. My faith means a lot to me. My friends, most of them are of my own faith.

Q: What was the least satisfactory response like?

A: I don't think I had any. People were unusually kind... During that time I was having this problem with my son, and I think everybody felt more sympathetic towards me... He kidnapped his child and took off. We didn't know where he was...

Q: Are there aspects of this experience that seem easier to talk about than others?

A: I was in such a turmoil at the time, to me it was like I don't even remember it happening, it was so fast and so quick.

Q: Have you noticed any changes in relationships with family and friends since the surgery?

A: ...The only thing I did find, and I decided- maybe a month after the surgery I told my husband, I said, now your family, they're always having big family picnics, etc., and he would go and put in an appearance at family Christmas parties and things like that, he'd go maybe for dinner, but then he always left... I did decide that if I really didn't want to go to something, I didn't feel that I was obligated to go just because it was a family thing... I do go if I want to go, but that was one thing I did decide.

Q: When you think of all the responses that you've received over the course of this experience, what do you think of as being the most satisfactory response? The least satisfactory?

A: [The most satisfactory:] I think probably because everybody told me I looked so great. Some of them didn't even know when I got out of the hospital.

[The least satisfactory was] in a way, probably my mother-in-law, because she'd say, Oh, you're doing so great... And she kind of falls apart about anything anyway... I think that bothered me more, because supposing you did feel bad, and there's somebody putting on almost like an act. And one of my friends, one time she was all upset because she had a grade 3 pap smear and she kept asking me if I thought she had cancer, and I said, well, why are you asking me? I've had cancer, you're feeling sorry for yourself, and you don't even know if there's anything wrong with you. It
kind of irked me at the time.

Q: When you consider all the aspects of this experience with cancer, which seem the easiest to talk with other people about? Which seem the most difficult?

A: I never found it hard to talk about it.

Q: How would you say that this has affected your life?

A: It has not affected the outward things at all. Mostly what it has affected is my relationships with other people... I've become a lot more aware of other people's problems. And I have this thought that maybe I can help them.

Q: Have you noticed changes in relationships with members of your family and friends?

A: No... a little closer, maybe, for some people. I think that maybe my husband and I even are closer than we were before... It was something we went through together, and I think that we feel closer now than we were before.

Q: When you consider the responses that you received that were both most satisfactory and least satisfactory, what constitutes the most and least satisfactory responses for you?

A: The most satisfactory was the concern, their offers of help... And that was the best thing, the very active concern... That people actually did something about it. The reaction that was the most distasteful was this lady that I was talking to... The look of horror on her face when she found out, and the fear... because if it could happen to me, it could happen to her--she's a little older than I am. I think it bothered people a lot that I was so young [32] and this could happen to me. It scared people a lot.

Q: What did you think about being so young?

A: Well, the only thing that bothered me was that if it didn't turn out well, if I did happen to die because of it, that my family is so young, and that they really need me. But I'm really convinced now that I won't have that problem for a couple of years, and I don't want to think about it.

Q: What aspects of the experience with cancer that you've had do you think would be easiest to talk with other people about, and which seem hardest?
A: I have not had trouble talking about any of it. The hardest part is the end result, the possible death. That's the hardest thing to talk about. The second most difficult would be talking about the physical appearance. I don't feel any different inside, but it's hard for people to understand that. And I think that I make people feel uneasy sometimes, because I don't make any bones about there only being one breast instead of two.

Q: Do you think this experience with breast cancer has brought you closer or made you more distant from members of your family and friends?

A: I think a couple of friendships have become much closer. Two gals that really went out of their way to be helpful. One drove me to the radiologist's every day for six weeks... And I had known her, oh, for just a couple of years, and we developed a very strong relationship. The other gal took my son in while I was in the hospital, and this was good for me... She just was so easy to accept things from--I don't accept things that easily. I don't think I've lost any friends because of this. A couple of my oldest friends have gone back to work, and that makes it hard to see them... Maybe my oldest son, he doesn't talk to anybody. He gets angry with me, more so than he used to, and I don't know whether that's because I have cancer, or whether it's just a stage he's going through. He never talks about it; the other three boys do, but he never mentions it. I think my husband and I are closer.

Q: When you think about the responses that you received that were both the most satisfactory and the least satisfactory, what do you consider the most satisfactory, and what do you consider the least satisfactory?

A: My husband was the most, because I could talk to him more than anyone else. I think he understands me. He knows sometimes when I... when to take me seriously, when I'm really upset, and when it's something that's not too important. He's a good listener. With the girl that drove me down, she was a good listener too. I didn't talk all that much, but I knew that anything I wanted to say I could say and this was very good... The people that I really felt I could talk to were the people I felt would talk to me if they needed to, and I wasn't boring them.

Q: What was the least satisfactory response?

A: Well, I think my oldest boy's. It's not that he didn't respond. I think that the lack of satisfaction was that he's a very very shy person, and you can't get through to him. I told him that
I had cancer, that I was having an operation, and he came up to see me, but there was absolutely no communication because I can't talk to him and he can't talk to me. He's a very reserved boy. I think [my sons] were all very concerned. In fact my second son, he would never have let me know, but his girlfriend dragged him to see me while I was in the hospital, and he let me know that he wouldn't have been there if she hadn't brought him. It's not because he didn't care. I think that in his case it's because he cares a little too much, and he was afraid to come in to see me, and... it's a hard age for boys, you know. You don't talk to mother about breast cancer.

Q: When you consider all the aspects of this experience with cancer, which seem the easiest to talk about? Which seem the most difficult?

A: The basic physical thing that you'd had surgery and everyone knew and they'd say, hi, how are you? You're looking great, and that was the easiest. I found I didn't feel self-conscious at all, and I thought I would. I thought it would be awkward to go out, because you feel that everyone would be looking at you and saying, which side? And only once did I notice someone looking at me. I find that I look at other women much more than I did before and think, Oh, doesn't she have a nice bust-line, but I'm not conscious of other women looking at me.

[The most difficult:] I never find anything really hard to talk to my close friends about.

Q: Have you noticed any changes in relationships with members of your family or friends since the surgery?

A: The family is concerned. My daughter was in California. She'd been out there for three years, she had a fantastic job, she made a very good life for herself, and she decided a month ago to come home. She felt she didn't really know what was going on with me, it was only a telephone contact, we called every week... She said, Ma, I don't really know what's going on with you. You tell me you're fine, but I have to see for myself... The main reason she came home was that she felt she should be at home right now, so she came back to live. And I will have to say they're all concerned. My husband and my children. We always were close anyway. Everybody has respect and love for the other one... I think mostly it's that I've tried to be super strong... to show them that I'm still able to get up and do things the way I was. I'm not down, so I don't want anybody doing for me... I know they're concerned, things that are said... There would be days when I would be on
the chemotherapy and I would be thoroughly disgusted because I
couldn't do the things I wanted to do... And I'd want to whiz
through the house and I couldn't do it, and I'd start to cry.
I would come out with things like, I just can't be an invalid,
I just want to keep going the way I was, and my little son, 15,
would say, Ma, you're going to be fine. And that's when you
know the concern comes in, and you know that they're all there
with you.

Q: When you consider all the responses to your experience with can-
cer, which seem the most satisfactory? Which seem the least sat-
isfactory?

A: [The most satisfactory was] I would say, from my family. That
I was still the same person, that they were all on my side, they
knew there was a problem, and they were just always there to help
me get through it.

[The least satisfactory was] people giving me advice and telling
me about this one and that one that had all kinds of problems,
who couldn't do this and that, and that I shouldn't let them give
me chemotherapy because it was going to do so many other things
to me. Kind of old wives'tales, and I just didn't like all this
outside advice from people. I just felt that everybody was trying
to be the doctor, and I didn't agree with them.

Q: When you consider all the aspects of this experience with cancer,
which seem the easiest to talk to other people about and which
seem the most difficult?

A: Basically, I can talk about any of it. I can talk about the breast
removal and I don't get all panicked... I can talk about the che-
motherapy, I did not enjoy it. I can talk about any of it...
You have thoughts sometimes when you're down, and I blamed being
down on the chemotherapy. I'd think, is this going to be my only
experience with it? Am I going to have it again somewhere else?
Sometimes I'd say to my husband, I wonder if this chemotherapy is
going to take care of it, I wonder if they got it all... I didn't
talk about it to me kids because I sheltered them, but to my hus-
band I'd let it out. I'd have the days where I'd be down, and
I'd say to him, I don't know if I'll ever get back up where I was,
on my feet being a whole person again. But he was always there
to listen.

Q: Have you noticed any changes in relationships with family and friends
since the surgery?

A: No, none. I didn't tell my family, except for my husband and my
children, because there has been a lot of cancer in my family. My family doesn't live in [this city]. They've never found out about it, and they never will. My neighbors know about it, and even they wouldn't have know about it except that a couple of them are volunteers at the hospital.

Q: I'm curious about why you decided not to tell your family.

A: Oh, because it would kill my mother. My father has cancer, and of the five children in her own particular group she's the only one alive, and she's the oldest... The last thing I'm going to do is tell her, my mother is 78 years old. And therefore I couldn't tell anyone else in the family. But since they don't live in [this city], and since I go to see my mother every three weeks, and I was able to work it to get there, there's no reason for her to know.

Q: Are you close in other ways?

A: Mom, yeah. But she never noticed the difference. Why would she?

Q: Out of all the responses that you received, which have been the most satisfactory and which have been the least satisfactory, in your opinion?

A: My friends and neighbors who did know about the condition didn't try to be overwhelmingly sentimental about it or anything. I had no problems talking about the problem to anybody. Nobody was unduly worried. You know, people ask you how you feel for six months and after that they forget about it, and that's fine.

Q: What was the least satisfactory response like?

A: The only thing I can put in that category is the way the doctor considered... did not consider all the problems I would have to contend with. That's really the only thing; with my family, my friends, and my neighbors, everybody was just super.

Q: When you consider all the components of this experience are there some aspects of it that you find easier to talk to other people about than others?

A: I don't talk about it except at [my support group] because I try to be busy, and it just doesn't hit my life that much. There are a group of people who I meet when I have my injections, because we're all undergoing chemo at the same time, but we don't even always just talk about that because we've been with each other for almost a year, and we all have other family problems that we have to contend with. Even in [the group] we don't talk about it all the time.
Q: Have you noticed any changes in relationships with family and friends since your surgery?

A: No, because we've been very outgoing about this whole thing. Everybody knew what was going to be done to me. There was nothing kept secret. The children, our grandchildren, knew it, even the little 8-year-old, our son explained it to him. So that there has been no embarrassment, no embarrassment since my coming back to work, none of that. Everybody has been so glad to see me up and about and well. I think if I had tried to hide it, it would have been an embarrassment. People would have been talking; well, they would have known. Everybody's talked about it. Everybody's asked me questions. People have examined themselves and gone to the doctor's. In fact, [my friend] had a biopsy last week. Hers was benign, but I think in the long run, that a lot of people gained from it.

Q: Out of all the responses that you got during this experience with breast cancer, what was the most satisfactory and what was the least satisfactory?

A: I think it was my friend [who is] a nurse. A husband's different. It's a different response. We discuss everything, and my husband is a very positive thinking person, but we don't - our son is the same way. They don't get that bothered by things, but still, they always, always look for the better side of things, so we don't get into philosophizing as much as [my friend] and I do. Then, because she knows more of the medical side of things, too, there's a little more professionalism there... She's very open, she's extremely frank, you know exactly where you stand. You know whether she likes you or she doesn't. She doesn't miss anything, and she will say whatever is on her mind. My first flower was one single red rose, and it was from her, and it was all I needed. She's a very special friend.

I can't think of anything that wasn't satisfactory.

Q: What aspects of this experience have you found easiest to talk about? Which seem most difficult?

A: We've talked about death, the possibility of my not making it, and it doesn't really bother me any more to think about it. Eight lymph nodes were involved. I mean, it's not good, but if the medication does what it's supposed to, then, o.k. I will probably live for a year, five years, who knows, but if a good attitude helps, then I should live for a long time. We've discussed all of that. I don't think there's anything we have not discussed.
...People have been very open to me because there's no secret about it. So I think people who didn't talk about it before are talking about it now, or will ask questions that probably they wouldn't ask anybody else.

I didn't look at myself while in the hospital, and when they changed the dressing, I had my head turned the other way. I didn't want to see. I don't like the mutilization of it, but if it keeps me from cancer, well, that's o.k., too. You're at a point where you have no choice, so you have to live with it.