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A Qualitative Study of the Experience of Breast Cancer Surgery: How Women Cope and What They Need

Malone Aderholt

A QUALITATIVE STUDY OF THE EXPERIENCE OF BREAST CANCER SURGERY: HOW WOMEN COPE AND WHAT THEY NEED

MALONE ADERHOLT, B.S.

A Culminating Project Presented to the Faculty of
the Graduate School of Lindenwood College in Partial
Fulfillment of the Requirements for the Degree of
Master of Art

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Abstract

This is a study of the internal and external experiences of women who have been breast surgery patients and have been forced to make adjustments in many areas of their lives. The study focused on the necessity of the breast cancer patient to face life in an altered state, which affects her physical, social, emotional and sexual well-being, as well as confronting her with the issues of death and dying.

The methodology employed in this study was qualitative. Information was solicited through the use of informal personal interviews conducted by the researcher. A single one and one-half hour interview was conducted with each participant in the research project. The sample consisted of 10 women who have experienced breast cancer surgery, from a lumpectomy to radical mastectomy, who volunteered to participate in the project.

The purpose of this study was of a practical nature. It is hoped that the data and analysis may be helpful to women experiencing breast cancer, their partners and families, surgeons who perform breast surgery and counsel breast surgery patients, as well as educators, therapists

and counselors who seek to improve the psychological, psychosocial and psychosexual recovery of breast surgery patients and their families.

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TABLE OF CONTENTS

TABLE OF CONTENTS (Continued)

CHAPTER I

Introduction

According to the Department of Health and Human Services (1980), "...in a 1976 study of Californians' attitudes toward cancer, 64 percent of those surveyed mentioned cancer as the serious illness which worried them most" (p. 55). Statistics released by the American Cancer Society concerning the prevalence of cancer indicate that "about 76 million Americans now living will eventually have cancer; about 30% according to present rates. Over the years, cancer will strike in approximately three out of four families" (p. 3). Since 1986, there has been an increase each year in the number of deaths per year due to cancer. The American Cancer Society quotes a prediction by the National Cancer Institute:

> This year (1989), about 502,000 will die of the disease--1,275 people a day, about one every 63 seconds. Of every five deaths from all causes in the U.S., one is from cancer. In 1987 it was 483,000; in 1986 the figure was 469,376" (p.3).

Because of the prevalence of the disease in our society, few families have been untouched by cancer. Most of us have been associated with someone who has had cancer or who has died from it, if not in our own family, in that of our friends or associates. Firsthand knowledge of the pain and suffering involved add to the aura of fear and trauma associated with the disease (U. S. Department of Health and Human Services, 1980).

In addition to firsthand knowledge of the suffering involved with cancer, media campaigns by national health organizations constantly promote cancer awareness and early detection of the disease. This media emphasis serves to keep the focus of the American public on symptoms, early warning signs, carcinogens present in our environment and groups at high risk for cancer. Stories about public figures having cancer are featured prominently in the news. It is ironic that the campaigns for public awareness of cancer also serve to heighten the fear of cancer, or what has sometimes been referred to as cancerphobia (U. S. Department of Health and Human Services, 1980).

This fear of cancer may exist because dying of cancer is believed to be slow, painful and unpleasant. Cancer is usually associated with death and pain. Many people believe cancer is invariably fatal and that nothing can be done to prevent death when cancer has developed. Breast cancer is the second most frequent cause of death in women. According to the American Cancer Society (1989) approximately 142,900 new cases of breast cancer were diagnosed in the United States during 1989. Approximately 1 in every 10 women will develop breast cancer at some time during her life. The mortality rate is estimated at 43,300 (43,000 females, 300 males). The society states that breast cancer is "second only to lung cancer, now the foremost site of cancer deaths in women" (p. 10).

Statement of the Problem

The study examined the subjective experience of women who have had breast cancer surgery, how they coped and what they need. In addition to facing cancer and the fear of death and dying, this group of cancer patients has a third major trauma to address--issues concerning body image and feminine identity.

Rubinstein and Cirillo (1985) supported the seriousness of the additional trauma associated with breast cancer:

> ...the diagnosis of cancer of any kind can arouse many profound fears in anyone--fear of the unknown, fear of what the disease may lead to, fear of how one's life may be changed, fear about death and the way one may die, or fear of chronic and painful disability. But for a woman, in addition to these fears, breast cancer is unique because it arouses many concerns about the loss of a breast. This can have profound meanings for any woman (p. 69).

A public opinion survey conducted by the Opinion Research Corporation of Princeton, New Jersey, indicated that "three-quarters of all women interviewed ranked the fear of developing breast cancer as their most important health concern" (Rubinstein and Cirillo, 1985, p. ix). Breast cancer patients facing the possible loss of a breast or breasts, experience a threat to a fundamental component of their identity. The value system in our society and culture places a high value on breasts, equating them with femininity and motherhood.

The Department of Health and Human Services (1980) asserted that:

> Many women believe that the size and shape of their breasts determine their sexual desirability (or lack of it) and define their acceptability as women in society's

> eyes....Her femininity, her self-image, and her measure of herself as a person are all threatened, especially if her breasts are perceived as a significant component of her identity or are crucial to her functioning comfortably in her career (p. 56).

Because of the value our society places on the female breast, a woman facing breast surgery fears a loss of sensuality, loss of self-esteem and worthwhileness as a person.

According to Campbell (1984):

> An increasing tide of books and articles proclaim that self-esteem is what human beings desire above all. A variety of thinkers, starting from different ideologies and backgrounds, have come to the conclusion that the self-esteem motive can explain virtually every facet of human behavior. Proposed by psychoanalysts, psychologists and lay thinkers are self-esteem theories of aggression, of laughter, of anxiety, of suicide, depression, altruism, crime, etc....we all want a good self-image. Each of us works incessantly and with ingenuity to brighten his or her self-image (p. xiii).

To support his emphasis on the importance of self-image, Campbell (1984) proposes the following as Laws of Human Behavior:

> First Law of Human Behavior: Each human organism seeks to maintain or increase its sense of its own excellence.
>
> Second Law of Human Behavior: Each human organism seeks to maintain or increase its level of sensual gratification.

> Third Law of Human Behavior: Virtually all human thoughts, words and actions spring from the two above motivations, operating singly or in combination.
>
> Fourth Law of Human Behavior: In cases of conflict between the first and second motivation, the desire for a sense of excellence usually prevails.
>
> Put in simplest terms: Virtually all of our human behavior springs from two motives: our desire for self-esteem and/or our desire for sense pleasure (p. xi).

Pulitzer prize winner Becker (1984) supports the importance of self-esteem, asserting that the most disparate life-styles are explained as different ways of maintaining a comfortable level of self-esteem. Self-esteem maintenance, he believes, is the underlying principle of a wide range of psychological problems, such as schizophrenia, depression, sadism, masochism, hypersexuality, homosexuality, passivity and aggressivity. According to Becker (1984), every aspect of our lives is affected by this principle, including our general health, interpersonal relations, stress, anxiety, worth, level of aspiration, productivity, and recovery from illness or surgery. These two motivations for human behavior described by Becker (1984) and Campbell

(1984), self-esteem and sensual pleasure, appear particularly appropriate to a study of the concerns of breast surgery patients, especially as they influence recovery from illness or surgery.

Purpose of the Study

The purpose of the study is to describe the internal and external experiences of a woman who has been forced to make adjustments in many areas of her life. She must not only face life in an altered state (affecting her physical, social, emotional and sexual well-being), but must also face the possibility of death and dying as well. The purpose of the study is a practical one because of the large numbers of women having breast cancer annually. The data and analysis may be helpful to women experiencing breast cancer, their partners and families, surgeons who perform breast surgery and counsel breast surgery patients, as well as educators, therapists and counselors who seek to improve the psychological, psychosocial and psychosexual recovery of breast surgery patients and their families.

CHAPTER II

A Review of Related Literature

Introduction

This study examines the impact of breast cancer surgery on the life of a woman. It examines the choices, doubts, concerns, traumas, fears, needs, and the coping strategies of post-breast surgery patients.

Psychological Concerns

Death and Dying

Literature on the subject of the impact of breast surgery on women attests to the severity of the trauma attached to this experience. According to Ingram (1988), studies by Kuehn (1986), McCollum (1978) and Ray and Baum (1985) indicated that when patients hear the first diagnosis of cancer, the initial reaction is one of shock and disbelief. "The client often psychologically associates the word cancer with death itself" (p. 24). A study by Goldman (1985) confirmed the intensity of this initial reaction and conveyed the power with which it is felt, "The fear of death is common to all humans but is magnified a hundred times under the impact of cancer....for many patients, each day brings haunting reminders of the possibility of recurrence" (p. 148).

Loss of Control

Closely linked to this fear of death and dying is the fear of loss of control felt by the patient. According to Goldman (1985),

> The cancer process has been aptly described as 'the wayward cell.' Loss of control is clearly implied. In concrete terms, this means that the woman cannot control or reverse what has happened. The breast will not grow back. Reconstructive surgery is a possibility for some, but still there's the fact that 'things will never be the same.' Irreversible disaster is a nightmare one wakes up to in the morning and remembers many times during the day and night. Not only is the patient powerless over what has already happened, but also over what is occurring in her body at a given moment. This is true for all living creatures, but more poignantly so for the patient suffering from a life-threatening illness (p. 150-151).

Anxiety and Distress

A study conducted by Polivy (1977) suggested that "biopsy patients showed a decline in body image and total self-image immediately after surgery," and "mastectomy patients....evidence a decline in body image and total self-image, but not until months after surgery" (p. 79).

Polivy (1977) quoted Renneker and Cutler (1952) as giving a more explicit statement of the issues involved:

> ...the loss of the breast, among a woman's most prized physical possessions, severely damages feminine pride, necessitates changing the mind picture of the body, and shakes the foundation of feminine identification. Bard and Sutherland found evidence that for some women, self-worth and acceptance as women were predicated on body attractiveness throughout their lives. The mere possibility of losing a breast led them to feel that life was no longer worth living" (p. 78).

Polivy also explored

> ...the dual psychological conflict posed by breast mutilation and invasion of the body by a potentially fatal disease. They found postmastectomy depression to be a frequent reaction among their patients, along with feelings of shame and worthlessness. Their response to cancer of the breast is not as much a fear of cancer or death as shock that the basic female role is endangered (p. 78).

The anxiety level of the client is extremely high; and the client's response may include both denial and depression, with depression being quite severe at times. However, Ingram (1988) stated that other researchers have found

> ...little evidence of serious depression or neurosis in this population. They found

> that in most cases these clients simply suffered from isolation and deprivation, reporting that there was no one to whom they could vent their fears and concerns. These individuals felt isolated from those around them, did not want to burden professionals with their problems, and felt left out of the mainstream of life without any control over the choices made which would govern their destiny (McCollum, 1978; Peterson, 1984) (p. 24).

Silberfarb (1978) mentioned the importance of taking a close look at anxiety and depression when considering treatment plans for rehabilitation of mastectomy patients. He noted,

> ...the occurrence of serious anxiety and depression postmastectomy is common. This distress can be completely appropriate to the patient's situation and does not necessarily indicate disease or psychiatric illness. Nevertheless, it should not go unrecognized since much can be done to alleviate the patient's distress. Many surgeons feel that no woman escapes serious emotional trauma following a mastectomy and that the patient's emotional suffering outweighs the physical. One published study from England indicates that 50 per cent of patients admitted to serious anxiety or depression postmastectomy; while another survey, also from England, indicated that only thirty-four out of 100 women admitted to varying degrees of depression postmastectomy (p. 159).

Denial

The intensity and seriousness of these concerns may explain why denial is such a recurring theme in working with postmastectomy patients.

Silberfarb (1978) appears concerned that the necessity for denial be understood. He suggested that

> An appreciation of the frequent use of denial in patients with physical illness is crucial to the adequate psychological intervention in women who have undergone a mastectomy... It has been the author's experience that the existence of denial is often protective, necessary, and useful in aiding the woman to deal with her altered appearance. The mere presence of denial is not a reason for intervention. It is only when denial obstructs appropriate and realistic management and reasonable return to function should psychiatric treatment be pursued. The therapist must be aware that the mechanism of denial may be evoked so strongly that it is not until several months postmastectomy that the woman's low self view becomes apparent (p. 165).

Psychosexual Concerns

Psychological Meanings of the Breast

In order to better understand the occurrence of postmastectomy distress, Silberfarb (1978) suggested that we need to look at the obvious psychological meanings of the breast.

> First is the association with sexuality which our culture has glamorized in ads, magazines, and entertainment, so that it is, in effect, the badge of female sexuality. The second psychological meaning is the association of the breast with the woman's role as a mother. It is the major visual

> symbol of motherhood...No one is surprised, then that the loss of a breast may be a highly charged issue. For, not only is the woman with a mastectomy coping with a cancer and all the charged feelings of death, disfigurement, pain, and the very real possibility of a long and lingering illness; but she is also coping with an attack on her gender (p. 160-161).

According to Ingram (1988), other researchers have concurred that

> ...pain and death are not the most feared aspect of breast cancer, but that the fear evidenced is due to a real threat to the female role, and self concept of the individual. The fear of loss of the breast in women has even been equated with that of loss of the penis in the male (Renneker and Cutler, 1952) (p. 24).

Emotional and Social Concerns

According to Rubinstein and Cerillo (1985), 75 percent of the women interviewed considered the possibility of developing breast cancer as the health risk they feared most. The emotional and social fears involved are such an integral part of the breast cancer experience, that they should be taken as seriously as the medical aspects of the disease.

A pilot research study conducted by Witkin (1978) explored several of these emotional and social aspects in a group of 41 women. She investigated the relative importance of psychosexual factors in the psychological recovery of mastectomy patients, as well as the importance of sexual counseling to the patients. She felt that sexual counseling gained its importance from two factors: (1) the large number of women undergoing mastectomies, (i.e., approximately 90,000 per year in the United States alone), and (2) the psychological well-being of the whole person is so dependent upon sex and sex-related factors. One unusual aspect of her study was that each of the 41 women included in the study was asked if they would like to speak to a psychological counselor specializing in sex therapy and all 41 agreed. Witkin suggested that this unanimity was very significant, since most people have inhibitions about sexual counseling and would hesitate to volunteer. A 100% response, she felt, was highly unlikely. That all 41 of these women did agree to see a counselor for sex therapy implies that the high anxiety level and desire for help were strong enough to overcome their inhibitions about seeking counseling. This might indicate that the traumatic effect of mastectomy is more severe than the patient normally chooses to reveal.

Importance of Sexual Role

In Witkin's (1978) study, three themes kept recurring as she counseled the 41 women. First, the central issue with these women was almost unanimously how the surgery had affected their sexual role and functioning in their psychological recovery. Many of the women mentioned that they were not afraid to die but were most afraid of losing the affection and sexual responsiveness of the man or men in their lives. One young woman told her partner, "I know this had to do with cancer and dying, but my main fear is that you won't want to screw me any more" (p. 22)! The women in the study had already survived surgery and were on their way to recovery, so possibly their fear of dying was either decreasing or being suppressed. It was obvious, however, that their psychosexual concerns had become very important to their emotional well-being. Witkin asserted,

> Once the immediate prospect of death has passed, psychosexual concerns dominated the thinking of these women and became of central importance to their emotional functioning. "I feel like I'm nothing now," said one woman. "If I could I would have kept my breast even if I had died in a few years" (p. 22).

Importance of Partner's Response

The second theme to emerge in the study is closely allied with the first, which is the importance of the response of the sexual partner. Witkin (1978) stated, "The ability of the women to integrate the mastectomy trauma--losing a breast to cancer--into her life depended on the reaction (real, perceived, or anticipated) of her husband or lover" (p. 22). Regardless of age or career role, from housewife to career woman, the attitude of the partner largely determined the attitude of the woman toward herself. One young woman in the study stated, "My boyfriend came once to the hospital, once to the house, and never came again. I've been depressed ever since" (p. 23). Another woman reported, "I don't know how I'd be without my boyfriend. He really is a lifesaver. Without him I really wouldn't feel like living" (p. 23).

Because the response of the partner is so crucial to the emotional recovery of the patient, Witkin (1978) believes the husband or lover should be an integral part of the entire recovery process, and optimally should be included in her psychological counseling as well.

A study by Frank et al. (1978) supported findings regarding the importance of the partner's acceptance to the woman. Certain behaviors of the partner were more helpful than others, such as the partner's attitude and skill in conveying to the woman that

> ...she is still an acceptable person and that the loss of a breast does not alter their relationship or his feelings for her. Male behaviors that support this attitude are, for example, encouraging the woman to be nude in the male's presence, and the male's expression of willingness to view the scar and to make overt displays of affection and tenderness to his partner. That these behaviors and attitudes may not readily occur is suggested by the present data (p. 25).

Frank et al. (1978) suggested,

> ... there is a period following the mastectomy and extending for at least three months in which sexual behaviors are altered, suggesting that the woman and her partner do not return to their pre-mastectomy levels of functioning...the data, although preliminary,

> suggest that routine sexual counseling should be an integral part of the preparation and rehabilitation of the mastectomy patient and her partner (p. 25).

This brings us to the third theme found in the study by Witkin (1978):

Importance of a Counselor

The third theme Witkin (1978) discovered was that a counselor was very important to the satisfactory adjustment of the patient "not only for the actual counseling provided, but also for somebody to talk to, someone to whom the fearful woman could unburden herself" (p. 23). Witkin (1978) suggested that the mastectomy patient's need for support could be interpreted in more than one way, perhaps "as a regression to an earlier stage of dependency under the stress of trauma" (p. 23). However, she concluded,

> ...for the clinical professional...the underlying cause makes very little difference; the operative factor is that the mastectomy patient is intensely concerned over her continuing existence as a full-functioning sexual person and that she needs as much support as possible to resolve these concerns fruitfully and expeditiously (p. 23).

The woman needs to be reassured that she can be a fully-functioning, sexual person; and she needs a lot of support to achieve this goal.

In summary, Witkin (1978) found that "in the 41 women in the study sexual concerns were, indeed, at the core of their emotional and psychological status and that emotional support was very much in order to help them resolve those concerns" (p. 23).

Dissenting Views

While the majority of the studies reflected agreement regarding the seriousness of psychosexual and psychosocial concerns of postmastectomy patients, there were dissenting views as well. While Silberfarb (1978) agreed that "women fear the loss of self-esteem, sexual attractiveness, and the general decrease in feelings of worth and well-being that accompany breast cancer," he feels that there is no absolute evidence that "links these reactions specifically to breast cancer alone rather than to the cancer in general" (p. 160).

Another study, Penman et al. (1987), expressed conflicting views concerning the degree of emotional distress following mastectomy. Penman et al. studied self-concept and social functioning in radical mastectomy, modified radical, and simple mastectomy, as well as breast biopsy for benign breast disease and cholecystectomy or no operative procedure across a fifteen month period in a cross-sectional design and across a twelve month period in a repeated measure design. Results of the study showed less degree of disability than previous findings after mastectomy, thus "refuting what they call 'previously published impressions of severe psychosocial maladjustments following mastectomy'" (p. 102). Women who received adjuvant therapies (radiotherapy or chemotherapy) did report more body-image dissatisfactions and feminine self-image concerns than the other group. It was suggested that those with poorer expected outcomes would be those with less quality support groups, had other life-stressors, pre-existing chronic diseases and who believed themselves to be less in control of their lives.

While Penman et al. (1987) challenged "the assumption that breast surgery automatically results in an increased incidence of psychosocial disability" (p. 126), they suggested,

> Adaptation may have been easier for the women in our study than in earlier decades because of the increased information about cancer available to the general public, the reduction of stigma attached to cancer as a disease, the generally greater acceptance by the treatment community of women's rights to participate in treatment decisions, the trend toward less radical surgical procedures, increasing opportunities for breast reconstruction, the widespread availability of the Reach to Recovery Program and a growing number of hospital support groups, and the increasing awareness of the importance of psychosocial factors by caregivers in oncology settings (p. 126).

Rosenbaum (1982) suggested that sexual problems may result "not so much from actual changes in a person's body as from how that person feels about those changes" (p. 89). He asserted

> If a cancer patient was comfortable with and enjoyed his or her sexuality prior to the illness, the chances are excellent that he or she will be able to keep or regain a good sexual self-image despite the changes brought about by cancer (p. 88).

Psychological and Psychosexual Counseling

Much of the literature reviewed for this study reflects a strong need for psychological and psychosexual counseling for post breast surgery patients. According to Gerard (1982), health-care providers need to examine the emotional support system of the breast cancer patient and be aware of "her tendency to present a face to her doctor and to the world of invulnerability and casualness about her surgery" (p. 314). The patient experiences a disservice from us if we take this facade at face value and make an assuption that her family and friends provide an adequate support system. "We must as psychologists, physicans, and health-care providers, present her with opportunities to let down her facade, to express grief over her loss no matter what her age or how long it has been since her mastectomy..." (p. 314).

Frank et al. (1978) recognized the need for counseling and agreed that women are hesitant to discuss the very sensitive area of sexual activity in relation to mastectomy. Of the 41 women in their study, the great majority had not discussed with anyone their feelings about how the mastectomy might alter their own sexuality or their sexual activity. Prior to the mastectomy, only three women spoke to anyone about sexual activity and this was with their doctor. During their hospital stay the number increased to eight, with four discussing sexual activity with their husbands. After hospitalization, there were only 10 who had discussed sexual activity with anyone and half of these involved their husbands. These figures very graphically point out how unwilling or how hesitant women are to discuss sexual activity with anyone. However, 40 to 44% of the women (on an anonymous questionnaire) indicated a desire to have had more discussions about sexual activity at some point before or after the mastectomy. The study concluded,

> It would appear that while few women actually discussed sexual matters, a number of others would have liked to do so but may have thought this an inappropriate topic for discussion, particularly if it was not initiated or volunteered by medical authority or those responsible for post-surgery rehabilitation. It seems logical that if sexual adjustment is of concern to the patient, this area should be routinely incorporated into any presentation to the patient before the surgery or while the patient is in the hospital, and/or after hospital discharge at the same time that the patient's physical recovery is being evaluated (p. 21).

Gallo (1977) not only agreed with the above study concerning the intensity of the issues involved, but also confirms the importance of early intervention following diagnosis of cancer:

> If possible, intervention should begin soon after the identified patient has been informed that hospitalization or biopsy might be required. In a study of the impact of severe illness on families, Kaplan, et al. have shown that the 'optimal period of intervention is during the early, acute stage of the crisis, immediately following the confirmation of the diagnosis' (p. 247).

Ingram (1988) agreed that counseling on sexual concerns should begin even before treatment of the cancer has begun, as a critical part of the total rehabilitation program. In his study of 20 post mastectomy women and their husbands, many of the women "become concerned, fearing that they have become unattractive to their husbands, or men in general. Those who have surgery feel ugly, mutilated and unwanted" (p. 25). Because the support of the husband or partner is so crucial to the women's recovery, Ingram (1988) suggested that health professionals have an ethical and moral duty to provide counseling on sexual concerns. He felt "it should be the responsibility of the health care professional to initiate discussion of sexual concerns and not assume the client's silence indicates a lack of concern regarding sexuality (Mantel, 1982; Tombrink Dierkhising, 1987)" (p. 25).

Group Therapy

There appears to be growing evidence that psychological group therapy is very beneficial to breast cancer patients and their families. Little research was found on the efficacy of individual therapy for the breast cancer patient. However, studies have been conducted on the results of group therapy with this population. According to Spiegel and Glafkides (1983), a comprehensive cancer treatment program must include recognition of the importance of the psychological support needed by breast cancer patients. Both group therapy and support groups are viable treatment approaches. Spiegel and Glafkides stated that physicians appear reluctant to encourage their patients to participate in such groups, either due to fear of their patients being demoralized by associating with other dying patients, or due to their own time-consuming schedule, necessary to the administration of the complex medical treatment required by breast cancer patients. The physicians feel that the medical aspects of treatment must take precedence over psychological needs. Spiegel and Glafkides' study with a therapy group involving women with metastatic breast cancer, results failed to validate the fears of physicians. There was no expected increase in depression and despair nor did the presence of dying members in the group demoralize the participants. Over the course of a year, the women in the control group, with no group therapy, suffered a loss or deterioration in psychological adjustment. The group who had group therapy improved in psychological adjustment in a number of ways: less fear of dying, using more effective coping mechanisms, better communication within families and with physicians, and an increased capacity to live life more fully in the present.

Another study by Clarke, et al. (1982) investigated the effectiveness of therapy with post-mastectomy patients and evaluated the results of an ongoing program (started by the Michigan Cancer Foundation). The results suggested that there is little recognition of the fact that "the cancer survivor's failure to rehabilitate is more often due to personal psychological problems than to physical and environmental factors" (p. 331). Two main sources of rehabilitative failure were felt to be notions of body injury and fragility, and fears of unacceptability to others. Clarke, et al. stressed the need for support for these patients. In a population of 450 mastectomy patients, the study found that over one-third of the group exhibited strong anxiety and severe depression "which went mainly unnoticed by the professional staff. After one year a significant number of women were still struggling to adjust" (p. 331). To research the effectiveness of group therapy for mastectomy patients, a group of 40 patients was divided into a control group and a therapy group for 10 weekly sessions. One therapist described the sessions.

> Group sessions consisted of the various members sharing their fears, feelings, and experiences in an atmosphere of acceptance and understanding. Issues ranged from the surgical experience, to reactions of relatives and friends, to feelings about one's own body, to fears of recurrence of cancer and many other areas. The therapist would intervene to develop group cohesiveness, provide emotional support and to help members feel valued and understood....many group members were able to work through negative feelings about themselves, resolve much anxiety

> and depression, ventilate anger without fears of retaliation, decrease a sense of isolation about their situation, and learn coping skills to deal with their present problems (p. 332-333).

Results of the investigating study showed improvement adjustment in both the control group and the therapy group; however, "the group in therapy...improved far more...the treatment group continued to show improvement after the end of the 10-week treatment period" (p. 333). The study group (Clarke et al., 1982) reported the following ranking as indication of the order in which change occurred, from greatest change to least: marital, family, social, work and sexual and concluded that:

> The results provide strong support for the position that the 10-week course of weekly group therapy was beneficial for the adjustment of women who had undergone mastectomies. The specific therapy program of the Michigan Cancer Foundation is supported, and generalization to the usefulness of instituting other programs of this sort seems clearly indicated (p. 333).

According to Kriss and Kraemer (1986), who conducted a therapy group for 12 months (35 therapy sessions),

> The statistical data alone do not convey the extent of the difficulty the women experienced in trying to accept their bodies. They referred to their scars as looking like a 'railway track that a heavy train has run over,' or as 'ugly' and 'cruel.' They talked about the loss of breast as the loss of an erogenous zone where they had previously felt sensation and sexual arousal. These outpourings of negative feelings expressed by virtually all subjects confirmed the depth to which the women were affected by their breast loss and the magnitude of inner struggle necessary to overcome these negative feelings (p. 449).

The study reported a movement of the negative feelings into a more positive range through the process of group sharing. Results of the study included "increased self-disclosure and willingness to risk new experiences; and many of the women reported putting more energy into new friendships, expanding their social lives and careers, and placing higher value on their person" (p. 449).

According to Spiegel and Yalom (1978) who described a long-term (12 months) support group for dying patients (with metastatic carcinoma),

> The group has focused not on dying per se but rather on living in the context of dying. The task has been not merely to face the fact of one's own death but to live in the face of it, to maintain meaningful family and social relationships and, in some instances, careers, and to live resolutely with neither

> denial nor depressive preoccupation--in short, to maintain a sense of purpose in life...One of the major tasks of the group has been the mourning and coping with the death of group members...The process of dying was detoxified and demystified for the group through their experience with it (p. 237-239).

This 12-month support group came to feel "less like passive victims of a disease process and more like experts on living" (p. 240). The members felt they had grown personally and that they have a message to share with others. "They especially wanted to influence the medical profession, to change physicians' attitudes toward the metastatic cancer patient" (p. 240). Another clear purpose that emerged in the course of the group's meeting was that they wanted other women to know that

> the diagnosis of breast cancer was not the end of one's life but, rather, the beginning of a different kind of life. The notion that through their experience they had something to teach as well as something to learn seemed to have a significant effect on their self-esteem and their sense of meaning in what remained of their lives (p. 241).

According to an article published in the Reader's Digest (1990), psychiatrist David Spiegel and his research colleagues found that "psychotherapy, used in conjunction with standard cancer therapies, lengthened--by a year and a half on average--the lives of female participants who had metastatic breast cancer" (p. 61). According to the article,

> Thirteen years ago, Spiegel had studied the short-term effects of group therapy on 86 patients with advanced breast cancer. He undertook a follow-up study originally to disprove what he calls the wish-away-your-cancer types. What he found instead stunned him. While those in the control group lived an average of 19 months after joining the project, those who received a year of group therapy averaged 37 months (p. 61).

Family Concerns

While emphasizing the crucial importance of sexual adjustment to recovery following breast surgery, Ingram (1988) strongly urges health professionals to remember that cancer is a family problem. While breast cancer affects the patient in all areas of her life (physical, psychological, emotional, financial and social), all other family members are strongly affected as well. They share in her sickness and fear. Because cancer is a potentially fatal illness, it has an impact on all aspects of family life. Often younger children manifest disturbed or delinquent behavior, problems in school, nightmares or enuresis. Older children must at times assume a parenting role while mother is in the hospital. The family's social, financial, vocational and educational goals are affected, placing stress on the entire unit of the family. Financial resources may be weakened by the high cost of treatment. Other family members' wants and needs may have to take second place. The family must struggle with their own anxieties and fears, while giving support and encouragement to the patient. Family support is of vital importance to the patient before, during and after the surgery. According to Gallo (1977), it may be "the key factor in psychological recovery" (p. 249). Ingram (1988) feels that

> the counselor must approach the woman with cancer not as a solitary individual, but as a member of a family, and if necessary to see the entire family together early for a family session, perhaps even before the client's discharge from the hospital, or if possible, even before surgery is performed (p. 26).

CHAPTER III

Methodology

The purpose of this study was to examine the experience of women who have undergone breast cancer surgery. This study sought to understand how they coped and what they needed. The specific concerns of the study included the following:

1. What were the feelings, thoughts and concerns of women who have undergone breast surgery:
    (a) Immediately after diagnosis
    (b) When making treatment choices
    (c) When experiencing side effects of treatment
    (d) When ending treatment

2. What was the reaction of the women's partner:
    (a) Before the surgery?
    (b) After the surgery?

3. What type of psychological therapy, if any, was recommended to the women, and at what time in the treatment plan?

4. If the women had psychological therapy:
    (a) What type psychological therapy did they have?
    (b) For what length of time?
    (c) Was this long enough?
    (d) Was psychological therapy individual or group?
    (e) Was the psychological therapy helpful? If so, in what ways? If not, how could it have been more helpful?

5. What type of self-healing, if any, did the women practice?

6. If self-healing was practiced:
   - (a) What type was practiced?
   - (b) For how long?
   - (c) Was it helpful? If so, in what way?
7. Was breast reconstruction recommended? Accepted? What were the results?
8. What would these women like to see changed about the medical or treatment procedures they received?
9. What would these women like other people to understand about their experience that no one seems to understand?

The methodology employed in this study was the use of an informal personal interview. A questionnaire (Appendix A) was developed, using general questions, as described above, to facilitate the interview. Responses varied according to each participating individual. The data received from these responses served as a base for understanding the subjective experience of breast cancer surgery in the lives of the women interviewed.

Subject Selection

Women included in this study were chosen because they had received some type of breast cancer surgery, from biopsy to four major types of mastectomy including,

(1) radical mastectomy, (not commonly used today) which involves removal of the entire breast, nipple and areola, pectoral (chest) muscles, some of the overlying soft tissue and lymph nodes, including those extending into the armpit.

(2) modified radical mastectomy, also removes the entire breast, nipple and areola, some of the overlying skin, nearby soft tissue, and lymph nodes in the armpit (pectoral muscles are left intact but the overlying cover of muscle is removed).

(3) simple mastectomy, involves removing the main breast structure and sometimes a portion of the overlying skin (usually the chest muscles and underarm lymph nodes are not removed).

(4) a partial mastectomy (or lumpectomy), only the tumor and the portion of the breast containing the tumor are removed.

Eligible women were located with the assistance of oncology coordinators in various hospitals, members of support groups in the Metropolitan St. Louis area for women who have had breast surgery, and friends who were familiar with the topic under consideration. In some cases the oncology coordinators personally contacted individuals who were eligible for the study. The researcher provided the nature and purpose of the research study. All aspects of the study and confidentiality were explained to the oncology coordinators. Copies of the questionnaire

(Appendix A), the informed consent form (Appendix B) and the demographics form (Appendix C) were furnished each oncology coordinator for use with the patients. The oncology coordinators contacted known post breast cancer surgery patients and presented the opportunity to participate in the study. The oncology coordinator informed the patients of their freedom to refuse participation in the study without pressure from the coordinator or the researcher. Women who were interested in participating in the study were either asked to contact the researcher or agreed to have their name and phone number furnished to the researcher for contact. The researcher then contacted each subject and arranged a convenient time and place for the personal interviews.

Description of Sample

The sample consisted of 10 women who have experienced breast cancer surgery, from a lumpectomy to radical mastectomy, who volunteered to participate in the study.

Of the 10 women who participated in this study, two were between the ages of 30 and 39, three were between the ages of 40 and 49, three were between the ages of 50 and 59, and two were between 60 and 69. Eight were married, one was divorced and one was single. All 10 were white, non-Hispanic. All 10 of the women lived in suburban areas. Seven had high school diplomas, two of the seven also attended a vocational school, two had bachelor's degrees and two others had 1-2 years of college. Annual income ranged from $20,000 to $70,000 and above, with one in the $20,000 to $29,000 range, four in the $40,000 to $49,000 range, one in the $60,000 to $69,000 range and four in the $70,000 and above range. Five were Protestant, three were Catholic, one was Lutheran and one had no religious preference. Five attended church regularly, two attended frequently, two seldom attended and one did not attend. Two of the women had four children each, two had three children, five of the women had two children and one had one child.

Two of the women had mothers who had breast cancer surgery, one had a grandparent who had breast cancer surgery and seven had no other member of the family who had breast cancer surgery. Eight of the women had modified radical mastectomies, one had lumpectomy and subcutaneous mastectomy, and one had lumpectomy with lymph disection. The average age of the women when they had breast surgery was 45.8 years. Two women were in their 30's; five women were in their 40's; two women were in their 50's and one woman was in her 60's. One woman had surgery 15 years ago, two women had their surgery five plus years ago and seven had their surgery three years ago or less. Of the seven whose surgery was three years or less, three had surgery less than a year ago.

The Interview

Interviews were conducted in the homes of the women who volunteered, whenever possible. If this was not convenient for the volunteer, the interviews were held in the home of the researcher or in a room made available at the hospitals involved. The interviews were approximately one and one-half hours in length, with one additional half-hour allotted to completion of the demographics form. The interviews were conducted in privacy, with only the woman and the researcher present.

Participants were informed that some of the questions were personal and that they had a right to refuse to answer any question asked of them and that they also had the right to withdraw from the study at any time. The interviews were tape recorded and later transcribed verbatim.

Prior to the personal interview, participants were requested to sign an informed consent form. When the interview was complete, each participant was asked to complete the demographics form.

Data Analysis

The recorded tape for each individual interview was transcribed verbatim, but without any identifying information, and destroyed by the researcher. The interviews provided the basis for an analysis of the subjective experience of breast cancer surgery by the ten women who volunteered to participate in the research study.

CHAPTER IV

FINDINGS

Physical Concerns

Pain

"Pain comes in varying degrees, ranging from bearable and manageable to excruciating, unrelenting and unbearable" (Photopulos, 1988, p. 115). Women who participated in the research project reported:

> The most excruciating pain I had was when I came to after the surgery. They (doctors) gave me something for it; and I never had bad pain after that.
>
> I just breezed through the surgery. I came home two days later. It (going home) was just great. I didn't have much pain; or no, I shouldn't say that. I had a lot of pain. But I discovered I'm a really strong person. I think my pain tolerance is high. This is what I have told people I have helped since that time (after surgery): You are really in a black hole, and you just keep pulling every little quarter of an inch. And you keep pulling yourself and pulling yourself. And it's black, but you keep going; because there might be light pretty soon. And inner strength is all that is. And you just keep fighting. And it just gets you there eventually. It's like every little pull and every little struggle helps. Trying to sit up was a major accomplishment, the first time out of bed, turning over, laying on my side, all those things. You just keep pulling and you can almost see yourself physically pulling yourself up, but you just keep on.

Radiation

Photopulos (1988) stated: "...when I received radiation treatments, the pain, anxiety, depression, and fear were so debilitating it took all the courage I had to make it from day to day" (p. 63). Women who participated in the research project identified with this reaction, describing their experience in terms which varied from "inconvenient" and "annoying" to "lonely, frightening and depressing":

> The radiation was very easy for me. I didn't have any special fear of the radiation the way some people do. I did get the red sunburn effect on the breast, which made it pretty itchy. That was very annoying, but they give you creams to put on your skin. You're in the grocery store, and you want to scratch, and you can't. You're moving all around, shifting your jacket or coat, hoping that will take care of it.
>
> I didn't know anyone who had radiation. I would have liked to talk with someone who had it. When you go in the radiation room, you are alone in that room; and that machinery is awesome! You feel so isolated. And the noise of the machine is overwhelming!
>
> The markings they do with the indelible pen gets all over your clothes, but you are warned ahead of time. I think the markings are a gruesome sight to see, but I think it bothers people that look at you more than it bothers you. Once I was going to a party wearing a V-neck dress, and the purple marking came up too high. So I just put make-up on it and went on to the party.

Chemotherapy

Chemotherapy and its side effects appear to elicit as much dread, fear and depression as the cancer itself. Women reported:

> When the doctor gave me the name of the drugs he suggested for chemotherapy, I said, "Oh no, not my hair!" I knew when you took this drug, you usually lost your hair. It was the biggest devastation of my life, like breast cancer was nothing. I said, "Are we talking 'cue ball?'" The doctor said, "Yes, it usually turns out that way." I asked if there were some kind of bargain, some way to avoid this (loss of hair). It just threw me for a loop! I just didn't know how I was going to do it--not having hair--it's like your whole being! I didn't know how I could handle it. Then I thought, "The first thing I'm going to do is to cut my hair short. It will be less shocking to see short hair on my pillow than a lot of hair." I think that was a form of taking control.
>
> My friend drove me home after having chemotherapy. They (doctors) told me to eat starchy things. So I ate macaroni and cheese while watching TV. I went to bed at 9:30 p.m., woke up at 12:30 a.m., realized I was going to be sick, and tore into the bathroom. We had this digital clock radio where you could see the red numbers. And it was every 20 minutes to the minute for 10 hours. And I would fall asleep in between, because I was getting exhausted. You know you're not rational. And you think you are going to die, even though you know you couldn't die just throwing up. It was like dying. It was horrible.

It was a tortuous process when my hair started falling out. It took about a month before it was all gone. You feel like you wish somebody would kill you, it's like being tortured a slow death. When I would come out of the shower and look at myself in the mirror, I would say the same thing out loud each time, "Oh my God!" It was so devastating. I would think, "Who is this? The voice sounds familiar, but who is this person I see in the mirror? Do I have to get used to her? Is that old person I knew for (age) years ever going to come back?" I didn't know. I felt real lost.

I would be brushing my teeth, and my hair would be falling in the sink. And I would think, "There it is down there. It's supposed to be up here on my head. What's it doing down there?" And I was getting bald spots. So I started wearing my wig. The first time I put it on, I felt absolutely ridiculous. I was horrified. And when I would stop at a traffic light on my way to work, I felt like everyone was staring at me. Of course, no one was. And when I got to work, some people didn't even realize it was a wig. So I began to adjust.

I went into the wig store and told the lady what I wanted. When she put this wig on me, it was horrible. And I looked in the mirror and started crying. And I saw my girlfriend's face in the mirror, and she was crying too. All I remember is seeing her eyes, like she pitied me to death. And I didn't want to be pitied. I felt sorry enough for myself. I just wanted to be out of this (cancer experience). Please let it be a dream. But when I saw other people (my girlfriend) feel the same way, I knew it wasn't just me. This was really happening to me. Of course, after she cut the wig for me, it turned out just fine. It was wonderful. It matched the exact color of my hair, and I thought I looked good in it. I guess having to buy it just brought the reality home to me.

Psychological Concerns

Anxiety and Distress

> "Because of the fear, anxiety, and distress it brings, cancer is not simply an enemy of the body; it is an enemy of the psyche as well. It attacks the emotions as it attacks the tissues, and often the damage to the patient's emotional well-being is more serious than the damage to the body" (Photopulos, 1988, p. 63).

Women who participated in the research project reported that dealing with physical aspects of breast cancer treatment is devastating enough, but understanding and managing the emotional aspects can be even more devastating in varying degrees during different stages of recovery:

> I was concerned, but I didn't have a lot of fear. I had read that only 10% are malignant; and I'm a person that thinks awful things can never happen to me.
>
> The doctor looked at the nipple that was irritated and said, "Oh my God!" But he jokes a lot, and I said, "What's the matter?" It's so shocking that you don't even connect with what he means. He said it looked like Paget's disease, it's a breast cancer. I said, "I'm (age) years old, don't be ridiculous! I've no family history, what are you talking about?" I thought he was overreacting. Then he said, "It's a rare form of breast cancer."
>
> I went from "there's nothing wrong, why are you worrying?" to "there's something wrong;

> something inside me is saying it's cancerous." I just kept vacillating, up and down, up and down, like a roller coaster. I had a few periods of crying, because I started to get scared at this point.

> I was devastated when I learned I had cancer. I wanted to run away and tell them (doctors) to take it all out. The quicker you get rid of it (cancer) the better. I was so fearful!

Two women reported fear of repeating the suffering and experiences observed in other family members with cancer:

> When I learned I had cancer, I remembered a (relative) of mine who had suffered a lot and died of cancer. I saw her in the last stages and was just devastated to hear her screaming. When my turn came, to me it just meant suffering, no hope and then dying. I thought I might have a year or two with a lot of suffering.

> When the doctors said, "It looks like cancer," I was devastated. I don't think there's another word in the dictionary that can scare you that bad. To me it meant suffering and death, because I saw my (parent) suffer for five years with cancer.

Another woman felt her feelings were denied before she had an opportunity to fully express them:

> (Partner) was saying to me, "Don't cry, you're going to be fine." I think he was feeling very inadequate because this (cancer) was happening to me, and there wasn't much he could do. And sometimes people don't understand that we need them right there with us (feeling what we are feeling) rather than cheering us up. There are times when you don't need to be cheered up, you need to be sad. You need

> to feel the sadness before you are ready to go on to something else. I didn't have enough time to grieve it before everybody was going, "rah, rah, everything is going to be fine." And it reminded me of my childhood and being told "Don't cry. There's no reason for you to be sad, you have everything." It felt like my feelings were being denied, and I began to feel isolated, really alone, and that no one really understood. And there was no one to talk to about these feelings. I didn't know where to go for help. And then--zoom--I'm on my way to surgery.

Another woman reported how good it felt to be able to release pent-up emotions:

> On the way from the doctor's office, I cried all the way. Things would be fine for a little while, then I would burst out crying again. It was totally uncontrollable. Then when I got home, I started calling people. Most of them would start crying, and I found myself reassuring them. But it was good for me, because it let me take another role instead of victim. Then when I called my very best friend in (state), she just started screaming; and then I could finally let it out. And I was screaming, and we both just lost it. Then we talked about it and it was O.K. She was the only one I could do that (scream) with.

Two women described a distancing from emotions with a "zombie or robot-like" response:

> When my regular doctor sent me to the surgeon and said he wanted me to go right now, I was starting to feel the panic; because I could see that he was worried. And I trusted him with my life...and I kind of numbly walked there (to the surgeon) by myself, sort of like a robot. When he said it looked like cancer, I got in my car and drove home. I cried and then I didn't cry. I would cry then I wouldn't cry; and I don't even remember driving home.

> After we (partner and I) were told I had breast cancer, we were on our way to see the surgeon the second time. We were very mechanical at this point, waiting for the elevator. The elevator doors opened; and it was full of people; and they were laughing! We looked at each other, like "Don't they know? How could they possibly be laughing?" We got in and the door closed in front of us; and we were just like zombies, staring straight ahead. All this laughter and conversation was going on all around us, but we completely tuned it out, like we couldn't even hear. We were in a different world, like little robots; and we drove home.

Denial

According to Photopulos (1988), "People were so afraid to say the word cancer, so unwilling to accept its existence, and so fearful it could happen to them, they simply denied it in any way they could" (p. 62). Denial can take many forms, denying or minimizing the seriousness of the illness, denying or minimizing the emotions stirred up by the illness or isolating and disassociating one's emotions when dealing with the distress. While these forms of denial appear to be delusional, they may serve a useful purpose, such as providing time to adjust to the diagnosis and come to terms with fearful parts of the experience. Women who participated in the research project reported various forms of denial:

When I went in to see the surgeon, he just felt the lump and said, "I'm quite sure you have cancer." I went into denial, because I thought he didn't know what he was talking about. I found out later that he was quite knowledgeable in these things. And sometimes a surgeon can tell by merely feeling the lump. But I was mad at him, really, because I thought he didn't know what he was doing and didn't know what he was saying.

It just wouldn't sink in. I felt like I was two people, and one was watching myself from afar. Like here's me and here's me, and we're not together on this. Like the person looks familiar, and you can't understand why this stuff is happening to her; but she's very separate from you. She looks like a victim, really downtrodden at the moment; but it's just not you yet.

When we (partner and I) stopped by to pick up the X-rays to take to my surgeon, I wore a dress that he (partner) got me for my birthday, because I thought it would be lucky. You think of weird things like this. You're just drifting and you have to have some little connection to bring you back to reality. There were moments when I thought for sure I had cancer. Then I would think "There's no way this could be me, it's impossible!" You really go back and forth. You feel as if you have concrete evidence why it can't be you, and the same concrete evidence that says "There's no way I can avoid this."

The doctor was saying to me, "Well, (name), the biopsy report came back positive." Now I've worked in the medical field and I'm aware of what's going on; but for some reason, I wasn't. I said, "So what does that mean?" He said, "Well, it's positive, it's malignant." I said, "So what does that mean?" He said, "Well, you have breast cancer." I said, "What are you trying to tell me here?" My mind just would not accept it!

> When he (doctor) said, "I'm afraid it's malignant," I was just stunned. I thought, "He's not telling me this, he's telling somebody else this."
>
> I just kind of blocked it (cancer) out of my mind. I'm very good at that. I was scared! The next day, she (doctor) walked in the door and said, "I'm afraid I have bad news." And my whole world just fell apart! That was the worst pain of the whole thing--hearing that. I went into shock. Then she mentioned mastectomy. It was just overwhelming. I totally tuned out! It was the most devastating news I've ever had!

Depression

Depression is a predictable consequence of illness or loss, and can make its appearance at any time during treatment or recovery. Everybody gets depressed. The women who participated in the research project were no exception. One woman who valued her independence describes feeling frustrated and vulnerable due to loss of control:

> I have done more crying in the last month than anything else, and went into depression. I feel frustrated. I was always a very organized person and in control. And there's nothing you can do to control this (cancer). You have to rely on only one person, and that's God. And I still have that tendency of trying to regain control of everything, because that's the way I have always been. And that's difficult. And I think that's

> more of what sends me into depression. And I am afraid if I talk about my depression too much to my friends, they won't want to be around me. And when depression hits, it's like there was a period of time when I could go from one room to another and not know why I went there. That's how bad it was. And it can snowball. The more you worry about it, the worse it gets. Because I'm not in control of things, it's almost like being a scatterbrained person. And I don't like being that way. I think the depression is more frustrating to me than the mastectomy!

Another woman reported feeling overwhelmed by a number of losses in succession:

> My career was gone. I lost a job I had for ten years. I didn't get to finish grieving that, when I got breast cancer. I didn't get to finish grieving that, when my partner was gone. It was like I needed to say, "Excuse me, God, time out. Let's take a break here. I'm going to go off the deep end if I don't have a minute to regroup." It was fifteen or sixteen months after breast cancer surgery and I felt myself going into this depression. I wasn't suicidal, but I was just so depressed I had nothing to say. I was like a body that went to work every day, but there was nobody home.

Death and Dying

One unavoidable fact comes to mind very quickly with cancer patients: Death is a possible outcome of cancer. "Even when the prognosis suggests containment and years of symptom-free remission are a reasonable expectation, death seems much closer than it was before cancer" (U.S. Department of Health and Human Services, 1982,

p. 23). Women confront mortality in their own unique way:

> I never really thought I might die.
>
> There comes a time when your own mortality sort of hits you in the face. When they (doctors) said, "You're going to have chemotherapy," I started thinking about losing my hair, getting sick and dying.
>
> It was a hard thing for me to go in that day and have it (mastectomy) done. I wanted to run away. I was afraid I might die. You take your body for granted, and now you have to deal with your mortality at the same time you have the surgery changing your body. I left a note for my children before I went in. I was afraid I would die.
>
> Death was this unknown thing. I say prayers every night, but I guess I didn't really know what faith was. I think I have some, because faith carries your through that black hole (fear of having cancer) until you find the light. And you don't realize that is what it is. But during this experience I really learned what faith was, because sometimes you have to operate on blind faith; and it might be the only thing you have at the moment, to keep you from sliding back into that hole.

One woman felt very vulnerable and isolated by being different:

> I felt completely out of control and vulnerable. I realized this was really happening to me when I came home from the hospital. In the hospital you feel very safe. People are all around you. If there's a problem, you push a button, and someone comes to fix it for you. But when you get home, everyday life is going on all around you.

> I remember going to the grocery story and being in the checkout line. I'd look around and think, "I bet nobody in here has cancer but me." At the movies I would think, "I'll bet I'm the only one in the whole theater who has cancer." You feel really isolated. It's a shock that the whole world is going on without you, with absolutely no recognition of how devastated you are--because you have cancer. You feel very different from other people. At night in bed, I would think, "Why can't I just be like everybody else again?" I wanted to worry about mortgages and kids in school like a normal (age) year old would. I didn't want to worry about surviving, life insurance and medical bills. It wasn't even the issue of maybe dying earlier, I just wanted to be like everybody else.

Fear of Recurrence

"Some patients remain disease-free for many years, but they are understandably nervous during their regular checkups, concerned that their doctors will find "something." They find it difficult to have a "normal" illness. Every cold, every ache, every strange sensation can be magnified into a potential threat" (Photopulos 1988, p. 119). A patient may experience more emotional distress with a recurrence than the level of distress caused by the original diagnosis, surgery, radiation, or chemotherapy. It is discouraging to discover you have to do it over again; only this time, you know what to expect and are reluctant to repeat it. The women reported:

> We all still have that fear, that it could come back some day. And when you go for your checkup, you do have that fear. You become a hypochondriac.
>
> When you're taking the radiation, you feel that you are actively combating the cancer. You feel like you have some control. You are doing something to fight it. And when you are released from that (no longer taking radiation treatments), you feel you are walking on a tightrope; and you could fall off again. You are afraid that cancer will engage you again and take over because you are not actively doing anything to combat it. You feel vulnerable and out of control.
>
> Getting through surgery, chemotherapy, losing your hair and all the categories of things you have to go through, you do them because you are a survivor. You just do it. But do you know what's the hardest part? The rest of your life! That's the hard part; because all this stuff is over with now; and it's living every day that's hard. Because sometimes you get scared. Sometimes you feel so totally vulnerable. When I'm tired from a trip, just so exhausted; and I'll come home; and there's nowhere I can go that I'll feel secure. I feel like a tiny little ant out in the middle if a large field. And there's a lightning storm going on! There's just no protection whatsoever. And I think, "Can I possibly be lucky enough to escape through this? I'm sure that I'm going to get it (cancer) again." And other days I'm just fine. You just go on with your life, and I don't even think about it,

> sometimes. I remember saying to my friend (name), "Will there ever be a time when a day passes that I won't think about it?" And she laughed and said, "Yes." And it wasn't two weeks later that a whole day passed and I hadn't thought about it. And it was a big milestone!

Psychosexual Concerns

Mutilation

"Patients undergoing surgery for cancer require a great deal of reassurance and encouragement if they are to overcome their feelings about mutilation" (U.S. Department of Health and Human Services, 1982, p. 23). Having the breast is identified with belonging, being active and being worthwhile; not having the breast is identified with the opposite of these feelings. Some women who participated in the research project felt a keen sense of having been mutilated:

> No one likes to be cut on. And after it's done, you kind of feel like you're not all there; and you're not!

> I was a little embarrassed that I didn't have the other part of me. Sometimes I felt like half a person.

> I wanted to look at it (scar) and I didn't. It was a weird experience. I didn't cry or dwell on it, I just knew I wasn't going to have anything there.

> When the doctor said "mastectomy," it seemed like mutilation, with this knife coming out and hacking off my breast.

Femininity and Sexual Attractiveness

To some women breast surgery appears to be an assault upon their self-esteem, sexual desirability and body image. To the women who participated in the research, these issues were vital:

> Now I have to think about meeting men and dating. I don't have much hair and I have this weird looking breast. Who's going to want me?
>
> I worried about dating and marriage. I was so scared. What if somebody bolts out of bed and runs away from me? I would be devastated. I know if he did that he wouldn't be worth it. But it's still going to stab you in the heart!
>
> One thing I have a problem with that I didn't realize would be a problem is that I don't feel as desirable or sexually attractive. My partner is a breast man, and my breasts were a source of excitement and pleasure to me also. So it's a double loss. However, he has been very supportive through this whole thing and has never made me feel rejected.
>
> I've had other surgeries, and they didn't compare in any way to this. Not physically but emotionally. If you lose a gall bladder, you've lost a gall bladder; but you can see this loss! And it's not like losing a finger or something. This is part of my sexual identity as a woman.

> We've lost part of our image with being a female and being pretty. You don't feel like you are attractive any more. You feel rather freaky. You just feel strange with one side flat and the other side normal. You can't really process how you can be attractive with that kind of situation.

> Not having a breast, that was devastating. I thought, "I won't be feminine any more. I'll be a freak!" And then I didn't want to see it (scar). I asked the doctor before I went to surgery, "Are they going to force me to look at this (scar) when it (surgery) is over?" And she said, "Absolutely not!" I had heard stories where nurses made you look at the scar before you left the hospital. I didn't look at it (scar) the entire time I was home. When I went back to the doctor to have the staples out, I said, "Well, I guess it's time for me to look at it (scar)." So I went to the mirror and looked. And it wasn't as bad as pictures I had seen! I thought it would look deformed, mutilated, horrible! But when I looked at it, it didn't hurt my femininity. I thought it would, but it didn't!

Sexual Pleasure

Rosenbaum (1982) reminds us that sexual problems may occur more readily due to the patient's (or the partner's) perceptions or feelings about changes in the body, rather than the actual changes themselves. For example, he indicated that "both partners may be nervous about initiating sexual activity or communicating feelings, and the waiting game can be mutually misinterpreted as rejection" (p. 89). The women who participated in the research project appeared less comfortable in volunteering information on this subject than other parts of the questionnaire, which might confirm the fact that discussing sexual needs and feelings does not come easily to most people. Some of the women reported that:

> Sex is not as spontaneous as it used to be. We are both aware that there has been a change in my body. And it's something you just have to cope with and work around. It did affect our sex life, a lot. I felt like a monster, like a part of me was missing. There was such pain from surgery that it was kind of scary. And it takes time to be able to touch one another and be able to know what can work out.
>
> My partner wanted to see the scar. And it was hard for me to show it to him. Because I trusted him, I had this trust that he could handle it. And he said, "You know, it really isn't that bad." And it was O.K. I think if his reaction had been different, I would have been devastated.
>
> My surgery was never a problem as far as what he might think of me, because I had all his love and support. It was more like as soon as the site healed, you could be back close to someone.

Importance of Partner's Reaction

The women who participated in the research project were almost unanimous in feeling that the response of their partner was the most important issue they faced:

> I guess my worst fear was how my partner would feel about it (loss of the breast). I had heard of people who had gotten divorced because of it. But after the surgery, I don't think there was any change in his actions, as far as his love toward me. My fear was how he would respond to it and how it would affect our love life. I would hate to think of what I might feel if he had rejected me or made fun of me. I don't know what I would have done.
>
> When he (partner) said he would rather have me with one breast than to take the chance of my dying, I guess that's when it was O.K.
>
> And my partner was really great! After surgery he got a bed and slept right beside me, and held my hand through the bars. I couldn't move my arm. And he was so supportive!
>
> My partner feels the same way I do, that we have gained from this (cancer) experience. I think that's why we have such a good relationship. We always thought we did. But we were so busy all the time raising and educating our children. And then these last three years, there has been this very sweet tenderness coming from him. We have this unique feeling that we don't have to say a word to understand where the other is coming from. Our private life has been real good. I guess when you've been through something this traumatic, your values get changed. You really learn fast what is important.

Breast Reconstruction

One woman who chose not to have breast reconstruction stated:

> At the time I had my surgery, I had never heard of breast reconstruction. I'm not sure I would have wanted it if it had been suggested. I would not want the additional risk of being opened up again.

Six of the 10 women interviewed did elect to have breast reconstruction and seemed pleased with the results. They reported:

> I had breast reconstruction about eleven months after the mastectomy. I just thought, "Well, I will try that. Maybe that's what's wrong." It helped some.
>
> I had breast reconstruction three months after my mastectomy. The first six weeks or so following surgery were very emotional, almost like a grieving process. I would be working and then for no reason I would get real weepy and sad. Hardly a day went by that my emotions didn't overwhelm me. It was like going up and down on a roller coaster.
>
> It seemed to me the best thing to do would be to have the breast reconstruction, so that's what I did. And I'm real happy that I did. I didn't really like wearing the prosthesis. I play tennis a lot and the prosthesis was very hot and cumbersome. And I always had this feeling that I was going to lose the dumb thing when you go down for a low stroke. And I like to swim too, and felt it could be a problem there. So this was really the best choice for me. I feel real lucky.
>
> When I decided on breast reconstruction, it wasn't to satisfy my husband. I just didn't want to be bothered with the prosthesis when I went swimming. And after I had it, I felt better about everything. I didn't have to do anything special, or be different.

Concerns with the Physician

One woman reported a very satisfying relationship:

> I had a wonderful doctor. The fact that we had a good relationship was a stability and a strength. He was wonderful to answer all my questions. I didn't question anything he wanted me to do, because I trusted him.

Two women reported being afraid to ask for the information they needed:

> You are in a vulnerable position with the doctors. You are afraid they won't take care of you if you ask the wrong questions. Or they might get mad! My husband asked a lot of questions that I was afraid to ask, you know, because your life is in their hands.
>
> You have a doctor who tells you that you should have this (treatment choice) done. And you've always believed what doctors say, as authorities. Well, they can be self-serving too, and don't always say that you have other choices or that you should have a second opinion, or that you should take time to think it over and discuss it. And then you are afraid to offend them by asking questions. And you are afraid they will get upset with you if you say you would like to get a second opinion.

Family Concerns

According to Photopulos (1988), "When cancer strikes one member of a family, it strikes them all" (p. 43). He explains it this way: "A chronic illness....imposes a great number of hardships on a family, and when a life is on the line, those hardships grow at quantum rate, multiplying and intensifying the pressures and tension on everyone" (p. 44).

It becomes very difficult for family members who are attempting to control their own fear and anxiety to give support and encouragement to the patient. The women reported,

> I think it was harder on my family than they thought. They didn't say anything, but they thought my life was over. They thought it (cancer) was going to progress, and this was the beginning of the end. It was maybe a year or more before I could get my husband to say "I HAD cancer" rather than "I HAVE cancer." I had to cope and keep on convincing them that I wasn't dying.
>
> While going through this, my oldest daughter was failing two courses in school. Some kids in school told her, "If your mother has cancer, she is probably going to die, and you will probably get it too!" And she was devastated.
>
> I'd take my children and go to Six Flags. But I couldn't do all the rides any more or do all the walking. But I would go. There were a lot of things I couldn't do. But you go ahead and do it for them. You have to. You have to function for them.
>
> The other thing we were faced with, I always drove my daughter and her friends to different functions. And now I couldn't say on such and such a day I could be there to drive. So this was hard for her. I had to say, "We will have to wait until that day and see how I feel. So that affected her social life.

My mother was here the week I had surgery. She couldn't take the hustle and bustle of my house, so she only stayed (number) days and went home. When she left, my partner was devastated about it. My family had never had to run the whole house without me. My husband didn't know what he was going to do, and he felt he had to take time off from work. He's been a great support. For every chemotherapy treatment, he would take off one day a month and spend the entire day with me. He would stay with me until it was time for the kids to get off the bus when coming home from school.

One time the nurses let my (age) year old girl come to see me. The nurse in the oncologist's office let her look at my blood through the microscope. She said, "Gee, Mom, your blood doesn't look purple. Are you going to die?" And she would talk about chemotherapy. But my other daughter was quiet and withdrawn. She wouldn't talk about it (cancer). It was affecting our whole family.

I had to go home and tell (name), my son, what the doctor had said. He looked at me and said, "It's cancer, isn't it?" And I said, "Yes." He grabbed me and hugged me, and we both started crying. And then he was O.K. He was very supportive, very positive about everything. I was worried that he might think I was going to die. I called his school and told them what was going on, and he got a lot of support too. We were very close.

My family pitched in to help a lot. They knew how to do laundry, and we ate out a lot. They knew if I couldn't function, I would just fix easy meals. I think my whole family learned to appreciate me more, because that was the first time they had really been without me.

> Two days after my surgery, my daughter and all the family got together. And they got balloons for each one of the children; and they all came marching into the hospital with those balloons. It felt so good. There was a gentleman down the hall who came in the next day and said, "That was the most beautiful sight I've ever seen, seeing all those children marching in with the balloons for you!"

How Women Cope

> You need more than a doctor when you are fighting cancer. You need someone to lean on, someone to talk with, someone who cares, someone who understands, someone who has not only walked in your shoes but who is still around leaving footprints" (Photopulos, 1988, p. 64).

Support Groups

When asked how they have coped with their experience of breast cancer surgery and recovery, 50% of the women mentioned support groups:

> I think the best thing any hospital can do is to start a support group. I called the cancer society, thinking I could talk with someone before I went through this (cancer surgery). But they said, "No, when you go in for the mastectomy, then someone will call you."
>
> Finding a support group was the best thing that ever happened to me. I hadn't been able to find anyone who would listen. I felt so totally lost! There comes a point in time when you need to be with someone who has had the same thing, who knows exactly how you feel. I've been with the support group five years now, and I find it very healing.

Going to a support group makes a big difference! Of course, you go there to hear the speaker and to exchange your feelings with the other women. But the biggest reason for going there is to see the other women who have lived for so many years and have cancer. That's reassuring every time you go. Also you share your feelings and they are validated by others. You are relieved because you are not the only one that felt that way. Your feelings are normal!

The thing that really helped me was the support group, and then getting active in caring for someone else made it 100%--even better!

The support group lets you see that you weren't the only one having some of the feelings, thoughts and problems. You realized that other people felt pretty much the same, different, but alike too. It was reassuring. You were O.K. in feeling what you did; you were not going crazy!

Religion

Before then (going into surgery), I just said a little prayer. I really just felt at peace going in. I was in my doctor's care and my Lord's care.

I really learned what faith was, because sometimes you have to operate by blind faith.

I started going to church about the time I was coming out of the depression, and I ended up joining the church. And now I know what faith is. And I think that my faith is unshakeable now. A friend gave me a little book called The Daily Word. And I read it before the day starts. It kind of keeps me going and helps me stay calm. It's just the best thing!

I just trusted the Lord to take care of me.

> The closeness I feel to God is just a beautiful gift I have been given.
>
> My religion is my way of coping with it. I'm not trying to sound brave, I'm not. But He (God) is the only one I've got to turn to. I don't know how people who do not have a religion, who do not believe in God, cope with it. What do they cling to? My religion has always been the place I've gone to when I'm really feeling troubled. It's the only place you can get some peace.

Friends and Family

> ...so I had all the support of my family, and wonderful support of all my friends, and everyone was just great!
>
> When I came home, I didn't really have to cook. All my friends and neighbors were sending in food like crazy. And that was really nice!
>
> There were four months I really didn't know if I was going to make it. Two of the months were real bad; I kept saying, "You're not going to die! You're not going to stop breathing from it." But I kept thinking, "Am I really going to make it? I don't know." And I had wonderful friends. I had tremendous support. But these people were on the outside. It's still you on the inside that has to deal with it.

Staying Busy

> They did the biopsy and it took a couple of days before they knew for sure. The unusual part of it was that I seemed to have this extreme energy. I was running to church, cleaning the house, keeping real busy, you know, until I got the results.

I just got real busy. I love to play tennis, and I love to swim, a lot of things, really. And I just planned two and three activities a day. I always have a lot going, and I just made up my mind I was going to fill up the time, play tennis, go to lunch, not let a lot of time in there to really think and worry about it.

Hugs

Sometimes I can just start to cry for no reason, and I can look at my husband and I'll say, "I don't know why I'm crying. Just give me a hug." You know, that makes such a difference!

And so my sister and I just hugged and cried!

Helping Other People

As soon as I got over being sick from chemotherapy, I would work with older people. There are so many older people whose children don't visit them and just don't care about them. One of the hospitals has a program where you take older people to doctors, take them grocery shopping, and be there if they need somebody to talk to.

Taking Some Control

I decided to ditch my wig. I didn't have much hair. I had very little on the hairline, very thin on the sides and like a crew cut on top. And one day I said, "I'm doing it. I'm just going to go for it. I've got to start taking some chances." So without my wig I went to (drugstore), and I ran in. I ran to the card rack and stopped to look around to see if anybody was looking at me. Nobody was. And then I went, "Phew! I'm safe!" So I started just going to work, and I never put the wig on again. And it felt great!

After chemotherapy, your skin is real clear and has a ruddy red glow to it, and you look real healthy, when you get out of the pale stage. And you are so happy you have hair. It's just like a bride on her wedding day, every bride looks good! Everybody whose hair has grown back looks great, because you are so incredibly excited. You are beaming! You are thrilled! You are so proud of yourself. You want to tell everybody what you've just done and what you have gone through.

It (having cancer) is like having to live in a different world now. You want to go back to the world before you had cancer, when you were like everybody else, but you can't. So I decided to get a wig ahead of time, and cut my hair short. It was my little form of having some control. There aren't many decisions you get to make at this point in time. It's a small thing, but it gets the ball back in your court. Because you feel all this stuff is happening to you. The surgeons have done surgery on you; this doctor wants to do chemotherapy on you. You feel like a victim, because all of this is being done to you.

Growth and Change

I think it just changes your life forever. You come to know that you are not immortal, and you have to face that. It gave me an urgency to do certain things and not to put off other things. I've put off doing so many things for myself for so many years, but still you have commitments. You have people you love that you need to take care of. And that's something I'm still trying to balance. There's a gut-level feeling that I want to do certain things, and I may not have that long to do it. And there's the pull on the other side to manage the care, giving and time you need to spend with your family.

> And I have to say that I have serious doubts if I would be at this point in my life that I'm at right now, had I lived to be 95, if this (breast cancer) had not happened to me. I'm serious. I know I am still growing and learning. I know I still have a much further distance to go. But I feel that I am a thousand percent better person. I used to be judgmental. I used to be impatient. I used to be extremely hyper. Now I am the one that says to people, "Hey, let's just ride it out and see what happens. Let's not worry about that."

> No matter how hard you try, until it (cancer) has happened to you, you cannot understand the experience. I think I took a lot for granted. I can't believe how beautiful I find things now, compared to how they were before. It totally changes the way you feel about just looking at a sunrise, or looking at the beautiful trees. You appreciate why God put them there.

> It (having cancer) changed my life so tremendously for the better. It clarified my path in life and where I was going. I weeded out all the crap and got myself together, and knew what I wanted out of my life. I clarified my values, my principles, and everything. It shook my whole system up to where I knew what was important and what wasn't. And partying and being young and dumb wasn't important to me. In fact, I rarely drink, even socially now, because I hate the feeling of that little buzz you get; because even that little buzz means you missed some things in life. And everybody seems to say the same thing. I heard this woman speak at the group the other night. She said, "You know, I always looked out the window when I do dishes. But after my breast cancer, I was calling my kids to 'come and see the sunset, it's incredible!' It's the same with all of us, all of a sudden

> you see things you never saw before. The whole world looks different; that's why it changed me so much.

What Women Need

Therapy

Nine out of the 10 women interviewed reported that their doctor did not refer them to a therapist. Therapy was suggested to one woman immediately after surgery and during the recovery period. Eight women reported they were not currently in therapy. One woman was in therapy, and one woman did not respond to the question. The woman currently in therapy stated, "It was very helpful; it made me feel less alone." One woman reported having two individual therapy sessions, which "helped me deal with the quality of life." One woman reported she had one individual therapy session and one group session which had been less than satisfactory. She stated, "I did not feel it was helpful because we just talked in general about my life. I would have liked someone more informed about cancer."

When asked "If therapy was not recommended, do you wish it had been," four of the women said "yes," four did not respond to this question and two said "no." Then asked, "When do you think therapy would have been most helpful," four stated "when making treatment choices," four stated "immediately after diagnosis," one stated, "immediately after surgery." One woman stated it would be helpful at several points: "immediately after diagnosis, when making treatment choices, when ending treatment, and especially when experiencing side effects of treatment." Six of the women gave examples of how therapy might have been helpful. One said, "You need someone to relate to; you need reassurance from someone who has already been through it." One said, "If you know you have choices, you feel more in control." One said, "Being able to talk to someone trained in the helping profession would have felt good." One said, "It would have been helpful to talk to someone who had this same type surgery before I did, and also would have helped to view some films on radiation treatment." One said, "Talking with someone who had already been through cancer surgery, maybe my age, would have made it less scary. The unknown is always scary." One woman said, "It would have given me more peace of mind."

Guided Imagery

Only two of the women had practiced any form of self-healing. One used imagery tapes during chemotherapy to picture chemotherapy drugs as "bright vibrant colors rushing through my veins and killing any weak cancer cells." This woman had also used relaxation methods. Another woman had one treatment in the hospital teaching of relaxation methods, but felt "I couldn't get into this over a short period of time." Another woman said she would like to start some type of self-healing, especially relaxation methods. Of those who had practiced self-healing techniques, one said she most strongly believed in "guided imagery in the midst of treatment, since it reduced my anxiety immediately before chemo treatment."

Changes in Treatment Received

> There's just one thing I would change. That would be having somebody talk with the patient that night or the next day before the surgery. A breast cancer patient to talk with would be very beneficial to patients. Because as much as the doctors, and the books you rush out to buy, and the family support and all that give you, the insight or encouragement from seeing a

live and well person would give you a tremendous amount of strength to pull you through the actual surgery. You meet them later through Reach to Recovery volunteers. But I think it would be better to have somebody beforehand. Because when you see this live and well person, it's great! It gives you hope. There's a special kind of wavelength from someone who has been there. You need to see one live and well person who looks good and has come through it. Because you have no idea if you are going to come out looking like some alien or something. I think it would help the communication be better between the physician and the patient concerning the options.

I wish I could have seen a film before the biopsy, a film on lumpectomy vs. mastectomy and on what is involved in radiation and chemotherapy and what are the different types of treatment. If you go this route, what are you faced with? What are some of the practical, everyday things that could be affected? I wish I could have seen such films and talked to someone (who had breast cancer surgery) before the biopsy. It would have helped both me and my family. We would have known more about what we were dealing with and what we had to face.

I wish there were some organized way that women who have had breast cancer could get in touch with women who have just learned they have cancer. It's right in the beginning when you need it most. And it would help to have had a sister to sort of walk you through it, who knows your concerns and how you feel. It would help women who can't talk about it feel they don't have to carry this burden inside of them. It would be great to have somebody right away who would say, "Listen, you can cry on my shoulder; and I will tell you what happened to me. There is life after; you will live, and things will be good." It would give you hope.

I would like to see doctors show more compassion and not be so technical when they talk to you about cancer and telling you you're going to lose a part of your body. I think they are missing the boat when they don't try to step into your shoes and know where you are coming from. If doctors would refer their breast cancer patients to someone who has already had breast surgery, when they first give the patient the diagnosis; it would make all the difference in the world. We wouldn't advise them (patients) of anything. And we wouldn't tell them anything other than 'here's a pamphlet or a book to help you cope; and if you want to talk, we will be glad to listen.' Hope is what they need most. And when they talk to someone who looks good and who has lived through it, it gives them both hope and courage. And a big part of the healing is having a positive attitude.

Once the doctors know you have cancer, if they could put you in touch with an individual or a support group, it would help so much. And if someone who has had cancer could come and talk to that person (who just found out she has cancer), what a difference it would make! I think a person who has gone through it knows what to say to a person that has just been confronted with it.

Doctors need to know how important it is to realize this patient is a "whole person" and not "they are coming to have their breast removed and that's it!" I think it (treating the patient as a whole person) should be part of their (doctors') medical training.

I would like to see the doctors more understanding, that they really take the whole person into account. It would have helped if they (doctors) understood that this is more than just a skin cancer, that it has more meaning to you as a woman. Because it is real important to the woman to know that what she is feeling is all right and that the doctor accepts and understands it.

> I wish doctors didn't see breast cancer as just mechanical. He (doctor) sees it as just cut and dried. "We take out the tumor; we do this, now this; now you are fine! So why do you need anything else? What's your problem?" But it is not that cut and dried to us! We are talking about femininity! We are talking about sexuality! We are talking about life and death! We need someone to talk to who has been through it, so we can see there is life on the other side.

Need for Understanding

Women who volunteered for the research project listed the following concerns they would like people to understand about their experience:

> That cancer is not an experience to be pitied for. It is the hard things that shape your life. The good things you breeze right past and take them for granted. But you don't get as much out of them as you do the hard, really tough experiences. That's what you learn from, and that's what shapes you. That's what changes your life and gives you direction, more than the good things, I think. Now I'm not so afraid of hard experiences or difficult situations. I force myself to take a brief look at going through chemotherapy, picture being sick, or not having hair, and think: "I did that, of course I can do this! I've already done the hardest thing there is, so I can do anything!" And I go on through it.

> I would like to have doctors understand where I'm coming from more. I had to tell my doctor, "I'm having a hard time communicating with you. I feel you treat me like a patient, not a person." He (doctor) would come to my room when I was already on the IV's, and I was drugged up; and he would say, "O.K., your blood tests are all right, we can give you the chemotherapy this time. See you in three weeks." And it was like I

> was just this body he was putting these drugs into. And I was losing myself! I was crying out, "Somebody notice me! I'm existing here too! I'm not just a patient, there's a patient and a person going through this." And after I told him (doctor) that I needed for him to see me as a person, then it changed.
>
> I would like people to understand that just because you have cancer of some kind does not mean you are doomed. When people hear the word "cancer," they think it is a death sentence. And that's not necessarily so!
>
> I wish other people could understand how this experience has brought me closer to God. I just feel vey special. I feel that my experience has been turned the right way in helping others. This feeling of closeness to Him (God) and the caring is the most beautiful gift I have received through all of this. And a friend of ours, a gentleman who lives down the street said to us (who had cancer), "There's just something about people who have experienced cancer, some beautiful gift comes out of it; and it shows!" And maybe he (neighbor) is right! I do feel closer to God and I would like this gift passed on to others.
>
> I would like people to understand that cancer is not as bad as you think it to be, that through experiencing cancer you can gain so much. You can get so much closer to God. Because your values change, there's a simplifying of life. I guess what I would like people to know is that there is hope; that good things can still happen; that you can't close up, you've got to reach!

Need for Reassurance

The importance of the psychosexual issues mentioned in the Review of Literature was validated by the women interviewed. Their foremost concern upon learning of the need for breast surgery was the reaction of their partner (see Importance of Partner's Reaction, p. 57). Areas of concern emphasized in their responses were: fear of rejection by partner, loss of sexual attractiveness, uncertainty regarding timing of resumption of sexual intercourse after surgery, and viewing of the scar by the woman and her partner. The sensitivity of these issues, coupled with the hesitancy of both the woman and her partner to discuss these subjects, suggests the need for counseling on psychosexual issues very early in the process, perhaps immediately after diagnosis of breast cancer.

CHAPTER V

DISCUSSION

This study has examined the physical, psychological, psychosexual and familial responses of women who have experienced breast cancer surgery. The purpose of the study was to gain an understanding of how women cope and what they need, both to survive and to transcend this experience.

The hypothesis of this study is that women faced with breast cancer surgery are immediately confronted with multiple major crisis issues: a threat to life and survival, loss of a body part or parts, possible long-term suffering and physical disability, a threat to body image, a threat to sexual identity and a threat to self-esteem of severe proportions. By their responses, the women in this study have confirmed the severity and significance of these issues.

This exploratory study was undertaken to add to our knowledge and understanding of the impact of breast cancer surgery, from lumpectomy to modified radical mastectomy, on the quality of life of the women involved. The intent of the study was twofold: (1) to discover how women cope with the experience of breast cancer surgery, and (2) what they need to survive and cope even better.

When discovery of a lump in the breast occurs, whether from self-examination, examination by a physician, or from a mammogram, a woman is immediately faced with the necessity of coming to terms with some major changes: physical, emotional, sexual, social, familial and financial. These changes may be overwhelming, and adjustment does not come easily. "Understanding, acceptance, and compromise are necessary to anyone who is undergoing treatment for cancer and learning to live with the emotional turmoil and the sometimes drastic physical changes that occur" (Rosenbaum, 1982, p. 81).

Learning to cope can be a slow and tortuous process; and becoming an active partner in your own recovery is critical. Women coped with the aid of friends and family, support groups, religion, by staying busy, by taking some control where they could, by growth and change and by helping other people.

Almost universally, the 10 women interviewed reported an intense need for psychological support, the need to talk with another person who had breast cancer and survived it. The need for this psychological support is strongest at the very beginning of this frightening journey, when cancer is first diagnosed. The reason given by women for so urgently insisting upon the importance of this one factor was the injection of hope. They needed hope for survival, hope for enduring the physical, psychological, and psychosexual assaults on the body that seem to accompany treatment of breast cancer. Hope increases the will to live and mobilizes the fight for survival. "Hope can be maintained as long as there is even a remote chance for survival" (Rosenbaum, 1982, p. 93).

The second prominent concern of the women interviewed was the need to be perceived by the physician responsible for their care in a more respectful, validating way as a whole person, as a human being and not just a disease. If the physician or surgeon does not understand the importance of these concerns to a woman, the woman feels isolated and alone in facing problems she cannot discuss with her physician.

This brings us to the third major issue mentioned most frequently (although indirectly) by the women interviewed, the desire for reassurance that they are still considered feminine and sexually desirable. While this subject is one most women feel inhibited in discussing, the universally-stated concern regarding the partner's reaction to breast surgery might suggest the need for health-care professionals to recognize the importance of this issue to breast cancer patients.

Women who volunteered for this research study found ways of utilizing untapped physical and emotional reserves they were previously unaware of. And in utilizing these reserves for surviving, found a surprising renewal in energy, strength and deep appreciation for life.

Evaluation of Research Procedure

In this study an informal personal interview was used to collect the data. This method was chosen to accommodate the need for both a subjective and descriptive analysis of the breast cancer surgery experience and its application to the lives of the women who volunteered for the research study. All of the interviews were recorded on audio cassettes, so that the full attention of the researcher could be directed to the respondent.

The one and one-half hour time framework for the interview proved to be adequate. An additional half-hour was needed to complete the demographics form (Appendix C). The personal interview format (see Questionnaire, Appendix A) provided the respondents an opportunity to share sensitive issues in privacy.

Due to the sensitivity of the subject matter, great care was exercised during the interview process. It was necessary to provide an atmosphere of privacy and respect for the individual participants in order to enable them to share in a non-threatening way.

Suggestions for Further Research

The intent of this study was to examine the subjective experience of breast cancer surgery, how women cope and what they need. Consequently, little space and time was devoted to the concerns of the partners of women with breast cancer, except to say how vital it was for the female partner to receive a positive response during the difficult times of diagnosis, surgery and recovery. Further research might be expanded to what partners themselves need during these times, as well as the assistance they require in understanding the needs of their wives and partners.

Mind/body healing is another area not specifically addressed by this study. Guided imagery was mentioned briefly, but volunteers had only minimal exposure to this method of treatment. Results of the study strongly emphasized the need for psychological support and injection of hope in the early stages of treatment for breast cancer. These issues might benefit from further inquiry into the relationship of mind/body healing to rapidity of recovery and prevention of recurrence of cancer.

Appendix A

Questionnaire

Researchers and practioners have reported different people as having different experiences, different thoughts, different feelings at times, and different reactions after having experienced breast surgery. IT IS VERY IMPORTANT THAT YOU REALIZE THAT YOUR IDEAS, YOUR EXPERIENCES, YOUR THOUGHTS, YOUR FEELINGS ARE UNIQUELY YOUR OWN AND THESE ARE WHAT I AM INTERESTED IN. Your experiences do not have to fit any preconceived ideas belonging to anyone else. There are no right or wrong answers! I am interested in what happened to YOU!

---

1. Describe your experiences, feelings, thoughts, etc., when you first felt you might have a probelm.

2. Describe your experience, feelings, thoughts, etc, after you discovered that you had a problem, if you didn't think you did.

3. Describe your experience, feeling, thoughts, etc., when the diagnosis of breast cancer was made to you.

4. What were your feelings, thoughts, etc., when you were going into the operating room?

5. Describe your experience immediately after surgery.

6. What were your greatest fears, concerns, thoughts?

7. Was the possibility of breast reconstruction discussed with you at the time of your diagnosis?

8. Are you considering breast reconstruction surgery in the future?

9. What did you read or hear about breast cancer before your own diagnosis?

10. What have you read or heard about breast cancer after your surgery?

11. Describe as best you can the reaction of your partner before surgery.

12. Describe as best you can the reaction of your partner after your surgery.

13. What were your worst fears concerning his feelings?

14. Describe as best you can the reaction of other members of your family.

15. Please share any comments about your experience that you feel were uniquely your own, that have not been included in the above questions.

16. What is one thing you would like to see changed about the medical or treatment procedures you have experienced?

17. If there is one thing you would like other people to understand about this experience, that no one seems to understand, what would that be?

Appendix B

Consent Form

Name of Participant____________________Phone________
Address____

Title of Project: A Qualitative Study of the Experience of Breast Cancer Surgery: How Women Cope and What They Need

1. Malone Aderholt, who is a candidate for a master's degree at Lindenwood College, has requested my participation in a research study at this institution. The title of the research is: A Qualitative Study of the Experience of Breast Cancer Surgery: How Women Cope and What They Need.

2. I understand the purpose of the study is to examine the adequacy of therapeutic support and treatment offered to breast surgery patients.

3. My participation will involve an individual informal conversational interview for approximately one and one-half hours. I understand that my participation in the personal interview will be voluntary. I also understand that some of the questions will be personal and that Malone Aderholt, a therapist in training, will be available to discuss the reactions and responses to the questionnaire.

4. I understand there are possible risks to me if I agree to participate in the study. There is a possibility that some unresolved emotional issues might surface in the personal interview. I also understand that an additional hour will be made available, if needed, to discuss these issues.

5. I understand that my name will not be used in this study and that any details which might identify me to another reader will be disguised. All tapes will be for the researcher's use exclusively and they will be erased or destroyed immediately following transcription.

6. I understand that my participation in this research study may be extremely valuable to others who have experienced a similar event or will experience it in the future. I also understand that there are no direct benefits to me that are anticipated.

7. I understand that I have the right to omit responding to individual questions during the interview and that I may withdraw from the research study at any time.

8. It is not the policy of Lindenwood College to compensate me or provide medical treatment for me in the event the research results in injury, although additional processing time can be made available.

9. Any questions that I have concerning the research study or my participation in it, before or after my consent, will be answered by Malone Aderholt.

10. I understand that my participation is voluntary and that refusal to participate will involve no penalty to me. I also understand that I may withdraw from the research study at any time without penalty or prejudice.

11. I have read the above statements and have been able to ask questions and express concerns, which have been satisfactorily responded to by the investigator. I believe I understand the purpose of the study as well as the potential risks and benefits that are involved. I hereby give my informed and free consent to be a participant in this study.

____
Signature of Participant

Date:____________________________

Appendix C

Demographics

Name_______________________Phone Number_____________

Address____

City________________ State________ Zip Code_________

1. Age: (1) 20 to 29; (2) 30 to 39;
   (3) 40 to 49; (4) 50 to 59;
   (5) 60 to 69; (6) 70 & above

2. Marital Status (circle one): (1) Married;
   (2) Divorced;
   (3) Remarried;
   (4) Single

   Number of years married:______________________

3. Occupation:_____________________________________
   Husband's occupation:__________________________

4. Education (circle one): (1) Grade School;
   (2) High School;
   (3) Vocational School;
   (4) College (no. of years) ___________

5. Residence (circle one): (1) Urban;
   (2) Suburban;
   (3) Rural

6. Annual Income (circle one): (1) 1,000 to 9,999
   (2) 10,000 to 19,999
   (3) 20,000 to 29,999
   (4) 30,000 to 39,999
   (5) 40,000 to 49,999
   (6) 50,000 to 59,999
   (7) 60,000 to 69,999
   (8) 70,000 and above

7. Ethnic Group (circle one): (1) American Indian;
   (2) Asian;
   (3) Afro-American;
   (4) Hispanic;
   (5) White, non-Hispanic;
   (6) Other (specify)
   ____

8. Religious Affiliation (circle one):
   (1) Protestant;
   (2) Catholic;
   (3) Jewish;
   (4) Other (specify) ____________________
   (5) None

9. Church Attendance (circle one): (1) Regular;
   (2) Frequent; (3) Seldom;
   (4) Never

10. Number of children in family__________________

11. Have any other members of your immediate family ever had breast surgery?
    Yes_____ No_____ Grandparents?______________
    Other?_________________________________

12. What type surgery did you have (circle one):
    (1) Radical Mastectomy (breast, lymph nodes & muscle)
    (2) Modified Radical Mastecomy (breast & lymph nodes from underarm area)
    (3) Lumpectomy
    (4) Other (please specify)____________________

13. How old were you when you had breast cancer surgery?________________________

14. When did you have the surgery?________________

15. What was the original diagnosis?______________

16. What is the prognosis now?___________________

17. When the doctor told you the diagnosis was cancer, how was this information relayed to you:

    (1) matter of factly?
    (2) sensitively?
    (3) detailed explanation?
    (4) brutally frank?
    (5) other?

    Use your own words:___________________________
    ____

18. Did you feel you participated as an equal partner with the doctor in making a choice of treatment for your surgery?
    (1) Yes (2) No

19. Did your doctor recommend that you see a therapist or psychologist?
    If yes, at what time during treatment was this suggestion made?
    (1) at time of diagnosis?
    (2) just before surgery?
    (3) immediately after surgery?
    (4) during the recovery period?
    (5) other?

20. What type of therapy was offered or suggested to you?____________________

21. Have you talked with a therapist, counselor, psychologist, family therapist, social worker, minister, priest, or rabbi?
    (1) For how long?____________________
    (2) Was this long enough?________________
    (3) Did you have individual therapy?__________
    Group therapy?____________________
    (4) Was/is your therapeutic experience helpful?____________________
    (5) If so, how was it helpful?______________
    ____
    (6) If not, why?________________________
    ____
    (7) Are you currently in therapy?____________

22. If therapy was not suggested to you, do you wish it had been?____________________
    When would it have been most helpful?
    (1) Immediately after diagnosis?
    (2) When making treatment choices?
    (3) When experiencing side effects of treatment?
    (4) When ending treatment?
    Can you tell me how you think it might have been helpful?____________________
    ____

23. Have you ever practiced any form of self-healing?
Describe your experience as best you can________
____
____
(1) For how long?________________________
(2) Where did you learn it?______________
(3) What types of self-healing have you practiced?
    (a) Relaxation methods?
    (b) Fantasy trips?
    (c) Fighting cancer cells?
    (d) Guided imagery?
Of the above, which do you believe in most strongly?
Do you practice it daily? Weekly?

24. Describe as best you can what effect you believe your self-healing efforts had on your current status.______________________
____
____

25. Who suggested self-healing?__________________

26. Have you practiced any other non-medical therapy treatment? Please list, with source of learning______________________________
____
____

27. Have you read any cancer self-help publications? List_________________________
____
____

28. What is the current status of your health?
(1) I would describe my physical health as:
____
(2) I would describe my mental health as:
____
(3) I would describe my relationship health as:______________________________________
(4) I would describe my spiritual health as:
____

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