



Making meaning of the experience of breast cancer
by Tamara Nelson

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in
Health and Human Development
Montana State University
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Abstract:

The purpose of this study was to understand the meanings that women had made of the experience of breast cancer. Audiotaped interviews were conducted with 19 women, who had been diagnosed with and treated for breast cancer from 13 months to 22 years earlier. The tapes were then transcribed. After the transcription, the texts were read to find themes of similarities and contrasts among the subjective perceptions of the experience. These themes were then organized and interpreted, looking for implied meanings in their explicit comments. Several themes emerged from their experiences: initial reactions of disbelief, shock, fear, and anger; searching for causes for their disease; seeking mastery over the disease through information seeking, humor, spiritual faith, and support; changing perceptions in their bodily image as a result of disfiguring surgery and in their various roles as partners, parents, friends, and workers; changes that they had made in their lives such as learning to do things that they want to do, informing others, and bonding with others with breast cancer. Another theme that was discovered was that of time, both in a sense of urgency to hurry to do things while there was enough time left and also in the sense that it took them time to adjust and change after the diagnosis. There are fears of recurrence, death, implications for their daughters and rejection which may result in anxiety, depression, and denial that may have clinical implications for mental health professionals working with this population. There may also be a need to help these clients become more assertive with medical professionals to make their wants and needs known and understood. Educating both mental health and medical professionals about the importance of taking the time to try to understand the implicit meanings underlying the woman's presenting issues may also be helpful in her adjustment and recovery.

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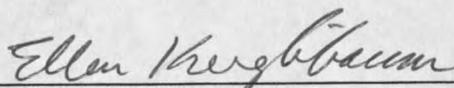
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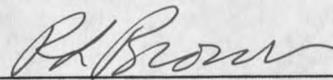
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TABLE OF CONTENTS

	Page
1. INTRODUCTION.....	1
Searching for Meaning.....	1
Purpose of the Study.....	5
2. LITERATURE REVIEW.....	7
Importance of Meaning.....	7
Searching for Causes.....	9
Seeking Mastery	15
Challenges to Perception of Self.....	17
The Role of Time.....	20
Process of Recovery.....	25
Conclusion.....	26
3. METHOD.....	29
Interpretive Phenomenology.....	30
Sample.....	30
Methodology.....	32
Limitations.....	35
4. FINDINGS.....	37
Initial Reactions.....	38
Search for Causes.....	41
Cosmic Purpose or Plan.....	42
Family History.....	43
Diet.....	44
Other Causes.....	44
Regaining Equilibrium.....	45
Information Seeking.....	46
Humor.....	46
Faith.....	48
Challenges to Self-Perception.....	50
Body Image and Sexuality.....	50
Partner Relationships.....	54
Friendship.....	55
Patient-Doctor Relationship.....	56
Role as Parent.....	59
Other Role Changes.....	60
Fears and Concerns.....	61
Money and Insurance.....	62
Daughters.....	63
Recurrence.....	64
Death.....	66

Changes over Time.....	67
Dimensions of Time.....	67
Taking Care of Oneself.....	69
Helping Others.....	70
Changes in Way of Being.....	71
Changes in Families.....	73
Sharing Experiences.....	74
Summary.....	74
5. CONCLUSIONS AND IMPLICATIONS.....	76
Implications.....	82
Areas for Future Study.....	84
Summary.....	86
REFERENCES CITED.....	87
APPENDICES.....	91
Appendix A-Letter to Subjects.....	92
Appendix B-Consent Form.....	94

ABSTRACT

The purpose of this study was to understand the meanings that women had made of the experience of breast cancer. Audiotaped interviews were conducted with 19 women, who had been diagnosed with and treated for breast cancer from 13 months to 22 years earlier. The tapes were then transcribed. After the transcription, the texts were read to find themes of similarities and contrasts among the subjective perceptions of the experience. These themes were then organized and interpreted, looking for implied meanings in their explicit comments. Several themes emerged from their experiences: initial reactions of disbelief, shock, fear, and anger; searching for causes for their disease; seeking mastery over the disease through information seeking, humor, spiritual faith, and support; changing perceptions in their bodily image as a result of disfiguring surgery and in their various roles as partners, parents, friends, and workers; changes that they had made in their lives such as learning to do things that they want to do, informing others, and bonding with others with breast cancer. Another theme that was discovered was that of time, both in a sense of urgency to hurry to do things while there was enough time left and also in the sense that it took them time to adjust and change after the diagnosis. There are fears of recurrence, death, implications for their daughters and rejection which may result in anxiety, depression, and denial that may have clinical implications for mental health professionals working with this population. There may also be a need to help these clients become more assertive with medical professionals to make their wants and needs known and understood. Educating both mental health and medical professionals about the importance of taking the time to try to understand the implicit meanings underlying the woman's presenting issues may also be helpful in her adjustment and recovery.

CHAPTER 1

INTRODUCTION

Breast cancer is a disease that will strike one out of eight American women some time in her life; it is the leading cancer diagnosis in American women (Arizona Cancer Center, 1993). But, this is just a statistic. The real story of this disease lies with the women who are living with this diagnosis. They are faced with a disease that may result in death, disfigurement, social rejection, uncertainty about the future, and financial hardship (Carver et al., 1993).

Several hypotheses have been advanced to explain the increasing incidence of breast cancer in the Western world such as genetic predisposition, dietary fat intake, multiple stressors, early childhood experiences, estrogen levels, environmental factors, and inability to express emotions (Hilakivi-Clarke, Rowland, Clarke, & Lippman, 1993). However, the fact remains that no one cause has been found, which leaves many women with breast cancer to search for their own explanations and meaning of the event.

Searching for Meaning

When traumatic events such as severe accidents, death, chronic or terminal illness strike, the assumptions the individual has about the world and themselves may be shattered. These events may cause a person to look at how

he/she can regain equilibrium in a world that is no longer predictable (Janoff-Bulman, & Frieze, 1983). Thus, following uncontrollable events and loss, there may be a time of searching for the meaning of that event, a looking back at the reasons "why me?", "why not me?", or "now what?" (Bulman & Wortman, 1977; Silver, Boon, & Stones, 1983).

When there is no meaning to life or to the events that happen in a person's life, it follows that there will be a sense of being adrift, of having no reason to be, which may cause one to feel psychologically hopeless and helpless. A traumatic event may cause one to be temporarily without meaning, disintegrated, empty (Taylor, 1988). He suggests that there is also some corresponding notion of what it would be to have meaning, to be integrated, to be full. Taylor (1988) theorizes that there is also a notion of a place from which this meaning, integration, or fullness might come. Among these places are unity with the cosmic order or God, harmony with nature, rational insight, and acceptance of oneself as well as one's finitude (Taylor, 1988).

Yalom (1980) speaks of two concepts of meaning. One is that of cosmic meaning, which implies that a coherent pattern or design which orders the universe exists outside of and superior to the person. The other concept is that of terrestrial meaning, a personal sense of meaning that Yalom (1980) defines as one's experience of life as having a

purpose to be fulfilled as well as goals to be achieved.

Throughout the ages, people have had to come to terms with events that seem unfair, that have destroyed their plans for the future as they saw it, and, yet, many have emerged from these cataclysmic turns of events with a renewed sense of who they are and what they are destined for, whether it be in terms of greater benefit to humanity or simply taking time to enjoy life (Frankl, 1963; Jaffe, 1985; LeShan, 1989).

Frankl (1963) asserts that even in uncontrollable events of pain and suffering, one still has the freedom to choose how one reacts to the event. A reexamination or formulation of a new life plan may be one way in which a person may respond to a life that has been altered by illness (Brody, 1987). Brody (1987) also suggests that there may be a sense of loss or grief over that which can no longer be.

Human beings grow up with culturally defined roles which give us a meaning, a set of values, a way that we should be in the world, a moral vision (Christopher, in press). These roles begin from birth and define us as children, as male or female, as siblings, as friends, as partners in love and in sex, as parents, as workers, as human beings with plans for the present and the future. According to Becker (1992), we define ourselves within these roles and evaluate our personal performance in how we

fulfill these life tasks.

When a woman is faced with breast cancer, even though there may be a family history of the disease, she still may be shocked, angered, and/or mystified by the event. Because the illness may recur, no matter how many years she is in remission, a sense of uncertainty about the future may overtake her (Hilakivi-Clarke et al., 1993). All of her old assumptions and roles may no longer be viable. If she is a young mother, she may realize that she may not be there to help her children grow up as she had always planned; the woman of her middle years may realize that this is the time to fulfill her dreams, not after retirement; the grandmother may realize how very much she had assumed that she would be at her granddaughter's wedding. Thus, a sense of urgency may become part of how the woman sees life (Fife, 1994). The woman who has given limitlessly of herself to others in her relationships or at work may realize that she has not taken time for herself.

In Western culture, femininity is often characterized by beautiful, or least, acceptable breasts. If a woman bases her self-image or the meaning of her sexual relationships on her breasts, she may have to rethink her entire concept of herself. Although a prothesis or reconstruction can hide the amputation of a breast from the general public, it is still highly visible to the woman and her partner.

Purpose of the Study

Following my own experience of breast cancer, I found that I searched for a meaning for this life-shattering event. I realized that I was faced with the reality of my own mortality. Over a period of years, I discovered that my priorities and values in life had been irrevocably changed by this experience. It seems that the experience of breast cancer was a subtle, but unavoidable, wake-up call to recognize that my purpose in life, my goals, and my role in relationships were based on a desire to please everyone but myself. As a result, I realized that I could make choices to go on living my life as usual or to make some changes. I chose to make several major changes in my life such as ending my marriage and going back to school to get my master's degree. I also found myself reaching out to others who could perhaps benefit from my struggle to find meaning in this experience and to reorder my life, so I began a support group for women with breast cancer and became a Reach to Recovery volunteer for the American Cancer Society.

As a result of these changes in my life, I became curious about the meanings that other women have made of their experience of breast cancer: did they, too, change their priorities; did they change the directions of their lives; did they reach out to others; did their relationships with family and others change?

In order to gain insight into the experience of other women, I chose to conduct this research from a phenomenological approach, to hear, recognize, and understand each woman's unique narrative of making meaning of breast cancer.

In this study, meaning is defined, in a broad sense, as purpose or reason. This purpose or reason then leads one to define one's values and goals in life and also the role one assumes in order to live by those values and achieve those goals. There are also two levels in interpreting meaning: the explicit level, which is what is actually said by the person, and the implicit, which is implied from what has been said and which may reveal the truer, deeper level of the meaning of the experience.

The purpose of this study was to listen to the stories of other breast cancer survivors to try to understand the meaning they have made of this traumatic event, both explicitly and implicitly, which may alter their perceptions of their purpose in life, their values, and their goals.

A counselor working with any client who has had a traumatic disruption in his/her life, may benefit by learning how others reframe the event, redefine themselves within the context of the event, and go on to construct new, meaningful goals and roles for themselves.

CHAPTER 2

LITERATURE REVIEW

This chapter will examine the literature that refers to various definitions and conceptualizations of the concept of meaning and the role it plays in the lives of human beings. It will also explore how meaning is used by victims of traumatic events such as incest and accidents as well as those stricken with chronic illness; cancer, in general; and breast cancer, specifically, as they struggle, over time, to accept the challenges to their self-perception and changes made in their lives as a result of the trauma.

Importance of Meaning

According to Yalom (1980) there are four ultimate concerns that are inescapable in human life - death, freedom, isolation, and meaninglessness. Meaninglessness occurs when we have no purpose in life, nothing for which to live (Carlsen, 1988). As he sought to make meaning of his years of suffering in a Nazi concentration camp, Frankl (1963) concluded that the need to find meaning in one's life is "the primary motivational force in man " (p. 99).

From an existential viewpoint, Yalom (1980) says that one meaning of meaning is that it relieves the anxiety of living life in an unstructured world and then gives birth to values, a set of guidelines that define how one ought to

live. Becker (1992) asserts that people seek meaning in their lives and strive to achieve goals. If those goals are changed by a traumatic event, then the person must recreate new goals in order to continue to make meaning of life.

According to Brody (1987), suffering is produced and alleviated primarily by the meaning one attaches to the experience. In order to find positive meaning in the experience of illness, one must be able to give the experience an acceptable explanation, be able to perceive that one is surrounded by caring individuals, and must be able to achieve a sense of mastery and control over the illness. Brody (1987) goes on to say that one of the primary ways that people assuage suffering is by seeking mastery and attaching a positive meaning to the experience.

Although there are semantic distinctions, Yalom (1980) refers to meaning as purpose, sense, or coherence and says that there are two approaches to inquiring about the meaning of life - the cosmic meaning and the terrestrial meaning. Cosmic meaning refers to the global sense of meaning of life as part of a design or plan existing outside of the person. Meaning, in this sense, is based on Judeo-Christian religious traditions that the world and humans are part of God's plan and that man must seek to fulfill God's will. From a fundamentalist viewpoint, God's plan is found in the scriptures; one has to have faith and can never know the plan with certainty. Another viewpoint is that one should

emulate God, who is perfection; thus the meaning of life is to seek perfection (Yalom, 1980).

In the terrestrial or personal sense of meaning, it is the activities that seem right and are satisfying that give meaning to life. Altruism, the desire to leave the world a better place and to help others, is one of these activities. Other meaningful activities are dedication to a cause; creativity; the hedonistic solution, living one's life to the fullest; self-actualization, realizing one's potential; and self-transcendence, a striving toward something outside oneself (Yalom, 1980).

Searching for Causes

In a theoretical overview of reactions to victimization, Janoff-Bulman and Frieze (1983) assert that the occurrence of a severe accident, natural disaster, or life-threatening illness changes the victim's world and personal view; the world is no longer a safe place and the victim is longer invulnerable. Victims of these events, therefore, are forced to change their assumptions of belief in personal invulnerability, the perception of the world as meaningful and understandable, and the view of oneself in a positive light. The individual loses a sense of safety which results in feelings of anxiety and helplessness and, often, in preoccupation with the fear of recurrence. The victim may feel totally unable to explain why the traumatic event

happened to him/her. Coping with the event will involve coming to terms with the new perception of the world and regaining a positive self-image (Janoff-Bulman & Frieze, 1983). The victim is faced with choice; while one may not be responsible for the event, one has the choice of how to respond to it (Frankl, 1963; Jaffe, 1985; Janoff-Bulman & Frieze, 1983).

Rather than simply reacting to the traumatic event, the first step in searching for meaning in an uncontrollable event is possibly that of searching for a cause. In a study of 29 victims paralyzed in serious accidents, Bulman and Wortman (1977) sought to find the attributions that each of the participants made for the accident. The researchers asked specifically if the victims had ever asked the question "why me?" and found that all of them had sought reasons for their accidents; only one was unable to find an attributional cause. Bulman and Wortman (1977) empirically measured coping and happiness with the responses to the search for an answer to this question and found that those who did find an answer were judged by social workers and nurses to be coping well with their accidents. Answers to the question of "why me?" were that God had a reason, which was the most popular response; chance; predetermination; reevaluation of the experience as positive; probability; and deservedness. The authors theorized that the attributions to God or predestination indicated a concern for order and

meaning by the participants. They also pointed out the need to study the meaning their participants found in their suffering and whether their causal attributions and meanings would change over time.

In contrast, a study of female cancer patients and their mates found that less than 25% of the respondents had asked "why me?" or "why her?" (Gotay, 1985). She studied two populations of women with cancer, those who were in the early stages of the disease and those with more advanced cancer and found that those who were more adjusted as measured by mood level, stress level, social adjustment, and personal adjustment were more likely to have attributed it to chance. Those with more advanced cancer attributed it to God's plan while those in the earlier stages attributed it more frequently to chance. The author theorized that because cancer is regarded by the patients and their families as a "terrible, frightening thing," they may be more inclined to believe that it is due to chance (Gotay, 1985, p. 830). She also theorized that coping may be made easier by thinking that it could happen to anyone. However, she did not go on to theorize or explain why this was not the case with those with more advanced cancer. Although she had no empirical evidence, Gotay (1985) indicated that those who felt they still had not finished an important goal were coping with the disease least successfully. She did not account for other variables such as social support and spiritual beliefs

that may have accounted for adjustment rather than simply finding an answer to the question of "why me?".

In another study (Linn, Linn, & Stein, 1982), 120 terminally-ill male cancer patients were found to be more likely to attribute the cause of their illness to God's will or heredity, while a comparison group of 120 other hospitalized males felt that cancer was caused by environmental and dietary factors on a 10-item causal scale. The authors said that for those with a life-threatening illness, the search for an explanation is "acute" and that the experience is so uncontrollable and without explanation that they endorse a reason such as God's will for their illness (Linn, Linn, & Stein, 1982, p. 838). These authors did not take into account the possible variable of the spiritual beliefs of the victims of the experience of cancer.

Searching for causes seems to be a common means by which women with breast cancer integrate and cope with the diagnosis and the effects of its treatments, according to Meyerowitz (1980). Assuming that women with breast cancer will search for casual attributions for their illness and that particular attributions are related to better psychological adjustment, Timko and Janoff-Bulman (1985) interviewed 42 women, who had been diagnosed with breast cancer, from 1 to 20 months post-mastectomy. They found

that the women who felt they had contributed to their cancer by past behaviors such as taking birth control pills and not having a proper diet were better adjusted psychologically, felt they would be able to avoid a recurrence of the cancer in the future, and felt more happy and optimistic. Those who attributed their cancer to character flaws or to others were less likely to believe that the mastectomy was successful in removing the cancer and were more likely to feel sad, ashamed, and scared. Timko and Janoff-Bulman (1985) suggest that this feeling that the surgery was unsuccessful was related to beliefs about cancer in general, that it is permanent and not treatable.

In a study of attributions, control, and adjustment to breast cancer (Taylor, Lichtman, & Wood, 1984), 95% of the 78 participants did have a causal attribution for their disease, while only 63% of their significant others did. This suggested to the authors that there is a greater need for the victim to find a cause for the traumatic event. However, only 41% of the women considered this important to their recovery from the illness, contrary to the authors' hypothesis and attributional theory, which suggests that a search for a cause is adaptive in adjusting to crisis. They found that blame of self, the environment, or chance were not related to psychological adjustment, while blaming others was associated with poorer adjustment. After examining the effects of information control, cognitive

control, and behavior control on the women, only cognitive control, which was operationalized as construing benefit from the cancer experience, was significantly related to better psychological adjustment. Seventy percent of the women said that cancer had made them think differently about their lives, with 60% reporting positive change. The most common change was learning to take life easier and enjoy it more. Taylor, Lichtman, and Wood (1984) therefore concluded that the participants' efforts to find meaning in their cancer experience seemed to be reflected more by their change in attitude toward life than by their attributions.

Lowery, Jacobsen, and DuCette (1993) argue that causal thinking is not universal and may be psychologically harmful. They studied 195 women who had been treated for breast cancer from 1 to 60 months previously. They found that 50% of the women had asked "why me?" and that this group felt a greater loss of control and had poorer adjustment than the group who said they did not search for a cause. They found that those most recently diagnosed with breast cancer, 11 months average, asked the question more often than those who were 6 months further along in their recovery. The authors theorized that the intensity at the time of diagnosis may evoke such thinking and that this intensity may subside with time (Lowery, Jacobsen, & DuCette, 1993).

Seeking Mastery

In addition to searching for attributional causes for a traumatic event or illness, other means of coping such as information seeking and attitude may be effective in the process of adaptation. While researching the role of coping mechanisms in psychosocial adjustments to chronic illness, Felton and Revenson (1984) chose to study the effects of information seeking and wish-fulfilling fantasy as coping responses in chronic illness. They studied 151 individuals with hypertension, diabetes mellitus, rheumatoid arthritis, and systemic blood cancers and found that information seeking was related to decreased negative affect while wish-fulfilling fantasy, used to avoid reality, was linked to poorer adjustment. The authors suggest that the use of information seeking, in addition to providing information about symptoms and proper care, may also be indicative of an optimistic attitude that the information will prove useful in the future, an adaptive coping mechanism. There are many other coping responses that could be contributing variables to the outcome of this study such as casual attributions, social support, and positive reframing.

According to Schussler (1992), the course of a chronic illness is not determined by genetic or biomedical factors alone, but also by how it is dealt with by the patient. He studied 153 patients with chronic physical illness and found

that those who viewed their illness as a challenge or as having value had better mental well-being than those who saw illness as a punishment, strategy, enemy, or relief.

Acceptance, the use of humor, and positive reframing were the most beneficial coping skills employed by 59 breast cancer patients in a study by Carver et al., (1993), while overt denial and thoughts of giving up were strongly related to distress, which was defined as mood disturbances such as anger, depression, and anxiety. The focus of this study was the measurement of short-term distress with patients from time of diagnosis to 7 months later, rather than on the long-term process of coping with the life-threatening event. Two of the objectives of their study were to learn more about what coping reactions have effects on well-being in time of crisis and the pattern of various aspects of coping over the period of crisis. Their study, which consisted of interviews with the breast cancer patients from the day before surgery, 7 to 10 days post-surgery, and at 3, 6 and 12 months, indicated that the number of coping mechanisms used dropped dramatically after 3 months post-surgery. Although the authors did report areas of change over the period of their study, they were concentrating on the reactions to the disease by optimists and pessimists. These authors suggest that optimists, who report a lower distress level, remain engaged with their life goals, while also adjusting these goals to the reality of their new life situation;

they also seem to be making new meaning of their lives and the future (Carver et al., 1993).

Greer (1991) originally studied the psychological responses of 62 women 3 months after they were treated with simple mastectomies in 1972. He found that these psychological responses could be grouped into several categories: denial, fighting spirit, stoic acceptance, helplessness/hopelessness, and anxious preoccupation. In a follow-up study 15 years later, it was found that the survival rate among those exhibiting a "fighting spirit" to be 45%, while those who expressed other responses had an average survival rate of 17%. "Fighting spirit" was defined as accepting the diagnosis, adopting an optimistic attitude, and expressing determination to fight the cancer; these women also sought information about cancer and sought to be active in their treatment. However, Greer (1991) did not look at the roles that other variables such as self-concept, social support, and spiritual values may have played in enabling these women to adopt this stance.

Challenges to Perception of Self

In a qualitative study of 38 cancer patients and the meaning they attach to their illness, Fife (1994) defined meaning as the person's perception of the potential significance of the event to the person and his/her ability to function in a social context. There are two components to

her definition of meaning: self-meaning and contextual meaning. She found that three changes in self-meaning emerged as the result of a serious illness: loss of personal control, threats to self-esteem, and changes in body image. Among the changes in the contextual sense of meaning were changes in future plan and in relationships. Her study emphasized cognitive changes that her subjects made of their illness, but did not discuss their feelings, what sense they had made of the experience, nor changes that they had made in their lives as a result of the experience. In addition, Fife (1994) did not indicate the time since diagnosis, which may be an important component.

In a society seemingly obsessed with good health as demonstrated by the proliferation of articles on nutrition, fitness, and physical perfection, illness is conceived of as an abnormal state (Hayden, 1993). Thus an additional burden is placed on those with a chronic illness, those who will never be well again and who have to learn to live with their illnesses. Hayden (1993) asserts that the chronically ill must learn to redefine themselves. She interviewed 16 adults who had been diagnosed with various chronic illnesses such as lupus, muscular dystrophy, Parkinson's disease and fibromyalgia. She chose not to include people with cancer because of the "powerful cultural beliefs and assumptions" about the disease (Hayden, 1993, p. 268). Her subjects felt that they were often misunderstood by those who were healthy

because they lived in different realities. They also experienced a sense of loss in not being able to perform in the roles of friend, parent, and worker as they had previously done. By redefining themselves in these roles, they were able adjust to their new reality.

In a study of 20 women with systemic lupus erythematosus, Leipold (1987), examined the personal meaning that her subjects gave to their illness. She found that the disease disrupts patterns of physical action and was unpredictable, which resulted in uncertainty and inability to plan life events. Another outcome of the illness was that it disrupted social interactions. In her study, Leipold (1987) found that the participants reported feeling misunderstood by those who did not have lupus, which affected their relationships with friends, family, and co-workers and resulted in social isolation, a finding echoed by Hayden (1993). Leipold (1987) also found that her subjects reported responding to the illness with anger, fear, frustration, and sadness. Although they all found that the disease was difficult to accept and to cope with, over time they learned to make changes not only in their actions, but also in their values, perspectives, and priorities.

Hilton (1988) conducted a phenomenological study of women with breast cancer that concentrated on the experience of uncertainty expressed by these women. Uncertainty was

defined as feelings of insecurity, inability to tell the future, being undecided, and a perception of vagueness. In interviews with 16 women, who had been diagnosed with breast cancer with a range of time from 3 months to 25 years, she found many themes that she interpreted as being related to uncertainty such as feelings of anxiety, seeking causal attribution, and beliefs about controllability. She found that a number of beliefs about cancer, mostly negative, emerged. The uncertainty of her subjects seemed to be influenced by lack of knowledge about the effectiveness of their treatment and chances of recurrence. Her participants coped by seeking information and support, strength, and relief from others; by focusing on the positive; and by minimizing, avoiding and denying the problem. Hilton (1988) did find that several of the participants had a different perspective on life and took more time to enjoy family, to complete life goals, and to concentrate on the quality of life. She implies that indication of a positive outcome was to make changes in attitudes, confidence, relationships, beliefs, values, and goals; in other words, making positive meaning of their experience, although she did not explore what meaning they had made of the illness (Hilton, 1988).

The Role of Time

The passage of time may be a factor in helping people find meaning in traumatic events. That the search for

meaning can continue for many years was confirmed in a study of women who had been victims of incest. Even though some of the encounters had ended 20 years earlier, over 80% of the women admitted to still looking for some reason or meaning of their experience (Silver, Boon, & Stones, 1983). Over half of those who were still searching had been unable to find any reason for the experience; only 20% of those were able to make some sense of it by considering positive outcomes. When looking at possible beneficial effects of finding some meaning, it was found that those who were able to make some sense of the incest reported less psychological distress, better social adjustment, higher levels of self-esteem, and greater resolution than those who were searching but had made no sense of it.

Meyerowitz (1980) suggests that it is not uncommon for women who have been diagnosed with and treated for breast cancer to have symptoms of emotional distress that persist for more than a year. Nelson (1993) asserts that the passage of time is essential if women are to find meaning in their breast cancer experience. Therefore, the 9 women she chose to interview for her phenomenological study had been diagnosed from 2 to 6 years earlier. In looking at uncertainty in the experience of breast cancer, Nelson (1993) found that several themes evolved among which were those of transition, choosing a new life path, confronting vulnerabilities, and gaining meaning by putting uncertainty

into life's perspectives. Nelson (1993) seems to have found patterns that indicated to her that the participants found meaning in their uncertainty as they shifted from an individual point of view to a cosmic one.

In an anthropological study (DeSantis, 1979) of the episode of breast cancer, 8 woman were interviewed monthly, beginning 1 month after their diagnosis for a period of 6 to 9 months, at which time it was concluded that their illness episode was completed. The episode was considered over when the women felt they were fully able to resume their normal physical and social activities and felt that they were in a state of good health (DeSantis, 1979). The purpose of this study was to determine what concerns the women expressed and to examine the sociocultural and physical factors of the illness as they unfolded. Since the study followed the experiences of the participants over a period of time, DeSantis (1979) was able to examine the process of their recovery.

DeSantis (1979) categorized the concerns expressed by the women in three dimensions: physical, emotional, and social. While her study records the concerns expressed, it does not address the meanings that may be underlying these concerns. The future goal of all of the women was to return to normal; none of the participants anticipated changing her life as a result of her illness. As one woman said, quite emphatically, "No, it's not going to change my life one

bit!" (DeSantis, 1979, p. 113). Perhaps, as indicated by Meyerowitz (1980) and Nelson (1993), at 9 months post-diagnosis, they still were too involved in the immediate recovery process to take time to reflect that the diagnosis of breast cancer does indeed change their lives whether they want it to or not. For, as she reports, "all the informants felt their experiences with cancer had made them appreciate life more and had afforded them an opportunity to grow as a person" (DeSantis, 1979, p. 140).

Identifying meaning in the diagnostic and treatment experience of 23 women, 6 to 8 months post-mastectomy, was the focus of a phenomenological study by Fulton (1990). She asked three open-ended questions about the respondents' thoughts, feelings, and perceptions when they were first diagnosed; as they were going through treatment; and their overall perceptions of the experience of cancer. The participants initially reported feeling shock, fear, anger, and loss of control at time of diagnosis. They said that they felt fear and uncertainty when undergoing treatment, but that they tried to find meaning in the experience by getting on with life, learning to appreciate life and others more, and reorganizing their priorities. The worst part of their experience was the loss of control, fear, and uncertainty. While this study did indicate that the participants tried to look for meaning in the experience, the specific meanings that they found were not delineated.

As in the study by DeSantis (1979), these women simply wanted to get back to normal.

Yet, in another phenomenological study of 20 women, who had been diagnosed with breast cancer from 4 to 18 months previously, Moch (1990) found that many of her subjects had spent time reflecting about life and what was meaningful. In her study, she attempted to understand the women's experience of health, defined as a process of expanding dimensions of personal-environmental interaction. Moch (1990) views illness as a factor that may instigate change within a person and feels that learning about and coping with illness provide an opportunity for growth or development. Her research was focused on three predetermined themes indicating health in the illness experience: changing relatedness to others in their environment, identifying meaning in the experience, and adding new perspectives about life. She found that her subjects had changed their relationships with others; identified meaning in the experience; and added new perspectives on life, which was described as a change in themselves and their world. A large part of her research focused on the process of the interaction between researcher and participant and her method of interpretation rather than on the meanings her participants made of the experience.

Process of Recovery

Jaffe (1985) suggests that survivors of severe trauma meet the challenge of that crisis either by numbing or by self-renewal. The term, self-renewal, is defined by Jaffe (1985) as the transformational process used by those who have undergone traumatic events to emerge stronger, more alive, and more whole than before. These people also have a new sense of hope, commitment, purpose, and mission; they have discovered a positive meaning in their adversity. He states that these people do not become victims because they do not choose to be victims. Jaffe (1985) also found that some chose to become role models for others in similar situations. He suggests that it may take people several years to create this new sense of self and direction following a traumatic experience.

In his work with terminally-ill cancer patients, Yalom (1980) reports that many of them used the crisis of their disease as an opportunity for change. He states that the awareness of death "shifts one away from trivial preoccupations and provides life with depth and poignancy and an entirely different perspective" (Yalom, 1980, p. 160). Among the inner changes that his patients reported were rearranging life's priorities, being able to choose not to do the things they do not want to do; living more in the present than the future; and communicating more fully with loved ones.

LeShan (1989), who has worked with cancer patients since the 1940's, states that if there is a fulfilling, life-affirming goal to life after the illness, then there is a greater chance that the immune system will be able to work more effectively. Once the patient has a meaningful goal, he/she is no longer a pawn in the illness experience, but rather one who is actively fighting for one's being. LeShan (1989) says that all the patients he has worked with have a song to sing and that singing that song is joyful and socially positive. He goes on to state that when a person is singing his/her song, using oneself in the way one was intended, "we know" (LeShan, 1989, p. 139).

In an article chronicling the search for the meaning of his own experience of cancer, Cunningham (1993) urges that the cancer patient get in touch with his/her spiritual side to be able to see every event as having meaning, transcending time and space, which will bring comfort; a sense of connectedness; a lessened fear of death; and a sense of purpose in life. He asserts that it is his willingness, his choice, to search for meaning in events that has lifted his "view of the world to a different, broader, level" (Cunningham, 1993, p. 68).

Conclusion

The literature reviewed suggests that the search for meaning is important in the lives of human beings,

especially those who face trauma, whether it is the result of an accident, incest, chronic illness, or cancer. After their initial emotional responses, many look for meaning in the event by attempting to find causes for it. The literature also suggests that while there is no definitive answer to whether finding a cause is important to psychological adjustment, it does suggest that this may be a first step in adjusting to traumatic events.

The diagnosis of a chronic illness seems to challenge the self-perception of many of those stricken. It may change their perception of their body image and ability to perform their roles of partners, parents, friends, and workers as they previously had. They may also feel that they are no longer understood by others. These challenges as well as fears and uncertainties about the future are apparent in many of the studies of women who have breast cancer.

These studies indicate that many of these women simply have a desire to return to normal. However, over time, it was found that they, like others who have suffered traumatic events, made changes in their lives. Many of those changes imply that they have found a purpose for the illness, have redefined their roles and their goals in life; however, when reading these studies, it seems that much of the research has focused on the explicit meanings of the experience of breast cancer as a life-changing event.

There seems to be a need to try to understand the implied meanings of women with breast cancer as they talk about their initial emotional responses, their search for causes of the disease, the challenges to their perception of themselves as women, partners, parents, friends, and workers, and the fears brought on by the diagnosis. Over time, there may be a recognition of a deeper meaning or purpose for having experienced breast cancer which brings about changes in their values and their goals.

CHAPTER 3

METHOD

Brody (1987) asserts that human life "assumes narrative form and can be understood, by humans, only in that form" (p.43). Phenomenologists seek to understand the experience of an event through the eyes of the individual, the only one who can tell the story from a personal perspective (Becker, 1992). To phenomenologists, knowing another's experience is the way of knowing another's reality, according to Becker (1992). The ultimate goal of phenomenological research is not to solve a problem, but to gain and articulate insights into the phenomenon as it is experienced by people involved in the phenomena so that it can then be understood and used by others (Becker, 1992).

In order to comprehend the impact of an event upon the individual, Benner (1994), like Brody (1987), considers narrative accounts to be essential. Telling one's own story allows the participant to include more details, to express concerns and meanings, and to state her perceptions of the experience. The interactive nature of the narrative process also allows the researcher to question, probe, and clarify in order to understand the story more completely. These texts, or stories, are the phenomenological researcher's source of data. Sources of texts may include individual or group interviews, participant observations, and documents as

well as other sources of information (Benner, 1994).

Interpretive Phenomenology

Interpretive phenomenology seeks to understand the lived experience of the participant through a thorough reading of the texts, questioning, comparing, and imagining the participant's world (Benner, 1994). By presenting commentary on the text, the interpretative researcher seeks to point out meanings and distinctions in the text to the reader. The goal of interpretive phenomenology is to uncover commonalties and differences in the experiencing of a phenomenon.

The purpose of this study is to learn if the participant had made any meaning of her experience of breast cancer, to understand the meanings that she may have made of it, and to discover commonalties and differences in the meanings each of the women may have made of the experience. Therefore, I chose to utilize the interpretive phenomenological approach to research, to conduct interviews with the participants in order to hear and understand their experience of breast cancer and the meanings they might have made of this experience.

Sample

Participants in this study were nineteen women who have been diagnosed with and treated for breast cancer. All of

these women have attended meetings of the Gallatin Valley Breast Cancer Support Group and are known to me because of my involvement with the support group since its inception in 1988.

The support group holds meetings twice a month at various members' homes. Attendance at the meetings is voluntary, no dues are collected, there are no officers and no planned agenda. Programs are occasionally presented by health professionals from outside the group. A list of those currently attending the meetings is updated four times a year. This list is maintained so that the women can be called with information about the monthly meetings.

The ages of the participants in this study range from 43 to 71. All of the participants had been diagnosed with and treated for breast cancer at least 1 year prior to the time of the interview with a range from 13 months to 22 years.

Fourteen of the women had had a modified radical mastectomy, a surgical procedure which removes the entire breast and most of the axillary lymph nodes on the same side, leaving the muscles of the chest intact (American Cancer Society, 1995). Two participants had also had a prophylactic mastectomy to remove the other, healthy breast because of their concern about recurrence in that breast. Two of the women had reconstructive surgery following their mastectomies. Five of the women had had a lumpectomy, a

surgical procedure that removes the part of the breast in which the cancer occurs as well as a margin of healthy tissue (American Cancer Society, 1995). Twelve had chemotherapy and/or radiation treatments following their surgery.

Methodology

A letter and consent form, which was approved by the Human Subjects Committee at Montana State University, was sent to 25 women who have attended meetings of the Gallatin Valley Breast Cancer Support Group. These documents explained that this study was being conducted to help physical and mental health professionals better understand the experience of breast cancer. Two copies of an authorization form were also included; both the participant and the investigator signed these forms and each kept a copy.

The letter and the consent form further explained that the researcher was interested in the participant's experience of breast cancer, how her life may have changed because of this experience, and the meanings she may have given to the event. The researcher explained that the study would involve a confidential interview of about one hour, which would be audiotaped. The potential participant was asked to telephone the researcher to set up an appointment for the interview. It was also explained that a follow-up

interview might be necessary. Each participant was given the option to discontinue the interview, to withdraw from the study, or to decline to participate further at any time.

Twenty-three women responded to the letter. Four were unwilling or unable to participate for personal reasons. Two did not respond. Because the participants were known to the researcher in another context, before beginning the interview, it was once again emphasized by the researcher that the interview was totally confidential, that the participant had the option to discontinue the interview or to withdraw from the study at any time. None of the participants asked to terminate the interview, declined to be interviewed further, or chose to withdraw.

Three demographic questions were asked at the beginning of each interview:

1. How old are you?
2. When were you diagnosed with breast cancer?
3. What was your treatment?

These were followed by open-ended questions:

1. Thinking back to when you were first diagnosed, what were your thoughts and feelings?
2. Do you make any sense of the experience of breast cancer?
3. Have you made any changes in your life since you found out that you had breast cancer?
4. What do you think is the meaning of life?
5. Do you have any fears for the future?

6. What kind of support was most helpful in your recovery?
7. What would you tell other women who have just found out that they have breast cancer?
8. Is there anything else that we have not covered that you would like to share?

It was found, however, that more questions were needed with some subjects than with others; some of those questions were needed to amplify and/or clarify statements or to probe more deeply into the experience. For example, if a woman simply answered that she had made changes in her life, she would be asked what some of those changes were. Those who had had mastectomies were asked if they had experienced any feelings of loss or grief. If not mentioned in answer to the question about fears for the future, those with daughters were asked if they had any fears for them. Some of the interviewees covered many of the intended questions during the flow of their narratives, thus fewer questions were needed.

After completing each interview, the researcher transcribed the tape. Following Benner's (1994) guidelines for interpretive analysis, each text was read in its entirety to develop an overall understanding of the participant's experience. Global commonalities and differences between the texts were noted. Thematic analysis, a search for patterns and concerns, was conducted on each of the interviews, to seek out inconsistencies, similarities,

and differences in the experiences of the participants. According to Nelson (1993), themes are "focal points of meaning in an experience" (p. 58). Exemplars, or vignettes, were then extracted from the texts to illuminate the similarities and contrasts of the themes that emerged from the interviews. The goal of the use of exemplars is to allow the reader to recognize the distinctions that the researcher discerns (Benner, 1994).

Limitations

Because each of the participants had attended support group meetings, this population may experience breast cancer differently than those who have not participated in the group; thus, it is not possible to generalize their experience to the wider population of women with breast cancer.

In addition, the lived experience of each participant is unique to her subjective interpretation of her experience, therefore it is not possible to generalize or predict how another may respond to a similar situation. Indeed, the intent of this approach to research is not to generalize, but rather to "gain insight and understanding" (Nelson, 1993, p.66). However, patterns of concerns or difficulties that emerge may enable mental health professionals to understand the coping mechanisms, fears, and concerns of the client with breast cancer.

Another limitation is that the prior association of the participant and the researcher may have colored the context of the interviews: the participant may have felt that she was being heard more clearly because the researcher had personal knowledge of the experience of breast cancer or she may have felt awkward or hesitant expressing her thoughts and feelings about her experience in light of her assumptions about the researcher's experience and adjustment.

CHAPTER 4

FINDINGS

Well, after I was first diagnosed...and, and I can't tell you, I can't describe it and I remember it like it was yesterday [seven years later], that feeling of, of, just like you're on an island, isolation, terror, partly from the diagnosis and partly from not knowing what's coming next....it changed my life profoundly, it was the closest I've come to a religious experience, I guess, because it absolutely focuses your priorities, you really understand what's important in your life.

There was a painting, or at least an art piece, of a woman who looked incredibly feminine and she had one breast that was normal and the place where the other breast was, had been, was a clock and the clock was ticking, you know.

For me, it was doing things that I wanted to do and being able to do these things. Thinking, actually sitting down and thinking. I want to go to Nashville before I die; well, now I'm going. You know, I sort of mentally had a list of things I wanted to do before I died, and yes, I'm not dying yet....but if I am, I may as well have done some of these things that I thought were important to me.

The diagnosis of breast cancer is an uncontrollable event that disrupts and changes many areas of a woman's life. The three women quoted above touch on a few of the themes that emerged from the interviews about the meaning of the experience of breast cancer. These themes are, in part, fear of the diagnosis and its implications, the struggle to regain equilibrium, rearranging priorities, the sense of urgency, acknowledgement of bodily disfigurement, and learning to live for oneself.

Several other themes also emerged from the analysis of the 254 pages of text transcribed from the recorded interviews; themes which indicate that many aspects of the lives of these women were affected by breast cancer. Each quotation may contain several meanings, explicit and implicit. For example, in the first quotation on the previous page, the woman expresses fear of isolation, of the disease, and of the unknown. She also touches on spirituality and the need to rearrange her priorities. Implicitly, there is also the fear of death and the acknowledgement that time is finite. Choosing which category of meaning to place her remarks therefore becomes an arbitrary decision.

Initial Reactions

The first thoughts and feelings of the participants after being diagnosed with breast cancer were those of disbelief, shock, fear, and anger. For some of the women, it seems that their assumptions about personal invulnerability were shattered.

Two of the participants expressed their initial reactions of disbelief and shock:

Well, I think at first, I just thought they must have the wrong person, because I'm this healthy person and I didn't think this ought to be happening to me and then, I think, it really hits you and you feel really bad and really sad.

I think my first feelings were shock because it was really unexpected to me. The first day I saw the

surgeon and he explained the alternatives and what I could do. My three daughters were with me, when he was through, one of them said to me, "Well, Mom, what are you going to do?" And I said, "Well, I'm going home." And I did, I left the office. I was back the next day, but I did leave that first day.

In addition to disbelief and shock, there was fear; fear of the word "cancer" with its implications as a death sentence.

One woman explained her fear about her diagnosis, "Anybody who has cancer, the big 'C' word, like they say, it's scary." Her mother was extremely worried because her mother and sister had died from cancer, so "she thinks cancer is death. And if you have cancer you're dying soon."

Others also talked about this fear:

I don't know what you really are afraid of, it's the word "cancer" I think you're afraid of that more than anything. Scary, it is, you think that's something that happens to other people.

Gosh, I think back to when I was a child, it was sin, whispers, I mean to admit that you had cancer, ha, ha, perish the thought. And then I can remember my dad saying one time about a family friend that had got cancer...and just went down like a rock; he was soon dead. And my dad said, "it's that name of that 'cancer,'" he said, "fellows get that and they give up, they're dead."

In urging others not to be afraid to talk about breast cancer, one woman was able to talk about her medical treatment without difficulty, but was not able to admit that she had cancer, perhaps out of feelings of fear and shame. She caught herself in this contradiction:

because now I had no problem telling people that I had had a mastectomy, but it took quite a while before I could tell myself that I had cancer....When I was

growing up, I mean, cancer was not a word that you used. I mean people just, I mean if somebody had cancer, it was spoken about in whispers.

There was also fear and anger at the possibility that this diagnosis would change their worlds and their plans for the future, especially in terms of their families.

One woman said of her initial reactions, "This can't happen to me, ah, for the first day or two, probably fear, even afraid to read about treatments, to face what was coming."

Another's reaction:

It's terrifying, it's terrifying; I had little children, they were three and seven years old and I think the first thing any mom thinks of...oh my god and all I want to do is live long enough to raise my children....you just fear for your life and your family.

Fear took on an added dimension for a woman who was seven months pregnant at the time of her diagnosis, and said it was, "very scary. I kept thinking the baby would survive...but I wasn't sure if I was going to and I cried a lot."

Disbelief, fear, and anger were all reflected by one woman:

At first, I was really scared and my next response was to make contact with my family and just to make sure that anybody who was close to me, I talked to...then I was really angry that it was happening to me and I was so young and "why me?" and "I really didn't deserve to have to deal with this".

One said that her first reaction was, "Anger at just that it was going to interfere with my life, I was gonna

die, um, I was gonna be robbed of time with my family."

Search for Causes

Most of the women sought attributional causes for their breast cancer. Many of them said that they thought it was part of a larger, cosmic purpose or plan, while others sought explanation in family history of the disease, diet, stress, or the environment. Three of the women reported that they had not searched for a cause for this unexpected illness.

One of the women who expressed indifference about the cause said, "Who knows why I got it? I don't know, I don't know and it doesn't matter. What are you going to do? No, it doesn't matter."

Another said, "I don't question things like that...I think it just happened."

In a few sentences, one woman exemplifies several implicit meanings: there is an indication of a search for a reason, there is the reference to the meaning of the word "cancer" itself and its implications, and there is rage that the diagnosis will change her world irrevocably:

Why? Is there a logical reason for this, God? And most of the time there isn't...Cancer has no, it can hit anybody from the smallest child to the oldest person, it has no respect for who you are or what you want to do.

One felt that she was as likely as the next person to get the disease, whether she liked it or not:

I guess you feel a certain amount of resentment, you know, a little bit of why did this happen to me and you think about that for a while and then you come up with, well, why not me...what makes you so special that it wasn't going to happen to you?

Cosmic Purpose or Plan

Most of those who had looked for causal attribution, found a cosmic meaning, expressing the belief that it was part of a larger purpose or plan. While they expressed that belief, they also struggled with trying to understand the purpose and to accept it.

"I believe God has a plan for each and every person on the face of this earth, whether we choose to acknowledge it or reject it, it's our choice."

I feel that God has a plan for us and sometimes we don't like what's in the plan...it's hard to accept that, but I think that's the way it is and we're all better off if we accept it."

"I have a lot of faith in God and I feel that he has a purpose for all of us...I just feel like right now I need to be here for some reason."

Heaven knows, I don't understand why some of these things happen, but I believe there's a purpose for it....a lot of it doesn't make sense, but I think in the end, I'll know what the deal is...I believe we're here to live the best life we can, you know, to God's glory.

One woman seemed to believe that there is a larger purpose or plan, but still seems to be searching for a reason for getting breast cancer:

I have no idea why....I thought I was part of the population that wasn't supposed to get breast cancer...I don't have any idea how I could have lived

differently and prevented it....I've got really strong beliefs in that God's allowing us to be here for a purpose, ah, I don't understand all of God's purposes...sometimes I think we're here to be tested and to learn from the testing and maybe that's partly where the breast cancer comes in.

Family History

Twelve of the women were aware that there is possibly a genetic component in some cases of breast cancer and mentioned this, whether they had a family history of it or not:

"There's cancer in the family, so for some reason it wasn't a big shock, I mean, I wasn't happy about it, but then you know, it wasn't that much of a shock." One with an aunt and a mother who had breast cancer said that she hadn't thought about the family history until her diagnosis and said, "I thought, I guess, I should have been thinking about this sooner."

One woman, whose mother had had breast cancer, seems to have discounted that as having any bearing on her because her mother had been a heavy smoker and "I felt that she had developed breast cancer through a general rundown of her health."

Others wondered at the possibility of the family connection: "I don't know, it could possibly be related to my grandmother being a cancer patient and my aunt." "I have sometimes thought, I wonder if my mother had breast cancer, but it wasn't diagnosed."

Some expressed shock at their diagnosis because there had been no breast cancer history in their families. As one said, "I couldn't believe it was happening to me because I knew it wasn't in my family history."

Diet

Confusion over mixed messages sent about possible dietary causes of breast cancer is evidenced by two of the women. Underlying their explicit concerns about what they are hearing, is also the message that they somehow feel that they are to blame for their breast cancer.

Where I could have possibly gone wrong and certainly it was in the area of fat consumption, so nutrition came to the forefront, since they're relating so much of a high fat diet to the onset of breast cancer....I had always thought I was giving my family a healthy diet... I thought I was doing better than I actually realize now that I was. We ate a lot of cheese, we ate a lot of red meat, all because I thought we were giving the family plenty of needed protein and on and on. And now I see that I really was not doing it right.

The other side of the story:

And I'm really happy to hear that it isn't eating fat that gives it to you. You know, all these damn things that come on TV, it's a guilt trip. Here is this woman who went and ate fat; it's her own fault. Fat-eating fool!...Like you went out and did it to yourself; well, maybe, you do some things yourself, not intentionally, when you're trying to do the best you can.

Other Causes

Some of the women thought that pesticides, stress, or medications may have been contributing factors, perhaps indicating that they may have felt helpless:

I do have some beliefs that...those eco-chemicals out in our environment...in California, I saw planes going right over me, spraying DDT and across, right across was Nevada, was open, you know, atom bomb testing, you know, so I know I got some of that exposure but why is it me instead of any of my brothers and sisters, or maybe that's just the way it is.

You wonder why?, where? and then when you see how many are around here, you wonder what is in the area, that may be is causing this to, the water? I don't know, stress, that's a good one too.

There was just none of that kind of cancer in my family, so I just don't feel it's genetic, it's environmental in nature....I'm convinced that my cancer was caused by the DES I was given when I carried my daughter and I had tons of it and it's such a sinful thing, they filled us poor women full of it because they had no idea what it did.

Regaining Equilibrium

Gaining mastery over an uncontrollable event may be one way of seeking to return to normal or at least to find a sense of control. A few sought information, some used humor, and several mentioned spiritual faith as resources in their search for mastery.

One of the women recognized the desire to return to "normal", but also realized that that was not possible:

In the beginning you strive to get back to normal, and first of all, what is normal and second of all, your life never will be back to what it was and I think, a lot of women want that, you want to get back to what it was and it never will.

One, whose life previously had been changed irrevocably as a result of a devastating car accident involving her husband, knew that another traumatic event would once again change her life, that it was hopeless to

wish otherwise:

now, it's my turn, let's just get this thing over with. We've gone through that other process of a change in our dreams...so I knew my life was never going to be normal again. I had gone through that before.

Information Seeking

Only a few of the women reported actively seeking written information; however, as will be seen in the section about their relationships with medical professionals, they also seek information about their disease and treatment in other ways.

One woman said that her husband:

searched the scientific literature, because he was trained as a scientist so he could read through some of this technical, medical jargon a lot easier than other people, enlisted the help of his friends and family who were in science to get us information.

Another realized that she needed to begin to cope:

My attitude was not going to help me and I certainly couldn't keep on crying so I started trying to find out what kinds of things would help me like reading books and so forth...a friend of mine's mother, who also had breast cancer, sent a book to me and that started my upward, more positive attitude that I was gonna try to work with this thing and not against it.

Humor

Humor and its importance, often as a way of bonding with others with breast cancer as well as defusing the tensions of an unacceptable situation, emerged as a theme throughout the experience. One said, "I think we need to be able to laugh at ourselves and laugh with, you know, have people laugh with you, too."

One woman began to use humor to defuse the threat of her situation from the beginning, "I was told I could have a choice of a mastectomy or a lumpectomy...actually, I asked Dr. S. if he any other choices, that I didn't like those two, but he didn't."

Another laughingly told about having a friend who advised her to go for a second opinion about her diagnosis, "I said, 'why should I go for a second opinion because I really didn't like that first one!...it wasn't going to get any better."

She also used humor later to diffuse feelings in her immediate family, who she said:

were just stewing and worrying. I had become very irritated with my family, my sibling family, so I came down one day and I said, "let's write my obituary" and they looked at me so funny and then shook their heads. And I said, "We need to write my obituary, I don't want to list any of those people."...That kind of lightened them up, but I quite often refer to doing this obituary. At first, they just rolled their eyes at me and thought I was going over the edge, but now it's kind of a joke...it was something I had to do to lighten them up because it bothered me so.

Later she added: "You have to laugh because if you cried that much you'd dehydrate. I mean you really do have to discover the humor of it, even if some of it is kind of off color."

Another woman used humor in a different context, perhaps to cover her feelings of loss, grief, and fear:

I remember one time, I had to laugh, because I was telling this professor up at the college that I almost came to his loss support group and he said "You did? Who did you lose?" And I said, "Well, I lost a breast"

and he said, "Well, that would have been interesting." I thought that was funny.

Stories about forgetting the prosthesis was another form of macabre humor that several women shared. After telling a story about going off to the eye doctor without it and thinking she had somehow lost it in his office, one woman said:

I have found out that several other women have also forgotten their prosthesis, going to the grocery store or going wherever and we've laughed about it and said who would ever have the nerve to tell us, "Boy, something's funny looking about you today." Maybe another one who's had breast cancer could say that to us and they could say that because everybody would laugh, but the normal person, even if you were huge on one side and flat on the other, nobody would ever say anything to you...my motto now is, instead for the credit card, "don't leave home without it"; it's my boob; "don't leave home without it."

Faith

Spiritual or religious faith was another source of meaning and comfort to many of the women with breast cancer.

One woman described a spiritual experience that occurred over 20 years ago, but which still seems to give her comfort, strength, and hope:

After the breast surgery, when I was beginning to wake up...I was in the recovery room and everything seemed dark [leans back in her chair, closes her eyes, and fans her fingers out in front of her] and I could just feel people beside me but I couldn't really see anything and then I went out again. Next time I attempted to wake up, I, ah, my eyes weren't open or anything and I was just kind of aware of a very beautiful softness, and I could kind of see without opening my eyes, the corner of the room. And, it seemed to me like it was kind of a soft mist, but mist doesn't really describe it. There was something that doesn't describe it, but it was kind of like a mist. And the

Lord said to me, "Don't be afraid, I am here."

She concludes, "If I lost my faith, I'd lose everything."

Others also talked about the importance of their religious and/or spiritual beliefs:

I've enjoyed getting to know God better, I've always been a Christian, but I've gotten to know Him better...I think we're only on loan, I enjoy life but I'm looking forward to the everlasting life afterward, seeing all of the family members that have gone before me, so life, life here on earth is just a temporary thing.

I guess I've always been a strong Christian all my life...I feel like I'm put here for a purpose, but I don't feel like I can just go around and do anything and nothing's going to happen to me because I consider myself a Christian.

I talk with God, as I view God, a lot more than I used to. What the master plan is, I still don't know, but I think I'm more receptive to, to how, I, I guess I can surrender myself to and trust in that things will work out, that they'll be like they are supposed to be.

Two of the participants talked about struggling to find a larger meaning in their experience:

I did start out searching in the religious area a little bit....I've always considered myself a religious person, but in my own heart and in my own home...I feel that heaven is being remembered in the hearts of the people you leave behind you in a good way and hell is "I'm damn glad that son of a bitch is gone!"

I went on like a spiritual search for two years and checked out different religions. The one thing that bothered me most when I was told I had cancer, was that I felt like I didn't do what I wanted to do. And then I kept thinking to myself, why didn't you do it or what do you want to do? And I didn't know, so I started this search trying to figure out who I was and what I wanted to do...God had given me life and I think I had forgotten and so I let everybody push me around, boss me around...I tried everything they did without looking within myself, so now, I've found my own path.

Another seems to have struggled for a spiritual meaning in her experience and has come to accept the fact that she alone is responsible for herself and her life:

Somewhere the idea was implanted in me that we live as long as we're improving; we have the chance to make ourselves better every year we live and maybe when we get as good as we're going to get, that's when we're going to die...and there's a rhythm to everything and everything comes and goes...and we are always alone. I think if you don't get that message when you get cancer, you probably won't ever get it, but we are always alone. I mean, people can help you, people can be supportive and everything, but it's up to you; you're responsible for you; we are always alone.

Challenges to Self-Perception

The treatment as well as the diagnosis of breast cancer may cause a woman to change the way she thinks and feels about herself. These personal perceptions can also cause changes in the way in which she views herself in accustomed roles as partner, lover, friend, parent, and worker.

Body Image and Sexuality

The loss of a breast in a society which seems to be obsessed by women's breasts can be a trauma in and of itself and marks the woman to herself and those with whom she is intimate as a victim of cancer. Every day, reminders are present after the experience of a mastectomy. Some of the women had difficulty adjusting to this loss, some were eager to have this diseased part of their body gone, while some saw the loss of a breast to be a small sacrifice to make in exchange for life.

One woman observed, "I mean you're reminded every time you look in the mirror...looking at myself I know I'm not the same." Another said, "It was hard to accept, looking at your chest, because it looked like a man's chest and I wasn't comfortable having a man's chest."

Others talked about the feelings of loss and grief:

I definitely felt as if it was a very great loss of my identity, of my sexuality and femininity as if it had all been taken away...much more painful than I had expected...it's still painful to get in the bath or to be naked...it still hurts even though I'm old and don't really need breasts a lot any more.

One woman spoke of ceremoniously mourning her loss:

I put a cross up and had a little funeral....I just said that I acknowledge that you were a part of me and I said I just felt bad, sorry that it happened and I cried. It was a little mourning for myself. It was just kind of an acknowledgement. I do that with deer, too, if I see them hit on the road, I always kind of say a little prayer that I acknowledge that you were important in life. And my breast was important.

Some chose to describe this part of the experience in graphic terms: one felt "misshapen, lopsided." She went on to say that she had a friend who she felt was one of the only people she knew who could sympathize with her loss; this friend had said to her "I think it must be as if you were bitten by a shark." Another said, "It's gross, it really is, but, I think after a period of time, it's surprising what you can look at and not really see."

One woman, who also described feelings of loss after the mastectomy was also embarrassed and afraid to have others see her; however, she was able to positively reframe

her experience:

There was also that terrible loss of being a mutilated person....I wish I'd got it in my big toe or something, you know, something that isn't connected to the self and I did, it was a terrible loss...I felt less a person....After my mastectomy, I wanted to go back to water exercise but I was apprehensive and anxious about how I would be regarded by the other women.

She said that she was told to think of herself as a survivor and to be proud, "so I thought to myself, 'I'm a survivor, I'll be proud,' so now I don't think anybody thinks anything about it."

Another woman seemed very ambivalent about the loss of a breast. Having large breasts had caused her problems while growing up and yet was part of her image. She seemed to be struggling to look at the mastectomy positively, to see the loss as a small price to pay to keep on living:

I remember feeling sort of humiliated about the whole thing; it's a very undignified surgery for one thing, it's a very personal thing, I think to a woman, that she's having a part of her body removed that has been, so to speak in our world, as a part of yourself as far as appearance goes.

When asked if she had feelings of loss and grief following the mastectomy, she said:

No, I didn't, I have always had large breasts, I developed early in life...I was always the sex symbol, but because of my religious training....this was not a great thing. This was something I should be hiding and I wasn't able to hide it...I'm not going to miss it because it's only brought me grief and it just goes to show, it's giving me grief now, you know, so I was right all along.

However, when a Reach to Recovery volunteer brought a temporary prosthesis to her in the hospital:

that was a shock to my system; that made me realize that there was a part of me gone...I knew why it was gone, I felt that it was a small sacrifice if I could keep my life and see my children and their children grow...a very small sacrifice to keep on living...it's a dreadful experience; you suffer indignities to your body and it's difficult to look in the mirror and see that you are only half there from your waist up and it's a difficult adjustment because it's such a drastic part of a woman's body that's taken away but then you have to look beyond that, too, and find something that's more important to you than having one of your boobs removed, you know, like living.

This theme of sacrifice of the breast for life was also important for another woman:

I think you feel kind of awkward with only one breast...breasts are nice to have around, but I think to be alive is more important...I want to be there when my kids grow up and have kids.

While she implied that she was glad to have the diseased breast gone, others seem to have disassociated more from this diseased part of their body:

"They gave me the option of the lumpectomy," said one woman who chose a mastectomy, "but I felt like, no, let's get it off and get it out of there, you know."

The quicker I could get rid of it, the better it was going to be. I really just wanted the mastectomy...I just wanted it gone....I never had a hard time looking...it's just a part of my life, I don't even think about not having that second breast any more.

Ever since I developed breasts, they were always painful. The time of my periods, my breasts were really painful, very tender...and there wasn't a bra large enough to hold those things, so emotionally and physically, they had been kind of a pain.

By the time of her surgery, she decided to have both breasts removed and has not regretted it.

Another woman who also had a double mastectomy and then chose reconstructive surgery was eager to get rid of the diseased part of her body and also to improve her body image:

First of all, I wasn't going to have any more children and my boobs had done their job; they were really unattractive, you know, I was losing a tit, but I wasn't losing much. When I thought about it rationally, it wasn't like losing an arm or a leg where your function would be impaired...I suppose this sounds gruesome, but I was excited about getting a new set. Let's get rid of the disease problem and then we'll go on to the fun cosmetic stuff.

Two of the women who had had double mastectomies, mourned the loss of this erotic apart of their bodies, which has changed their sexual feelings:

A lot of my sexual feelings are related to being touched on my breasts and I miss that, but not enough to ever have said to myself, "I wish I had done it differently"...another area where the cancer experience is a little surprising is in the area of sex; I'm not sure exactly what's responsible but there's been a total loss of desire.

"You lost feelings you're never going to get back" said one woman who has had reconstructive surgery following a double mastectomy, "I think physically I look super, I have no problem with that part, but that sensation is different."

Partner Relationships

Most of the sixteen women, who were married at the time of the study, felt supported by their husbands throughout this experience. One woman, whose perception of herself has changed, is grateful for this support:

The most important support came from my husband and I can stand before him and I've got no breasts at all and my body has drooped in its shape....I'm falling apart and he'll still tell me that he loves me...so that makes you real strong when you don't feel very good about your body.

Another woman is grateful for a different reason and said, "My husband evolved into being a wonderful husband ...that [the breast cancer experience] was the turning point in our marriage and fortunately it was for the better."

However, at least one relationship with a husband has been affected very differently:

He refuses to look at me since the surgery and even though he says it doesn't matter to him, but to me it does, it makes me, in my eyes, I don't feel less of a woman, but I think I am to his eyes although, he says that nothing's changed, but to me if he honestly felt that way, he wouldn't feel bad about looking at me. It's rough. I tear up when I talk about it.

Friendship

Many of the women felt that the support of good friends was very important in the process of their recovery: "I guess you appreciate your friends more; they were so helpful."

I have some very deep, deep friends and so I go there. And the one who knew me since, my best friend, we knew each other since second grade summer...it was very, very helpful for me to have her and she really knows me through everything.

"One of my friends just said, 'What can I do?' And, I just said, 'Well, sit down and cry with me a while, I guess, because I don't know what else you can do.'"

The diagnosis of cancer, however, also negatively affected how some felt they were perceived by others, which perhaps raised fears of being lonely and isolated, fears about cancer, and fears about being judged for somehow being responsible for their disease.

I think, probably the feeling that, at first, that we have the plague or have leprosy or something like that because people don't know what to say to you and don't know if they should say something to you, so they try to ignore you a lot of times altogether and you get the feeling then that there is something definitely wrong with you, that you've got a contagious disease or something like that and it's not.

Somebody came up to me and said, one day, they knew I had cancer, and she's a pretty good friend of mine at church and she said to me, "Well, you're so good, how could this happen to you?" And I felt like saying "Well, I don't think that has much to do with it, maybe you better go read the book of Job"...you don't just know that you're going to sail along without anything ever happening to you, I don't think that's true, but I don't think I got cancer because I was a bad person.

Patient-Doctor Relationship

It seems that it was an assumption that most people in our society tend to revere doctors, who they picture as caring and compassionate. This experience caused several of the women to re-evaluate and give new meaning to the patient-doctor relationship. Several of them expressed anger and disappointment at the way they were treated and may have equated that inadequate care with their perception of cancer as a death sentence. Some also felt that they were not understood by their doctors.

One woman, who had actively engaged in information-seeking said, "I was appalled, absolutely appalled at the literature...that your doctor gives you...there was nothing there in the way of encouragement." She told her oncologist about how she felt about this literature, felt that the doctor had defended it, and said, "I was sad because I realized that she didn't understand what I was trying to tell her."

Because she came from a medical family, one woman was quick to disclaim that she did not revere doctors as gods, however, she felt:

very disappointed in the medical profession. I don't think I got good care; I don't even think I got adequate care, which is about all we can hope for is adequate, nowadays. And I felt sort of like I was on the scrap heap, you know...she's not worth bothering with really, maybe not fair, but that's the way I felt about it.

There were also undertones of animosity toward male doctors; it seems that some of the women felt discounted by them.

One woman spoke of sharing her anxiety about returning to water exercise with her doctor, only to have him reaffirm her fears:

Uncharacteristically, when the doctor asked me, was there anything I was having difficulty with, I did, I blurted out about how I was full of anxiety about showering after and also how I would be regarded by the group...and his, his response to me was, oh well, maybe you could just leave your suit on and pull something over and you can go home and wash in your shower or maybe, you know, all these things which just reinforces that I am so damn unsightly I shouldn't be let out, you know.

Another obviously felt that she was not being heard:

If I had to say I ever get angry, I still sometimes get a little bit uptight that the doctors still "pooh-pooh" the self breast exams or that "us women" come in saying what we feel like and things like that, they sometimes don't truly listen to us...I knew something was wrong and...the doctors kept saying, nothing is wrong and it took going, I had had three mammograms in a year and he still never said "let's remove that lump and see what it is." And finally, my guardian angel pushed me one more time and said "let's go again." So, I called the same office and a nurse practitioner could see me...when she saw me, she said, "I really don't think this is a whole lot," but she said, "let's get it out of there and see what it is." And, and, it was definitely cancer, so.

One woman who was concerned about financial problems and having to go elsewhere for radiation treatments found that a radiologist seemed to disregard her concerns:

He basically just told me, well, you're going to have to figure it out and I think of all the people I came in contact with, I was real fortunate in the sense that I think he was the only negative person, but that was one of the initial contacts. And I don't give him any Brownie points at all, I think that was very poor on his behalf; he could have been a lot more caring and understanding. Sure it's my problem, but you don't have to put it that way...people need to be more compassionate.

There was also a tendency to be cynical at times, one woman, who doesn't see the point in the repeated follow-up check-ups requested by her radiologist in addition to her other check-ups, fantasized about being "nasty and saying, 'Why do you need to look at me again, just to get my money? I'm well, I'm cured!'"

Several seem to have learned to stand up for themselves and to actively participate in their treatment, which may give them more feeling of control in this situation and

possibly more control in the future:

It's your body, your life, question the doctors. I'm learning that more and more and more. Don't just take what they say for total law, be as well informed as possible.

"Go to the doctor and find out what's going on; if you're not satisfied there then go some place else." "Try the best you can to get the best health care that you can find and it might not be here; it might mean going some place else but it's important."

One woman met with her potential surgeon:

I just bombarded him with questions; I wanted to know exactly what was going on and I wanted to feel comfortable with him or else I'd have to go somewhere else and I really didn't want to do that. I wanted to stay locally if I could and he answered all my questions satisfactorily and I really liked him as a person. We connected well and I felt comfortable having it done here.

Role as Parent

Two women perceived their role as a parent differently as a result of having had cancer. One woman described feeling a loss of independence as she had to change from her role of parent to that of being dependent on her children while going through her treatment:

I let my daughter bathe me. I couldn't do anything, my arm was immobilized and it was very, very humiliating to me to have to do this, because I've always been a person that has done all these things for myself, certainly for my children, you know, as far as caring for what they need and things...it was out of my control...I'd feel like my children were smothering me...I really was more than well taken care of, but in the same sense I kept losing my independence. It seemed to me that I was losing my independence more every day, every day. I was not in charge of myself even any more,

