University of San Diego

Digital USD

Dissertations

Theses and Dissertations

1996-12-01

Young Adult Women's Responses to Undergoing Treatment for Early Breast Cancer

Donna Abrashoff Schutte DNSc
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/dissertations>

Part of the [Nursing Commons](#)

Digital USD Citation

Abrashoff Schutte, Donna DNSc, "Young Adult Women's Responses to Undergoing Treatment for Early Breast Cancer" (1996). *Dissertations*. 271.

<https://digital.sandiego.edu/dissertations/271>

This Dissertation: Open Access is brought to you for free and open access by the Theses and Dissertations at Digital USD. It has been accepted for inclusion in Dissertations by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

YOUNG ADULT WOMEN'S RESPONSES TO UNDERGOING TREATMENT
FOR EARLY BREAST CANCER

by

Donna Abrashoff Schutte

A dissertation presented to the
FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the
requirements for the degree
DOCTOR OF NURSING SCIENCE

December 1996

Dissertation Committee

Patricia Roth, EdD, RN, Chair
Mary Jo Clark, PhD, RN
Mary Abascal-Hildebrand, EdD

Abstract

In the nearly two decades of cancer research in the United States, there has been little emphasis on the experiences of young adult women with breast cancer. I therefore adopted a qualitative multicase study method to explore the experiences of five young adult women from the time of discovery of a breast mass through the first three months of recovery from mastectomy. Utilizing data collected via semi-structured interviews, this study sought to describe their concerns, the way in which their concerns changed over time, and the influence of contextual factors. Three themes were identified. These included: "I'm going to die!" reassessing self, and seeking help from others. The findings identified areas for health care reform. These reforms include areas dealing with increasing the awareness of breast cancer in young adult women, facilitating early breast cancer detection, minimizing delays in treatment, and making adjustments in care such as improvements in education, early referral to the American Cancer Society, follow-up care, and the provision of individualized care to meet differing cultural needs. These "action areas" can be used to guide funding and the allocation of scarce resources for young adult women undergoing treatment for early breast cancer. Resource allocation is a topic of increasing importance in the latter part of this decade as the health care industry continues its pivotal shift from hospital centered care to managed care.

DEDICATION

This paper is dedicated to my children Ryan Joseph and Marissa Kathleen. Eleven years old, Ryan Joseph never knew anyone to rewrite papers more than once. He was concerned about the number of revisions required for this paper; yet, he never waived in his support and encouragement of my great undertaking of doctoral studies! During this time, it was Marissa Kathleen who added joy to our lives as we celebrated her birth and marveled at her vast accomplishments during her first three years of life.

ACKNOWLEDGEMENTS

There are many individuals who contributed to the success of this project. First, I want to thank my family for the support and encouragement they gave me during my doctoral studies. I am grateful to my husband, Richard, for all the changes he made in his life to assure that our family was always well taken care of. I am grateful to our children Ryan and Marissa for their enthusiasm and excitement about learning and going to school.

Next, I want to thank the members of my Dissertation Committee for their time and guidance afforded me. To Dr. Patricia Roth, I'd like to say thank you for guiding me through a qualitative research project and for reinforcement of excellence. As Chairperson, your coordination of Committee work was also greatly appreciated. You tapped into everyone's strengths to make the project successful. To Dr. Mary Jo Clark, I am grateful to you for being on the Committee and always giving me prompt and comprehensive feedback. You contributed greatly to the review of studies and project editing. To Dr. Mary Jo Abascal-Hildebrand, I would like to thank you for reinforcement of qualitative research techniques and writing style.

I would also like to thank the Board of Trustees of Riverside Community College, President Salvatore Rotella, and Vice-President of Academic Affairs, Tom Johnson, for granting me a full sabbatical this past academic year to complete course work and dissertation requirements. I am also grateful for the nursing faculty's support and encouragement during this time.

Finally, I would like to thank Sigma Theta Tau, Alpha Gamma Chapter for a \$500 research grant to complete this study. I am also grateful to Kristen Pritchard, Field Services Director of the American Cancer Society, Inland Empire Office, for assistance in participant selection and \$250 given to defray expenses incurred by participants.

TABLE OF CONTENTS

Abstract	
DEDICATION	ii
ACKNOWLEDGEMENTS	iii
TABLE OF CONTENTS	iv
LIST OF APPENDICES	vii
LIST OF FIGURES	viii
CHAPTER ONE: FOCUS OF THE STUDY	1
Purpose of the Study	3
Methodological Assumptions	3
Role of Researcher	3
Significance of the Study	4
CHAPTER TWO: REVIEW OF LITERATURE	6
Breast Cancer And Young Adult Women	6
Discovery Of Breast Cancer	9
Emotional Distress	10
Informational Needs	11
Coping Strategies	12
Treatment Selection	13
Decision-Making Processes	14
Decision-Making And Well-Being	17
Mastectomy And Recovery	18
Patient-Provider Communication	19
Nursing Care In Recovery	20
Psychological Functioning	23
Body Image	27
Social Support	30
Analysis And Critique	34
CHAPTER THREE: METHODOLOGY	36
Research Design	36
Data Collection	39
Entre	39
Selection Of Participants	39
Setting	41

Ethical Considerations in Protection of Human Subjects	41
Interview Process	44
Data Analysis	45
Developing Inductive Categories	46
Cross Case Analysis	48
Verification of Data	49
Credibility	49
Fittingness	50
Generalizability	50
 CHAPTER FOUR: THEIR STORIES	 52
Angela's Story	52
Jennifer's Story	60
Stacie's Story	71
Karen's Story	82
Susan's Story	89
 CHAPTER FIVE: THE FINDINGS	 100
"I'm Going To Die!"	100
"It's The 'C' Word!"	100
Living Through Surgery Itself	101
Dying From Chemotherapy Complications	102
"Not Living Forever!"	103
Reassessing Self	104
Finding Strength From Within	104
Getting A Grasp On It	107
Sticking Up For Self	109
Being Prepared	117
Rebuilding Body Image	118
Regaining A Sense Of Focus	121
Seeking Help From Others	124
Relying On Family And Friends	124
Searching For Understanding of Others	126
Reaching Beyond Family And Friends	128
Seeking Spousal Support	130
 CHAPTER SIX: DISCUSSION OF FINDINGS	 132
Dealing With A Threat Of Dying	132
Reassessing Self	136
Finding Strength From Within	136
Getting A Grasp On It	137
Sticking Up For Self	138

Being Prepared	139
Rebuilding Body Image	147
Regaining A Sense Of Focus	149
Seeking Help From Others	151
Relying On Family And Friends	152
Searching For Understanding of Others	154
Reaching Beyond Family And Friends	154
Seeking Spousal Support	155
CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS	157
Strengths And Limitations Of The Study	157
Conclusions And Recommendations	158
Increasing Awareness	158
Facilitating Detection	159
Minimizing Delays In Treatment	159
Referral To American Cancer Society	160
Educating About Surgical Experiences	161
Providing Follow-up Care	161
Individualizing Care	162
Areas For Future Research	163
Concluding Remarks	164
References	166

LIST OF APPENDICES

APPENDIX A	173
Informed Consent	173
APPENDIX B	174
Interview Questions	174
APPENDIX C	175
Committee Approval For Study	175

LIST OF FIQURES

Figure 1	176
Young Adult Women's Responses To Undergoing Treatment For Early Breast Cancer	176

CHAPTER ONE

FOCUS OF THE STUDY

In 1996, managed care and integrated health systems characterize health care reform in the United States. Hospitals, the traditional channel for acute care, no longer represent the center or core of the health care spectrum. Instead, primary care and keeping people healthy are focal points with health care being provided in outpatient settings. In addition, all components of the health care system are required to share in the integration and assumption of costs associated with health care provision. To become a part of these health care delivery systems, hospital administrators have implemented aggressive cost reduction practices and case management to reduce their financial burdens. Cost reduction currently represents a predominate objective. This emphasis is demonstrated by planned outcomes of reduced admissions, reduced lengths of stays, and a greater role of the individual in assuming responsibilities for his or her own health care (Prescott, 1993; Sovie, 1995). On its part, case management is being utilized to improve the allocation of resources, maximize quality of care, and shorten hospital stays. In case management, a registered nurse or other provider assumes the role of case manager and as such, is responsible for certain client outcomes. Formal case management plans (also known as critical pathways) serve as the structures for the development and management of individual plans. These critical pathways define the optimal sequencing and timing of interventions for a particular diagnosis or procedure by physicians, nurses, and other staff members. By realigning the balance between cost and service, cost reduction and case management have radically altered long-standing attitudes towards and methods of health care delivery in this country. Obviously, health care providers and the public need to learn more about the effects of these changes on the quality of care provided to the

innumerable individuals experiencing significant illness today (Sovie, 1995; Brooten & Naylor, 1995). For this study, I have chosen to look at the responses of young adult women to treatment for early breast cancer within managed care systems.

The onset of this study provoked a series of interrelated questions about the context in which young adult women's responses to treatment for early breast cancer occur. How do cost reduction and case management affect those individuals diagnosed with life-threatening diseases for which early treatment demonstratively affect long-term prognosis? Are adjustments in care being made to achieve acceptable outcomes of care? Are special needs being identified and followed-up, or are providers asking patients with scant knowledge to assume a greater role in their own health care at a time when they are experiencing great emotional distress? Clearly, participants in this study addressed many of these issues. For example, in the health care environments, providers are shifting mastectomy educational programs from the postoperative to the preoperative period to reinforce self care and are shortening hospital stays. However, the need to address individual client needs in order to maintain satisfactory outcomes remains and has been identified in this study and by several researchers (Hunt, Feig, & Ames, 1995; Burke, Zabka, & McCarver, 1995).

A methodical survey of cancer research demonstrates a critical lack in comprehensive assessment of needs in women with breast cancer; this lack is most singularly evident in the initial phase of early breast cancer recovery, which encompasses the period from initial discovery of a breast mass through the first three months of recovery from mastectomy. Further, little attention has been directed to the experiences of young adult women with early breast cancer, yet they comprise a group of increasing numbers characterized by more advanced tumors (Stage II or III) at diagnosis (Sariego, Zrada, Byrd, & Matsumoto, 1995). Fortuitously, this juxtaposition of need and numbers occurs at a time when more is becoming known about the importance of psychological

intervention in early breast cancer and the influence of this intervention on women's long-term survival.

Purpose of the Study

Since there has been little emphasis on the experiences of young adult women with early breast cancer, the purpose of this study was to explore the experiences of these women during the initial phase of early breast cancer recovery in a managed care environment. Little data exist concerning the effects of cost reduction and case management upon the identification of individual needs in order to maintain satisfactory outcomes of health care. This study sought to describe the concerns of young adult women from the time of discovery of a breast mass through the first three months of recovery from mastectomy, how these concerns changed over time, and the ways in which these individuals dealt with existing and emergent concerns. I chose a qualitative approach so that I might more fully understand the meanings of the initial phase of early breast cancer recovery to these young adult women.

Methodological Assumptions

I undertook a qualitative approach in this study, as this approach is considered to be the primary means of constructing or examining social and psychological phenomena (Chenitz & Swanson, 1986; Morse & Field, 1995; Strauss & Corbin, 1990). More specifically, I chose qualitative multicase study methodology as my particular research design. Anchored in real-life situations, multicase study methodology offers the means to provide intensive, holistic description and analysis of these women's experiences across cases, and as well to qualify these experiences by context. Merriam (1986) promoted qualitative multicase study research as a method better able to assess social change than more positivistic designs. I identified this approach as useful to this study because social change is inherent in the continued movement of health care delivery into managed care modes.

Role of Researcher

In a qualitative approach, the researcher identifies theoretical hypotheses or assumptions, then places these assumptions in the foreground to understand more about the experiences of the subject while avoiding the imposition of preconceived hypotheses. In this study, I suspended several assumptions so I could use them to compare the results of the study following data analysis. I suspended the assumption that the issues surrounding health care economics were complex and included both positive and negative aspects. Focused on profound cost reduction measures to survive in a competitive marketplace, hospitals have begun only recently to evaluate client outcomes of managed care. In their role as client advocates, nurses are needed to address issues of quality of care and the outcomes of care in the managed care environment, and as well to suggest necessary adjustments in care. Another suspended assumption centered upon the importance of a therapeutic relationship between the nurse and client in meeting the psychological needs of the client. Since young adult women who undergo mastectomy for early breast cancer possess individual and significant psychological needs, a therapeutic relationship was assumed to be central to their care.

Significance Of The Study

Since breast cancer is not experienced by all women in the same way, this study addressed the need to identify the concerns described by young adult women as they experienced treatment for early breast cancer. Each woman's narrative relates an unique, individual experience. The singular meaning of "cancer" for each individual, and distinctive methods of coping with the disease, are embedded within the descriptions of these women's concerns and experiences. These descriptions may encourage other young adult women recovering from mastectomy to reflect on their own strategies to cope with this life-threatening disease. Nurses can utilize these participants' descriptions to provide answers to other patients' questions about the breast cancer experience.

As health care reform continues to produce cost reduction, widespread public concern correspondingly grows concerning the quality of care as hospitals transition into managed care. Mandates also exist that call for health care systems to regain their client-focus and address individual needs (Brooten & Naylor, 1995; Sovie, 1995). Since the findings of this study identify the need to individualize care to maintain satisfactory outcomes, these findings contribute to a greater understanding of the experiences of young adult women undergoing treatment for a life-threatening illness. Accordingly, I make recommendations for individualizing care and improving health care services.

CHAPTER TWO

REVIEW OF LITERATURE

I began my review of literature for this study by focusing upon extant data concerning young adult women with early breast cancer and its treatment. Initial forays underscored an early assumption regarding the scarcity of literature directly related to this population. I therefore expanded the review to include literature that focused upon women of all ages diagnosed with early stage breast cancer and the initial phase of breast cancer recovery for these individuals. This chapter begins by discussing breast cancer in young adult women and then presents the findings of studies that concentrated upon the initial phase of early breast cancer recovery. These studies focused on the discovery of breast cancer, the selection of treatment modalities, and mastectomy and its recovery.

Breast Cancer and Young Adult Women

As described by the American Cancer Society in 1996, breast cancer is the most commonly occurring cancer and the second leading cause of cancer deaths among women in the United States today. The American Cancer Society estimated the likelihood of 185,700 diagnoses of new invasive breast cancer cases and a 44,560 deaths in the year spanning its study. While all women confront a one in eight statistical chance for developing breast cancer, white women experience a higher incidence of this disease than African American, Hispanic, and other minority group women. Although the incidence for breast cancer in young adult women since 1975 has remained fairly consistent around one in 213, the American Cancer Society (1996) reports an increase in the number of new invasive cases to above 34,000 because of population growth of this age group. Regardless of ethnicity, young adult women have been described as having the poorest prognosis when compared with middle aged and elderly women (American Cancer

Society, 1996). Other recent studies, however, challenge this hypothesis, and in doing so provide some illuminating new conjectures regarding the treatment of this population. (Recht, 1996; Sariego et al., 1995).

The five-year relative survival rate for all women in the United States -- including those who are in remission, disease-free, or under treatment -- has risen from 78% in the 1940s to 94% today. Seventy-three percent of women whose cancer had spread regionally at the time of diagnosis survive five years after that diagnosis while 18% of those with distant metastasis are alive in the same span of time. However, unlike many other cancers, breast cancer survival rates decline five years after the initial diagnosis is made. Sixty-three percent of women diagnosed with breast cancer are surviving 10 years after diagnosis; the survival level drops to 56% at 15 years (American Cancer Society, 1995).

Using findings produced by a retrospective review of 81 young adult women under the age of 35 in a single institution, Sariego et al. (1995) argue that statistical information concerning breast cancer in young adult women is misleading. While these researchers agree with figures that reflect an increasing incidence of breast cancer in young women over the past ten years, they reinforce that the increase in numbers is primarily a product of population growth in this age group. The incidence of developing invasive breast cancer for women under the age of 39 years increased only slightly from 0.46 (1 in 217) in 1995 to 0.47 (1 in 213) in 1996 (Parker, Tong, Bolden, & Wingo, 1996).

However, Sareigo et al. (1995) found the aggressiveness of young adult women's breast tumors corresponded more to the delay and difficulties associated with detection and diagnosis rather than the virulence of the tumors themselves. Study findings also reinforced the difficulty of detecting breast masses with mammography because of the dense nature of breast tissue in this age group. In their sample, 45 of the young adult women had metastasis to lymph nodes or distant sites; this number represents 56% of the overall sample. The overall survival rates identified in the study approached those of the

general breast cancer population. In young adult women with disease localized to the breast, the study reported five- and ten-year survival rates of 89% and 78%, respectively; five- and ten-year survival rates in the broader population are 65% and 49%. Sariego et al. also reinforced the importance of early detection for this group. “Early breast cancer” refers to Stage I or Stage II breast cancer. Stage I breast cancer is characterized by a small primary tumor (less than 2 cm in size) without lymph node involvement or detectable metastasis. Stage II is described as a primary tumor of greater than 2 cm but less than 5 cm, with or without lymph node and metastatic involvement.

The findings of recent studies concerning survival rates for the general breast cancer population hold significant implications for young adult women. One critical area of concern is the overall decline in survival rate beyond 5 years for breast cancer patients, a decline not evinced by other cancer populations. Some researchers (Fawzy, Fawzy, & Hyun, 1994) have challenged an established view that links the characteristics of the tumor or node status to this decline; instead, Fawzy et al. correlate the overall decline in breast cancer cases with the unpredictable behavior of the host in early breast cancer disease. In this view, the behavior of the host can be influenced by a variety of factors during the earliest stage of breast cancer; that is, the host mobilizes the body's defenses and improves cellular immunity. Such a level of unpredictability has not been found to occur in advanced breast cancer where the course of disease is considered to be predictable, though this non-correlation is still being studied.

Accordingly, researchers (Dean & Surtees, 1989; Fawzy et al., 1994; Greer, 1990; Maier, Watkins, & Fleshner, 1994) have hypothesized that interventions that encourage active coping rather than avoidance or passive acceptance of the illness decrease the psychological distress caused by the stress of the illness, decrease requirements for psychosocial adjustment, improve overall quality of life for patients, and promote extended survival times. The interaction between behavior and the body's

nervous and immune systems thus presents an area for study that may possess singular implications for young women diagnosed with early breast cancer.

Discovery Of Breast Cancer

The time from discovery of a breast mass to diagnosis of breast cancer is considered to be one of the most stressful times in the life of a woman. From a joint review of literature and clinical experiences, Payne, Sullivan, and Massie (1996) categorize initial responses to lump discovery into emotional reactions of "terror", "shock," or "panic", followed in minutes or days by emotional numbness, denial, or disbelief. In their view, most women are able to contain their emotional distress long enough to present for initial medical evaluation and then comply with physicians' recommendations for biopsy. The patients in the study reported that their anxiety remained high as they underwent biopsy. When these woman received diagnoses of breast cancer, their emotional reactions included sadness, despair, and rage. The researchers recorded specific fears at this time. Among the individual responses were statements such as:

'I may die, become disabled, and become dependent upon or a burden to my family and friends.' ; 'I lack the emotional strength to undergo necessary cancer treatment.' ; 'I have given breast cancer to my daughter(s).'; 'I should have never had children; they will grow up to be damaged adults because I will be sick (or dying or dead).'; 'My husband deserves better than this.'; 'No new boyfriend (or partner) will want me, a sick and deformed person.' ; 'I'll never get a new job, a transfer or a promotion because I'll be perceived as a poor risk, inadequate, damaged, expensive, and unable to compete with healthy people.' (p. 89 - 90).

My review of literature also identified several other studies that addressed the discovery of breast cancer. These studies focused on the level of emotional distress experienced at discovery, the informational needs of the women, and the coping strategies utilized during the period of time between discovery and diagnosis of early breast cancer.

Emotional Distress

While Northouse, Jeffs, Cracchiolo-Caraway, Lampman, and Dorris' 1995 study increased our understanding regarding the magnitude of emotional distress experienced by women and their husbands prior to biopsy, only a very limited understanding concerning contributing factors was gained. Using a convenience sample of 300 women (aged 25-75) and 265 (aged 26-83) husbands, standardized instruments were used to measure the independent variables of social support, uncertainty, marital satisfaction, family functioning, concurrent stress, and hopelessness. The overall distress level for the women was .57 (SD=.43, range 0-2.13), a level significantly above the mean of .30 for the normal population ($t=9.40$, $df=296$, $p<.001$). The level of anxiety was three times greater than the average reported for the normal population and the level of depression was two times greater. The distress level for the women was significantly higher than the overall distress level reported by their husbands of .37 (SD=.29, range 0-1.92); the male level was just slightly above the mean (.30) for the normal population ($t=5.93$, $df=254$, $p<.001$).

This study points to educational level as the single demographic factor significantly related to women's distress scores ($r=-.19$, $p<.001$). Women with less education reported a higher level of distress prior to the biopsy. Demographic factors such as age, number of years married, employment status, and income were not related to either the women's or the husbands' levels of distress. Women who had other medical problems, such as heart disease, reported significantly more distress prior to biopsy than women without other medical problems ($t=2.24$, $df=289$, $p<.03$). Using multiple regression, all of the independent variables taken together accounted for only 42% percent of the variance in the women's distress scores and 42% of the variance in husbands' distress scores. Concurrent life stress emerged as the factor that had the strongest association with both women's and husbands' distress however, concurrent life stress accounted for only 22% of the variance.

Informational Needs

Shaw, Wilson, and O'Brien (1994) conducted a qualitative descriptive study of the information needs of women and their significant others prior to breast biopsy and explored the influence of information on the breast biopsy experience. These researchers used semistructured interviews to study a convenience sample of 11 women and 8 significant others between the ages of 35 and 72 from a tertiary care center. Participants identified their primary need for information through a single question: "Is it cancer?" The researchers noted a considerable amount of uncertainty among the women regarding the outcome of the biopsy; this uncertainty contributed to feelings of increased distress for these individuals. Information management, in which an individual controls the amount and type of incoming information, emerged as the major strategy utilized by the women to reduce distress. For example, the women wanted to know biopsy results before hearing about treatment options; however, the significant others wanted to know about treatment options even before a positive biopsy diagnosis was made. Additional coping strategies included faith, both in God and health professionals, keeping activity high, and normalizing behaviors. Shaw et al. use the term "individual" to describe the emotional responses of the women to the diagnosis of breast cancer. Emotional responses included shock, fear, anxiety, powerlessness, and fatalism. The incidence and intensity of anxiety also varied among the participants. For example, those women who had previously experienced a negative breast biopsy reported less distress than those with no previous encounter with the prospect. In addition, women reported less emotional distress when their physicians informed them about the need for biopsy in a positive, reassuring manner.

Luker, Beaver, Leinster, Owens, Degner, and Sloan undertook an exploratory study in 1995 to establish the priority information needs of women newly diagnosed with breast cancer and to assess if this information need was influenced by variables such as age, level of education, and social class. They interviewed a random sample of 150

women with breast cancer with a mean of 2 - 5 weeks from diagnosis; the interviews took place following hospital admission but prior to surgery. The women ranged in age from 32-84. Researchers recruited a sample of 200 women who had undergone biopsy but whose breast masses were not malignant to provide a control group for the study. All subjects were asked to compare items of information and responses were analyzed using a Thurstone scaling model to develop rank orders. Kendall's coefficient of agreement was used to assess consistency in judgments. No significant differences were found for the ranking of the items between the two groups. Luker et al. perceived information about the likelihood of cure, the spread of the disease and treatment options as the most important items of information at the time of diagnosis for both groups. The other information needs, in order of descending priority, included information about the risk to family, side-effects of treatments, impact on family, self-care, effect on social life, and sexual attractiveness. However, one-way ANOVA revealed significant differences in terms of ranking of information with age. Women less than 40 years of age and women between 40 - 60 years of age rated information pertaining to sexual attractiveness as more important than did women over 60 years of age ($f=3.438$, $p=0.05$). The women over the age of 60 rated information pertaining to their social life as more important than did younger women ($f=4.047$, $p=0.03$). No significant differences were found between the ranking of items in terms of level of education or social class; these findings thereby underscore the need to address age-specific concerns.

Coping Strategies

A descriptive, retrospective study was undertaken by Benedict, Williams, and Baron (1994) to determine the amount of anxiety recalled by women who had benign breast biopsies. Two hundred and thirty-six women from five southern states participated in this study. The mean age of the participants was 52 years. Caucasian women represented 80% of the study group with African American women comprising the remaining 20%. Benedict et al. asked the women to rate their recalled anxiety from

discovery to diagnosis on a 10-point visual analogue scale and to answer a question concerning coping strategies they used to deal with the anxiety. For these women, the mean length of time from discovery to definitive diagnosis was 35 days. No statistically significant relationship was found between the length of time from diagnosis and the amount of anxiety experienced; however, 58% of the women recalled severe amounts of anxiety during this time. Five patterns of coping strategies were identified in qualitative analysis: diversionary, spiritual, interpersonal, hopeful, and avoidance. A diversionary pattern is characterized by attempts to stay physically busy and mentally occupied. Those individuals utilizing an interpersonal pattern sought reassurance and information through sharing and talking with others, while those using a spiritual pattern relinquished the problem to a higher being. A hopeful pattern is characterized as the implementation of active positive thinking; in contrast, individuals using the avoidance pattern block the experience from the mind. Study findings demonstrate that considerable anxiety is experienced during the time between discovery of a breast mass and definitive diagnosis. Benedict et al. therefore suggest that nurses reinforce the need to decrease the time during the diagnostic process, counsel women regarding the anxiety they experience, and present coping strategies such as diversional techniques, prayer, communicating with others, and remaining hopeful.

Treatment Selection

Treatment selection represents the second major focal area in studies on early breast cancer. Once a diagnosis of breast cancer is confirmed, the women are required to make decisions concerning treatment. Several treatment choices are included in this spectrum of alternatives including modified radical mastectomy versus lumpectomy with radiation; preoperative or postoperative adjuvant chemotherapy if on a clinical trial; immediate versus delayed reconstruction; and consultations with other specialists or second opinions. Payne, Sullivan, and Massie (1996) described some additional considerations confronting the patient during this time:

How to adjust to the loss of the breast versus how to adjust to living with a breast that became diseased ("my body turned against me"). How to find the 'best' surgeon; how to find a surgeon I can trust and how to sort through conflicting pieces of information given by different medical professionals, books, journals, friends, and co-workers. . . Information must be collected, collated, weighed, and acted on while a woman is 'numb' or stunned, in 'healthy' or adaptive denial, or terrified, with or without responsible adult family members' or friends' assistance.

Massie and Holland (1991) describe the important roles the surgeon and the nurse play in providing information during this crucial time to assist women in reaching an informed decision. From their clinical experiences with women undergoing mastectomy, the researchers argued that a referral for psychiatric counseling is helpful for women experiencing difficulty in decision-making. One to three sessions were usually found to be sufficient to reduce anxiety.

The current literature concerning treatment selection focuses on the decision-making processes following diagnosis, and the impact of both diagnosis and treatment selection on patients' well-being.

Decision-Making Processes

In my review, I found several studies that concentrated upon decision-making processes utilized by women whose biopsies proved malignant. Pierce (1993) used a grounded theory approach to study the decision-making process that women with early breast cancer employed to select among treatment options. Forty-eight women between the ages of 25 and 90 recently diagnosed with early breast cancer were selected from a major medical center and community physician referrals to serve as the study group. These women participated in open-ended, semi-structured interviews before they declared a choice of treatment. Five concepts influenced their decision-making: perceived salience, decision conflict, information seeking, risk awareness, and deliberation.

For the women in this study, perceived salience overshadowed any consideration of other available options. Perceived salience occurs when a woman is attracted to a

particular alternative based on the information given to her by her physician. Decisional conflict emerges when the decision maker considers more than one option and so is motivated to take or avoid action such as seeking additional information. Decisional conflict occurs when one of three conditions were present: first, when the participant wanted an holistic alternative but was not offered or was discouraged from considering this option; second, when the patient was unable to discriminate between the recommended options yet was required to make a choice; and finally, when one medical treatment option was strongly recommended but did not represent the subject's preferred treatment. The participants described the experience of these conflicts as distressing. Individuals thus took action by seeking information, counsel or support, or avoided conflict by selecting one of the options quickly. They tended to defer to the physician's recommendations to avoid any information with the potential to arouse fear and as well to avoid further conflict.

According to Pierce (1993), information seeking emerged when subjects were unable to discriminate between alternatives. Subjects then experienced a good deal of conflict. The women varied in their preferences for both the type and amount of information sought. Some subjects read the material themselves while others asked relatives or friends to tell them what they had read or heard. Supportive and consistent information reduced conflict. Low information seekers found information of little value in making a choice. They avoided further information once they had chosen a particular course of action. They varied in the degree to which they avoided risks or were willing to take risks. The majority tended to avoid the term "risk" in favor of the term "safety"; however, no consensus existed among the participants about which of the procedures was more risky or more safe. Those individuals experiencing incidence of conflict required more time for deliberation because they sought additional information. Participants who divided their decision problems into smaller segments requested more volume and variety of information than those participants who did not.

Pierce (1993) identified three patterns of decision-making, listed in order of increasing complexity: deferring, delaying, and deliberating. Forty-one percent of the participants used the deferring style which is characterized by a decision to choose a treatment that is perceived to be safe, easy, and quick. These women frequently selected the treatment option recommended by the physician, thereby deferring to his or her expert judgment. The women using this style of decision-making were older, with a mean age of 56 years. Women who used the delaying style comprised 44% of the sample. These individuals vacillated between the alternatives until they perceived a difference between options or until a clear preference between options emerged. Those individuals who utilized the delaying style had a mean age of 45 years and thus younger than the deferrers. Women using a deliberative style were closer in age to the second group, with a mean age of 40. Representing only 15% of the total study group, individuals that employed the deliberative style had specific strategies, considered risks, and expressed confidence about their decision-making process. However, these women also expressed uncertainty about the outcome of their choice, and felt they might later regret the choices they made. Through his identification of the varied styles used in the decision-making process by this population, Pierce identified the need for individualized interventions and support for women making the difficult decisions associated with treatment for early breast cancer.

The findings of Pierce's (1993) grounded theory study differed from previous findings concerning decision making in treatment. Previous researchers held that while some women needed special counseling for decision making, most women were able to make a choice regarding treatment once options were explained (Sinsheimer & Holland, 1987; Owens, Ashcroft, & Leinster, 1987). In a study by Ward, Heidrich, and Wolberg (1989), none of the 22 women who had chosen between modified radical mastectomy and lumpectomy with radiation wanted the decision to be made without their involvement, although half of them shared the decision with someone else such as a physician, spouse, or family member. The majority of the women (64%) stated that their distress at the time

of the decision did not impair their thinking; 77% held that they had adequate time to make a decision. Study participants identified "people" information sources -- such as physicians, nurses, family, and friends -- as more important than impersonal resources such as literature and videos. Ninety-five percent agreed that they had adequate information on which to base their decision. These women, however, had received information which included an unbiased surgeon's description of each procedure, viewing of a videotape, reading of a surgical options comparison sheet, and a review and discussion of information with the nurse.

Several studies have attempted to determine the factors women consider when selecting treatment. The studies by Ward et al. (1989) and Wilson, Hart, and Dawes (1988) argued that women who chose modified radical mastectomy over radiation therapy expressed more concern about efficacy and side effects, inconvenience, or disruption by radiation than about the factors relating to the surgical procedure. These women were also concerned with the uncertainty produced by the possibility they might require mastectomy at a later time. In contrast, women who chose lumpectomy with radiation were significantly younger. These individuals' concerns were based primarily upon concerns of bodily integrity and, to a lesser extent, on the opinions of physicians or significant others, as well as other individuals' negative experiences with breast cancer surgery. They gave a significantly higher importance to survival rates for the two types of surgery, concerns about losing a breast, and the feasibility of breast reconstruction than those women who chose modified radical mastectomy.

Decision-Making And Well-Being

Hughes (1993) undertook an exploratory study to understand the impact of diagnosis and type of treatment on patients' physical state and psychosocial well-being. He utilized a convenience sample of 52 women (ages 36 to 62) newly diagnosed with Stage I or Stage II breast cancer; each woman had undergone modified radical mastectomy or lumpectomy with radiation. Each of the participants completed

instruments designed to measure the dependent variables of uncertainty (Mishel Uncertainty In Illness-Community Form, alpha coefficient .90); quality of life (Quality of Life, Cancer II Version Instrument, alpha coefficient 0.95); functional status (Medical Outcomes Study General Health Survey-Short Form, coefficient alpha .81-.88). Reaction to diagnosis was also measured, as well as the degree to which the diagnosis elicited confronting or optimistic responses (Reaction to the Diagnosis of Cancer Questionnaire (RDCQ), alpha coefficient .89). These responses were measured at the time of diagnosis but before treatment selection, and again 8 weeks after surgery. Mean score results indicated that perceptual uncertainty and aspects of functional status (physical, social, and role functioning) declined over the initial course of treatment but quality of life was unaffected ($p < .05$) for all participants, whether their treatment was modified radical mastectomy or lumpectomy with radiation. Similarly, no correlation existed between the type of breast cancer treatment and patients' uncertainty, quality of life, and functional status at eight weeks following surgery ($p > .05$). Mastectomy and lumpectomy patients also displayed no significant differences in scores for mental health, pain, and overall health perceptions ($p > .05$), nor was there a marked difference in mean reaction to diagnosis scores ($p > .05$). Mean scores on the distress and confronting subscales of the RDCQ were unrelated to type of treatment, and thus indicated that both groups experienced similar amounts of distress at the time of diagnosis.

Mastectomy And Recovery

Although most of the studies in the literature concerning breast cancer have focused on women with early breast cancer, very few studies have addressed mastectomy and recovery. Extant studies, dating to the 1950s, characterize this period as one of grief reaction. Researchers have held that grief reactions render women undergoing mastectomy unable or unwilling to participate in research (Fawzy et al., 1994; Frank-Stomberg, 1989; Hughes, 1993). In the sole study describing this period, Payne, Sullivan, and Massie (1996) argued that women believed that the preoperative period

would be the most stressful time during the perioperative period; however, the same researchers later reported that waiting for the pathology report after surgery was the most stressful time during this period. The lack of comprehensive research addressing this period points to a corresponding lack in understanding the totality of patient needs that accompany breast cancer diagnosis and treatment.

The recent studies uncovered in my review of literature that dealt with mastectomy and its recovery focused on patient-provider communication, nursing care in recovery, psychological distress, body image, and social support.

Patient-Provider Communication

Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, and Martin (1993) performed a quantitative study of communication at a cancer center, with a study group comprising 97 women between the ages of 25 -79 with Stage I or II breast cancer. The researchers sought to describe the prevalence and types of patient-provider communication deficiencies and to identify patients who were most likely to report problems with communication. They evaluated patient-reported communication problems before postoperative therapy (which comprised either radiation therapy or chemotherapy) and the level of psychological distress experienced by individual patients three months after treatment.

Demographic and clinical data for the study were obtained from medical records. Three coping style indices were administered prior to the initiation of the study: the Fighting Spirit Subscale of the Mental Adjustment to Cancer Scale (alpha coefficient =0.84), to measure cognitive coping style; the Rathus Assertiveness Schedule (8-week test-retest reliability, 0.78, split-half reliability, 0.77) to measure the level of assertiveness skills; and the Miller Behavioral Style Scale (MBSS), to measure information-seeking coping versus avoidance/distraction coping (coefficient alpha>0.8). The researchers evaluated patient-provider communication before the initiation of postoperative therapy by using the Medical Interaction (MI) factor (coefficient alpha=0.87) of the Cancer

Rehabilitation Evaluation System (CARES). The Profile of Mood States (POMS) was used to measure mood states (coefficient alpha=0.87).

Eighty-four percent of the participants identified a minimum of one of 11 potential communication problems. Participants most frequently reported problems in the following areas: difficulty understanding physicians (49.5%), difficulty expressing feelings (46.3%), desire for more control over the medical team (45.3%), and difficulty asking physicians questions (42.6%). No demographic or clinical variables -- age, race, marital status, stage of breast cancer, type of surgery, chemotherapy, radiation therapy, hormonal therapy, and comorbidity -- were found to have a significant correlation with communication. Communication problems experienced before postoperative therapy were associated positively with anxiety ($r=0.31$, $p=0.003$), confusion ($r=0.35$, $p=0.001$), depression ($r=0.28$, $p=0.007$), and anger ($r=0.35$, $p=0.005$). Study findings also pointed to a strong positive association between communication problems and total mood disturbance as measured before postoperative therapy ($r=0.35$, $p=0.001$) and at the three month follow-up ($r=0.29$, $p=0.005$). The solitary subscale significantly correlated with the total mood disturbance ($r=0.32$, $p=0.001$) was patients' difficulty in communicating with the medical team. From these findings, Lerman et al. (1993) identified the population of breast cancer patients most likely to report communication problems are those who experience the most distress and lack of hope and least measure of optimism. The researchers, then, argued that women's perceptions of their communication capabilities with their providers strongly affects their overall psychological adjustment to the disease process. This central finding holds significant implications for those seeking to improve efficacy in managed care treatment of breast cancer patients.

Nursing Care In Recovery

Palsson and Norberg's (1995) report represents the only study in existing literature to focus specifically on nursing care and recovery from mastectomy. Concerned about the lack of research on nursing interventions during the initial phase of

breast cancer recovery, the researchers attempted to develop and implement interventions directed at the psychosocial needs of newly-diagnosed breast cancer patients and, further, to describe the breast cancer patient's experiences with said interventions. This research study centered upon an initial project wherein both the content and organization of care were altered from existing procedural standards in a surgical ward of a general hospital and in a primary health care area in the Southeast of Sweden. The changes in the content of care included training for hospital and district nurses; these alterations were described as "training in the nursing care and medical treatment of breast cancer patients, psychological reactions, coping strategies, and crisis intervention"(p. 278). The changes in the organization of care included decreased waiting times for test results and the provision of emotional support during diagnosis, hospital care, and home rehabilitation.

Palsson and Norberg (1995) interviewed twenty-six women between the ages of 35 and 69 who had been diagnosed with early breast cancer (Stage I and II) within the previous 6 months. Three themes were identified; these focused upon receiving organized care, regaining a sense of control, and contemplating the future. Patients reported changes in the organization of care as primarily positive. For example, women felt it important to obtain the results of tests on the same day as the test was performed, describing the uncertainty as difficult to bear. The continuity of staff engendered feelings of safety and security and reduced feelings of abandonment after the hospital stay. Participants reported feelings of certainty and security in connection with the nurses' information about nursing care while relating feelings of uncertainty and insecurity to insufficient information from physicians. A "confirming relationship" was experienced when nurses and physicians showed understanding. This relationship was characterized by the care providers' use of positive feedback, demonstrations of interest and respect for the woman as a human being, and utilization of a "permissive tone of conversation", a mode wherein women felt free to ask questions and show feelings. Participants reported that disconfirming relationships were sometimes experienced in connection with

physicians' follow-up examinations and led to feelings of disappointment at being regarded as an object. Women also reported that access to hospital nurses and district nurses reduced the anxiety associated with the disease; their ability to share the varying illness-related difficulties with these professionals further reduced the burden on their husbands and families. The district nurse was described as a central support for the women during rehabilitation.

Participants reported that establishing relationships with other women newly diagnosed with breast cancer as an important external source of emotional support. These relationships were described as useful in handling feelings of helplessness. The bonds also alleviated sensations of isolation, as hearing that others had reacted in the same way fostered a sense of communality. Finally, these women remained in contact with one another at the end of the study, thus extending the benefits of this resource. Similar findings were noted from a survey designed to identify the reasons women attend breast cancer support groups following mastectomy (Stevenson & Coles, 1993). In addition, the women identified that their contacts in local breast cancer societies provided a great deal of empathy and served as visible evidence that problems and fears associated with breast cancer could be overcome. Participants considered the support of husbands, sisters, children, friends, and/or colleagues to be an important component in their overall coping strategies. Conversely, women perceived family and friends' inability or difficulty in expressing support as a burden.

Some of the women stated that their future held hope and promise, and held that having cancer was not a completely negative experience. Several positive outcomes from the disease process were identified: increased cohesiveness in the family unit; increased openness in communication with others; extensions of assistance from sources outside the primary family circle; and a moderate to low impact on everyday life. For these participants, the immediate present and near future appeared more important than before the illness. The women appeared to do things they wanted to do and focused more on

themselves. However, some interviewees could not relax from thoughts about their terrible situation and told about uncertainty in contact with other people and fear that the loss of the breast could be visible. Uncertainty about the future involved fear of recurrence, further treatment, and death. Some of the women focused their fear on physical symptoms and said that they watched every bodily change.

Psychological Functioning

The experience of breast cancer recovery is characterized by periods of emotional distress. About 25% of women with breast cancer develop clinically significant and persistent anxiety and depression in the first 2 years after diagnosis (Dean, 1988). Several recent studies were identified in the literature which addressed psychological functioning.

A study to identify the potential risk factors for psychological distress among 205 women with newly diagnosed breast cancer was conducted by Maunsell, Brisson, and Deschenes (1992). The population of study participants came from one hospital in an area over the course of a year. Interviews were conducted at 3 and 18 months after initial surgical treatment. Standardized instruments were administered. The proportions of women with high psychological distress increased regularly with the number of stressful life events reported for the five years preceding diagnosis. A history of depression before diagnosis also showed a strong association with psychological distress at three months and at 18 months. Age, education, and marital status were not associated with the levels of psychological distress experienced. The stage at initial diagnosis also was not associated with psychological distress at three months but it was at 18 months.

A descriptive correlational study with interviews was undertaken by Wong and Bramwell (1992) to identify the levels of uncertainty and anxiety in 25 women between the ages of 33 and 76 following partial or complete mastectomy for breast cancer and to examine their responses to breast cancer during the early rehabilitative phase of surgery. The participants completed a demographic data form, standardized instruments, and a

semistructured interview schedule 1-2 days before and 1-2 weeks after hospital discharge. The levels of anxiety were higher before discharge than after discharge as were the levels of uncertainty; however, these differences were not significant. The correlation between uncertainty and anxiety at discharge was moderate and significant ($r=0.42$, $p=0.02$). The results of the first interview were not reported. At the time of the second interview, twelve regarded the experience of breast cancer as one of uncertainty. Twenty-two of the women experienced some degree of anxiety. Uncertainties regarding chemotherapy treatments were mentioned most frequently (12), followed by recurrence (7), and the meaning of physical symptoms (5). Nineteen of the informants identified more than one source of anxiety. There were sources of anxiety that did not reflect the theme of uncertainty. These included body image changes (4), physical discomfort with arm pain and swelling (2), and the social stigma of having cancer (3).

For these women, the initial appraisal of threat or shock and disbelief was described as gradually changing over time to an attitude of uncertainty or calm acceptance. Subjects reported that their lack of knowledge about breast cancer, poor comprehension of additional treatment effects, and fears of recurrence were sources of anxiety that became more intense after discharge but then decreased. Family support was pinpointed as essential in helping them cope with the uncertainty of breast cancer. The need for follow up after hospital discharge was noted. During the home interview, many informants asked numerous questions regarding the etiology and progression of cancer. They also asked about ways in which they could change their diets, exercise habits, and general life style patterns to prevent recurrences. In addition, they reinforced the importance of instructing patients on arm exercises, skin care, and choosing prostheses. The need to explain events that had already occurred or were being experienced was cited.

A study of a representative community sample of 274 women with breast cancer was undertaken by Vinokur, Threatt, Vinokur-Kaplan, and Satariano (1990) over a year

to examine changes in physical and mental health functioning and the factors that predicted or facilitated the recovery process. The women were 40 years of age or older. The participants completed questionnaires some of which were standardized or had internal reliability estimates of $>.80$. Comparison using MANOVA of the outcomes at 4 and 10 months after diagnosis indicated significant and consistent improvement in physical functioning; however, there was an absence of any improvement in indicators of mental health and well-being ($P<0.03$). Cross sectional analysis identified that physical impairment at four months was a significant predictor of deteriorating mental health at time 10 months ($P<0.01$). Younger age exacerbated the impact of impairment on mental health ($P<0.01$). The more physically impaired younger patients experienced significantly greater deterioration in their mental health and well-being than similarly impaired older patients. Older women experienced more limitations in activity than younger women ($P<0.05$). An additional finding was that patients interpreted the threat of breast cancer on the basis of various physical symptoms and impairments and not necessarily the stage of disease. This was correlated by the researchers with the level of information received or the use of psychological processes such as denial and an illusion of control by the women which served to distort the meaning of the objective threat.

The researchers discussed that it was difficult to predict the length of time that elapsed before women with breast cancer returned to the level of physical and psychological functioning of women of the same age without the disease. In one of their long term follow-up studies on a screening population, Vinokur, Threath, Caplan, & Zimmerman (1989) found that those who survived the disease for 5 years or longer exhibited the same levels of adjustment as a disease-free control group. Breast cancer patients who had their diagnoses less than five years earlier did not attain the level of adjustment and functioning characteristics of their asymptomatic counterparts. They concluded that the process to recovery was a long one.

More recently, Trief and Donohue-Smith (1996) surveyed women diagnosed and treated at a regional breast care center within the previous three years. They sought to describe the women's level of emotional distress; the frequency with which they sought some form of counseling or felt it would have been helpful; and the time in the course of their treatment they felt they most needed counseling. The response rate for the mailed questionnaire was 65% with 151 out of 233 surveys returned. Data were not provided concerning the characteristics of the nonrespondents. Overall, the mean age of the respondents was 58.1 years (range 27-93). Of the participants, 62% were married, 41% had a positive family history of breast cancer, 49% had a modified radical mastectomy, 54% had a lumpectomy, 52% underwent radiation therapy, 31% underwent chemotherapy, and 48% had taken tamoxifen.

Several findings were reported in this study. Younger women (<54 years) reported more distress overall with 51.9% of younger women reporting a great deal of anxiety, depression, or anger as compared with 16.2% of older women. There were no significant differences found in the level of reported distress when women in different marital status groups were compared. There were no significant differences found between mothers with younger children and other women on reports of emotional distress. High distress was not uniquely associated with lumpectomy, mastectomy, radiation, or tamoxifen but was significantly correlated with chemotherapy treatment. Of those who were identified as having a family member with breast cancer, 42% reported high distress versus 29% of those without a family member with breast cancer. In addition, the majority of the respondents did not feel it necessary to seek formal counseling from either a professional counselor (66%), volunteer counselor (57%), or support group (53%). A sizable minority had sought counseling with either a professional counselor (15%), a volunteer counselor (28%), or a support group (25%). Other women reported that they did not seek counseling but felt it would have been helpful (professional counselor (19%), volunteer counselor (14%), or support group

(22%)). Of the participants, 60% responded that they had received help from a friend who had breast cancer. Other sources of support were identified but specific frequencies were not reported. These included physicians, nurses, family, and clergy. When asked at which time counseling if it were available was most needed, 41% of the respondents indicated the time of diagnosis, 21% identified the need during treatment, 14% highlighted the time period after treatment, and 24% responded that counseling was not needed. For all three time periods for possible counseling intervention (time of diagnosis, during treatment, and after treatment), younger women (<54 years) were twice as likely to identify a need for counseling. Finally, women who underwent chemotherapy identified counseling needs significantly more often during treatment ($p=.003$) and after treatment ($p=.001$) than women who did not receive chemotherapy.

Body Image

Body image is described as the physical picture one has of oneself. It includes the attitudes and perceptions regarding one's physical appearance, state of health, skills, and sexuality. Body image is an integral component of one's self concept. One's self concept is the total perception an individual holds of self, who one believes one is, how one believes one looks, and how one feels about one's self. Influenced by one's physical, personal, social, and moral-ethical self, self-concept influences the way an individual perceives the world or interacts with it (Roid & Fitts, 1988).

A review of body image studies by Mock (1993) summarized the findings of past body image studies on women with breast surgery. A negative impact of mastectomy on body image in pre- and postmastectomy studies was identified. Women treated with breast conservation consistently reported more positive feelings and greater satisfaction with their bodies than woman treated with mastectomy. Fears of recurrence and death were less intense after breast-conserving treatment than after mastectomy. Breast conservation groups showed less sexual dysfunction, earlier resumption of sexual activities, and greater sexual satisfaction. Breast construction was viewed by women as

restoring feelings of femininity, wholeness, and normalcy. No differences in psychological morbidity were noted in women who had immediate reconstruction and women who had delayed reconstruction.

Concerned with methodological inconsistencies in the studies on body image in breast cancer, Mock (1993) undertook a study to describe body image differences in women with conservative treatment, modified radical mastectomy, immediate breast reconstruction, and delayed breast reconstruction utilizing random sampling of a population of breast cancer patients and standardized instruments of measurement. Data were collected by mailed questionnaires using self-report instruments. The response rate was 57% with 257 women completing the questionnaires. The minimum number of participants (45) in each of the four groups was able to be attained.

There were no significant differences among the groups concerning body image and self concept; however, body image scores were lower than norms and self concept scores were higher than norms. A significant difference in body satisfaction among groups was noted. Scheffe's post hoc analysis indicated that the conservative surgery group had significantly higher body satisfaction scores than either the mastectomy group or the immediate reconstruction group ($F=3.74$, $p<.01$). The delayed reconstruction group had higher body satisfaction scores than the immediate reconstruction group but the difference was not significant.

A group of researchers (Schover, Yetman, Tuason, Meisler, Esselstyn, Hermann, Grundfest-Broniatowski, & Dowden, 1995) conducted a mailed questionnaire survey to compare the effects of partial mastectomy and immediate breast reconstruction following mastectomy on psychosocial adjustment, body image, and sexuality four years after their surgeries. Questionnaires were sent to 499 women treated at a cancer clinic. The overall response rate was low at 44%. Questionnaires were returned by 218 women who had partial mastectomies (47%) and 146 were returned by women who had breast reconstructions (42%). The average age of the women was 54 years and 95% were white

women. Standardized instruments were utilized. Fewer than 20% of the women reported poor adjustment on the domains measured. The two groups did not differ in overall psychosocial adjustment to illness, body image, or satisfaction with relationships or sexual life. There was a reported specific advantage of partial mastectomy over breast reconstruction in terms of maintaining pleasure and frequency of breast caressing during sexual activity. Breast caressing decreased for 40% of partial mastectomy clients and for 69% of breast reconstruction clients. Pleasure with breast caress had decreased since cancer treatment for 44% of the women with partial mastectomy and for 83% of women with breast reconstruction ($P<.001$). Younger women worried more often about a recurrence of their cancer ($r=-0.31$, $P<0.001$). Relationship happiness and the impact of cancer on the relationship did not differ with age. Expression of affection and overall sexual satisfaction did not differ across age groups. There were significant relationships between younger age and more frequent sexual activity ($r=0.28$, $P<0.001$) and sexual desire ($r=0.35$, $P<0.001$). Women who had undergone chemotherapy had more sexual dysfunction ($P=0.0001$), poorer body image ($P=.007$), and more psychological distress ($P=0.0001$). They worried more about their cancer recurring ($P=0.001$); had sex less frequently ($P=0.032$); tended to desire sex less frequently ($P=0.032$), and had more dyspareunia ($P<0.001$). Hormonal therapy and radiation therapy did not measurably affect quality of life. Factors predictive of greater psychosocial distress included a troubled marriage, a poor body image, sexual dissatisfaction, less education, and treatment with chemotherapy. The researcher concluded that local treatment had little psychosexual impact whereas chemotherapy was associated with long term impairments.

Another group of researchers (Schain, d'Angelo, Dunn, Lichter, & Pierce, 1994) carried out a study to examine the psychological comfort level of women having lumpectomy with radiation therapy versus modified radical mastectomy. In this study, 142 women participated in a clinical trial that randomized patients to the two types of treatment. Standardized psychological assessments were administered before

randomization and at 6, 12, and 24 months after surgery. At six months, women who underwent modified radical mastectomy reported significantly less control over events in their lives ($P=.003$) than women who underwent lumpectomy with radiation therapy. The women with modified radical mastectomies had more problems with sexual relations ($P=.021$) at six months but the differences diminished over the two years. The researchers concluded that breast conservation surgery protects women's perception of their bodies but did not contribute to a positive sexual adjustment over time.

Social Support

Eleven studies were reviewed by Nelles, McCaffrey, Blanchard, and Ruckdeschel (1991) to examine the role of social support in coping among breast cancer patients and their families. Demographic factors, stage of disease and treatment, the types of social support patients received and the methods of measurement were examined. Methodological inconsistencies were noted in each of the eleven studies. The researchers concluded that they were not able to evaluate the relationship between stages of the disease process and the type of social support best suited to the individual patient and her family. The need to clarify the types and measurement of social support and to address the effect of social support on patients' adjustment and survival were noted.

Concerned about the problems of low validity and low reliability in studies on coping in breast cancer, Jarrett, Ramirez, Richards, and Weinman (1992) undertook a study to develop an instrument to measure coping in breast cancer and to describe the cognitive and behavioral coping strategies used by women following primary treatment for early breast cancer. The method of sampling was not described. Women (153) completed a standardized Ways of Coping questionnaire and participated in an interview using a new instrument, the Faith Courtauld Coping Schedule. Demographic data concerning the sample were not presented.

Frequency analysis of the Ways of Coping questionnaire showed that the distribution of the questionnaire scores was skewed. Over 70% of women identified 9 of

the 53 ways of coping as "sometimes" or "a lot". These were grouped into 4 strategies: cognitive avoidance, positive reappraisal of their illness and life, control of emotional expression, and concentration on aspects of the disease over which they have some control. Over 70% of the women identified 10 of the 53 items as "never used" or only "occasionally used". These were grouped into the following categories: wishful thinking, social avoidance, and blaming of self and others. Nine women identified 35 of the 53 items as "never used". The items they reported using consisted mainly of strategies of cognitive avoidance such as "I try to forget the whole thing" and positive reappraisal such as "I came out of the experience better than when I went in". Factor analysis using orthogonal rotation identified that the highest percentage of variation in scores (7%) was related to the two factors of seeking social support and wishful thinking. The variance explained by all of the remaining 17 factors was 35.6%. Because only 42.6% of the variance was explained by the factors, the researchers concluded that the factors which had been derived from populations with other diseases were not applicable in assessing coping in women with early breast cancer. Other factors were involved.

The frequency analysis of the Faith Courtauld Coping Schedule identified that 65% of the women described fear in relation to their diagnosis and treatment. Seventy-five percent expressed uncertainty regarding their prognosis. Ninety percent used some form of cognitive avoidance in relation to their cancer and 65% described a positive reappraisal of their illness or life in general. Only a minority of women (between 6%-8%) included the use of humor and behavioral attempts to facilitate recovery such as adopting a special diet, religion and prayer, social avoidance, or seeking information. Less than 5% of the women said that they did not consider their prognosis at all and very few believed that they would suffer relapses. Only 20% of the women made statements regarding their perceived control over the disease. Twelve percent of the women gave conflicting responses. They expressed the belief that they were cured yet they expressed uncertainty about their prognosis. Ten women utilized three different coping responses

during their interview. These responses included avoidance, positive reappraisal, and expressions of fear regarding the implications of the diagnosis. A larger group of 21 women utilized avoidance, positive reappraisal, fear of implications of both their diagnosis and treatment, as well as uncertainty regarding their prognosis. When the researchers divided the women into three groups according to their time since diagnosis, there were no differences in the median number of responses made by the women in the three groups ($p > .05$).

Roberts, Cox, Shannon, and Wells (1994) explored the effects of perceived social support from friends, family, and spouses on the psychological adjustment of 135 newly diagnosed breast cancer patients. The participants completed three instruments which included: the Social Support Questionnaire (reliability alpha coefficient .90) to measure the degree and source of perceived social support; the Standard Checklist 90 Revised (SCL-90R) to evaluate psychological symptomatic distress; and the Social Desirability Scale ($r = .70$) to measure social desirability. When the effect of social desirability was controlled, the correlations between social support and psychological distress dropped from $-.43$ to $-.10$ with the exception of the correlation between spouse support and psychological distress of married women. This correlation dropped from $-.27$ to $-.18$ which reflected a weak but significant relationship ($p = .05$) between higher spousal support and fewer symptoms of distress. For single women who reported less distress in the face of good support by friends, the correlation dropped from $.41$ to $-.10$. The researchers had two interpretations of these findings. First, several of the women placed the best face on their situation consciously or unconsciously to minimize their distress and rated the support of others highly. Second, these women had strong coping mechanisms and good premorbid psychological adjustment that protected them from high levels of distress when diagnosed with breast cancer. The researchers concluded that characteristics of the person rather than the situation underlie the apparent relationship between social support and adjustment to illness. They identified ego strengths and past

psychological functioning as better predictors of patient adaptation to disease than perceived social support. Cognitive and behavioral coping responses to the diagnosis were also described as correlated with individual differences in psychological adaptation by Fawzy, et al. (1994).

Suominen, Leino-Kilpi, and Laippala (1995) studied via questionnaire the support provided for breast cancer patients in Finland and the evaluation of this support by patients and nurses. Patients were asked to answer questions concerning personal data and to evaluate their own treatment and guidance that they had received in terms of information, support provided before, during, and after their hospitalization, and teaching of new skills. Of a random sample of 140 women between the ages of 32 to 78, 78% of them responded to the mailed questionnaire. Questionnaires were mailed to 128 ward nurses and 48 nurses working in outpatient areas working in one university hospital and six area hospitals. Response rates were 70% (89) for the ward nurses and 75% (36) for the nurses working in outpatient areas.

Both patients (58%) and nurses (63%) reported that patient support was insufficient before hospitalization. The nurses felt that patients primarily needed social support following the surgery whereas patients reported that social support was most beneficial before the operation. One-third of the patients felt that they could best help themselves by relying on their own resources such as a positive attitude and personality. Only 3% of nurses shared this belief. More than one-third of patients felt that they received insufficient support during hospitalization. Patients felt that nurses did not talk to them, share experiences with them, listen to them, or treat them on an individual basis. Both patients and nurses thought that nurses were preoccupied with their work routines. Nurses stated that they could not respond with the appropriate type of support for the patients because they felt inadequately prepared to recognize psychological or social distress. In addition, nurses attached importance to the connection between the patient's recovery and the support received from her relatives. Patients perceived that good

recovery was dependent on the comforting support of nurses. Social support was not included in the four most important factors for good recovery. It was more important to patients to have nurses who had a positive attitude toward them and behaved in a friendly manner.

Analysis And Critique

This study's review of recent study findings concerning survival in breast cancer bears significant implications for the young adult female population in the United States. Sariego et al. (1995) suggest that the poor prognosis in young adult women with breast cancer is correlated with difficulties associated with early detection and diagnosis, rather than with the virulence of the tumor itself (as previously hypothesized). This information emerges at a time when we possess increasing evidence regarding the relation between psychological intervention in early breast cancer treatment and these women's long term survival. Studies support the need for early detection and diagnosis in young adult women and reinforce the importance of psychological intervention in early treatment. These developments are juxtaposed against widespread professional and public concern about the quality of health care, a concern that continues to mushroom as hospitals continue the transition into managed care. This coalescing anxiety crystallizes in mandates for health care systems to regain their patient-focus by addressing individual client needs.

At the same time, the review of literature reflects the limitations of existing knowledge concerning the needs of specific sub-groups of women undergoing treatment for early breast cancer. Young adult women comprise a major constituency that has been abysmally underrepresented as research subjects. Studies have focused on the majority of breast cancer patients: women who are older and who receive care at large cancer treatment facilities. The women identified in these studies as "younger" are in their forties. In addition, although the use of valid and reliable instruments has increased the total body of knowledge, researchers have primarily focused upon only specific stages of

the disease process. While information is available regarding individual stages (i.e. the discovery of breast cancer, treatment selection, and mastectomy and its recovery), a compelling need exists for a comprehensive focus with an emphasis on process. If we are truly to acquire a complete scope of insights regarding the needs of young adult women undergoing treatment for early breast cancer, researchers must refocus studies to delineate the individual and shared concerns of these women at the outset of the process, alterations in these concerns over time, and the primary and secondary methods by which they handle their concerns.

CHAPTER THREE

METHODOLOGY

While a review of extant literature does not link the unique needs of young adult women as they experience treatment for early breast cancer, it does promote the need to develop a holistic description of their experiences if health care providers are to fully understand the meaning of the women's experiences. Knowledge of how young adult women make sense of their lives, what they experience, how they interpret their experiences, and how they structure their worlds are critical points in fostering a comprehensive understanding of this population's concerns and health care needs. This compelling need for holistic description lends itself to qualitative case study methodology.

In this chapter, I present the qualitative multicase study research design utilized in this study. I describe the method of data collection and the analysis of data. I incorporated the safeguards utilized in the research design to address the ethical considerations for assuring the protection of the participants. Finally, I describe strategies utilized in this study to assure the verification of data.

Research Design

While several descriptions of qualitative case study research are identified in the literature, qualitative case study research is described as a process that can provide an intensive, holistic description and systematic analysis of a phenomenon under study as the phenomenon unfolds over time (Merriam, 1988; Miles & Huberman, 1994). As described by Lincoln and Guba (1990), qualitative case study research examines an instance of action in which the properties of the class to which the class belongs are revealed. Qualitative case study designs are differentiated from other research designs in

that they deal with "interpretation in context" to uncover the interaction of significant factors characteristic of the phenomenon (Merriam, 1988, p. 10).

According to Merriam (1988) the central goal of qualitative case study researchers is to understand the meaning of an experience; accordingly, their main concern is discovering how all parts work together to form a whole rather than examining component parts or variables. Becker (1990) contends the purpose of qualitative case study is to arrive at a comprehensive understanding of the phenomenon under study, and to develop general theoretical statements about regularities in its social structure and process. As presented by Patton in 1985, the purpose of qualitative case study research is:

to understand situations in their uniqueness as part of a particular context and the interactions there. This understanding is an end in itself, so that it is not attempting to predict what may happen in the future necessarily, but to understand the nature of that setting - what it means for participants to be in that setting, what their lives are like, what's going on for them, what their meanings are, what the world looks like in that particular setting - and in the analysis to be able to communicate that faithfully to others who are interested in that setting.

Several elements characterize qualitative case study research. First, qualitative case study research is described as particularistic, as it focuses on a specific situation or phenomenon even though it could illuminate a general problem. This type of research is also descriptive, providing rich, thick description and analysis of a phenomenon. "Thick description" is an anthropological term that refers to complete, literal illustration or interpretation of the meaning of the data in terms of cultural, social, and psychological and other influences (Merriam, 1988). Qualitative data consists of detailed descriptions of situations, events, people, interactions, and observed behaviors; direct quotations from

people about their experiences, attitudes, beliefs, and thoughts; and excerpts or passages from documents such as correspondence, records, and case histories. Thirdly, qualitative case study research is heuristic; it illuminates the reader's understanding of that which is studied. New meaning can then be discovered, as case studies provide new insights into the phenomenon. In its final facet, qualitative case study research is inductive. The data is grounded in the context itself and results in the discovery of new relationships, concepts, and understanding. Accordingly, the methods rely heavily on interviews, observations, and documents. The interviews are described as conversations that seek to obtain a special kind of information. Patton (1990) describes this special purpose as an effort to gain the perspective of the person being interviewed; the selection of informants is therefore purposeful, i.e. the researcher selects those individuals he/she considers to be the most appropriate for exploring the research questions. Since the key to the data is the type of question asked, these questions -- aligned with the needs of the study -- determine whether interviews adopt a structured, semi-structured, or unstructured form. While the fluidity and variety of alternatives shape the eclectic nature of the data analysis process, all data analysis involves both category development and the comparison and contrast of data in a systematic way (Creswell, 1994). The researcher observes possibilities and seeks contrary or alternative explanations for suspended assumptions and the findings. The knowledge researchers and participants gain from qualitative case study research is different from knowledge gained from other research methods; the former method produces more particular and contextual knowledge, developed more by researcher, participant, and reader interpretation and based more on reference populations determined by the reader (Merriam, 1988).

Qualitative case study research is particularly suited to situations where it is impossible to separate the phenomenon's variables from their context (Patton, 1990; Yin, 1991). I therefore selected qualitative multicase study as the specific methodology for this study. The rich, thick description of concerns across several cases, and how these

concerns are qualified by local conditions, provides a compelling, advanced level of sophisticated description and explanation (Merriam, 1988; Miles & Huberman, 1994).

Data Collection

As described by Creswell (1994), data collection activity encompasses gaining entrance to the participants; selecting participants; setting description; developing strategies for data collection; and recording interview information.

Entrée

Since the American Cancer Society administers the Reach to Recovery Program, my entrance to the participants in this study was made possible through the support of the Field Services Director of the American Cancer Society of the southern California community in which this study is set. Reach to Recovery is a rehabilitation program designed to help women with breast cancer meet the physical, emotional, and cosmetic needs related to their disease and/or treatment. The program also provides information and support to loved ones and friends. Reach to Recovery is described by the American Cancer Society as a forum wherein women reach out to share and support one another in a time of need. At the outset of this study, I provided information regarding its purpose in tandem with such informed consent issues as benefits and risks to the participants. In response, the agency participated in the selection of participants for the study.

Selection of participants

The five individuals who agreed and were selected to participate in this study met the four original criteria for participant selection: they were of young adult age, 20 - 39; had undergone mastectomy for early breast cancer (Stage I or II) between January and March, 1996; were able to speak, read, and understand English; and were willing to describe concerns experienced in their recovery from mastectomy. During the selection phase, chemotherapy was found to be extending the recovery of possible participants and several individuals in the participant pool stated they were too ill to participate. I therefore employed theoretical sampling to select participants whom I thought could best

provide the requested information. I chose to interview women who had completed their chemotherapy treatments within the past two to three weeks or who were currently in their last cycle of chemotherapeutic drugs. In line with this selection criteria, the five young adult women selected for the study had undergone their mastectomies within the past four to five months. I did not include membership in a managed care program as part of the selection criteria, as I did not want to limit the number of possible participants. I further hypothesized that the treatment philosophy governing managed care was widespread in this southern California community. The central premise of this philosophy is based upon obtaining maximum value through an emphasis on health promotion (prevention) and the treatment of individuals in the lowest possible cost setting (Sovie, 1995).

The following procedure was used to gain access to the informants in this study. A volunteer approved by the Program Coordinator and Field Services Director of the Agency used the agency's data bank to identify the names of women who appeared to meet the criteria for the study and then compiled a preliminary list of 23 potential participants. The volunteer was unable to contact 14 of the women, an inability ascribed to wrong numbers, numbers no longer in service, and calls not answered. The volunteer successfully reached the remaining women and informed them of the study, utilizing a script I had developed. The volunteer related to me that each of the women she contacted voiced a desire to help others in similar circumstance; however, health and logistical considerations prevented several individuals from participating in the study. One potential participant had just completed chemotherapy treatment and was returning to work in another state the day after the call. She underwent her surgery and treatment in the area so that her mother could help her. Others refused because they did not feel well enough to participate; two women canceled scheduled interviews for this reason. If a woman voiced an interest in participating, she was asked if her number could be given to me for follow up purposes. If permission was granted, the volunteer forwarded the name

and phone number of the woman to me. Once the five interviews were completed, the volunteer disposed of the list. When I contacted a woman concerning study participation, I explained the reasons for the study and the areas of informed consent; which included what the study entailed for the informant and explanation of risks and benefits (See Appendix A - Informed Consent). All participant questions were answered, and the selection criteria was validated. If the woman voluntarily agreed to participate, we mutually determined a time and place for the interview.

Setting

I conducted interviews for this study in an environment that was viewed as conducive to communication by the participant and the researcher. Although the participants' homes were considered to be their natural environments, the potential for interruption by children and family responsibilities led me to seek alternative sites that equally encouraged open communication. Accordingly, I sought approval to utilize the following sites as settings: a conference room at the American Cancer Society; conference rooms within the Early Childhood Center at the area's community college; and the local Y.W.C.A., where on-site child care was also available. I subsequently conducted two interviews at the area Y.W.C.A., and three interviews in the homes of the young adult women.

Ethical Considerations in Protection of Human Subjects

As in all forms of research, this researcher was charged with the responsibility of conducting this study in an ethical manner to assure the protection of participants throughout and following this study. Extant literature identifies three areas as vulnerable to ethical dilemmas in qualitative case studies: data collection, data analysis, and the dissemination of findings (Merriam, 1988; Miles & Huberman, 1994).

I addressed ethical concerns associated with the collection of data through the components of informed consent for this study. Upon approval from the University of San Diego's Committee on Protection of Human Subjects, I began the selection of study

participants. Once I made face to face contact with each potential participant, I obtained informed consent from each individual. As described in the Informed Consent Request Form (Appendix A), I explained the research topic, its purpose, and the time of involvement. Each volunteer was informed that the interviews would be audiotaped and that their participation was contingent upon signed informed consent. A copy was given to them.

As a researcher, I faced a number of ethical considerations throughout the study process. I therefore maintained an underlying focus during the progression of our conversations, I also listened to determine when and if the questions became upsetting to the individual participants. This precaution was prompted by my understanding regarding the difficulty of assessing potential harm to the patients. As a researcher, I had appropriate concerns about the difficulty of assessing potential harm to the participants and of the potential for unanticipated side effects. I was also aware that unanticipated long-term effects could result from their participation in the study. Of the five young adult women who comprised the study group, four wanted to help others and they did not become upset when talking about their difficult experiences; instead, they were pleased that they had progressed through the most arduous times. This attitude may perhaps be traced to their recent completion or near completion of their chemotherapy treatments at the time of interview. Only one of the young adult women became tearful during the interview process; she related this emotion to her belief that her family, oncologist, and close friends did not understand the changes and challenges that confronted her now. As she continued, however, she reminded herself that one avenue of support available to her was the American Cancer Society's support group for young adult women.

Another ethical consideration that I confronted during the collection of data dealt with conflict between researcher and clinician roles. As I embarked upon each interview, I focused on the obligations and goals associated with the role of researcher so that I could gain the fullest understanding of their stories. I knew that I was not there at

that time to intervene. I was uncomfortable when one of the young adult women stated she was being considered for tamoxifen therapy as she was estrogen receptor negative. Given her status, this type of therapy was not considered to be standard treatment. While the potential for harm caused concern on my part, I was also aware that there were recent developments in this area of treatment that might mitigate my knowledge. My concern was also alleviated by the discovery that she had received and was reviewing information from the American Cancer Society. Other significant concerns arose only as I sought to identify the findings of the study; at this juncture, I came to question aspects of their treatment such as delay in treatment and follow-up care. I therefore decided to use this information in suggesting recommendations for adjustments in care, health care reform, and areas for further study.

Analysis of the data presented an additional area for ethical concern, this one associated with researcher bias. I incorporated several strategies into the research design to address this issue. In all phases of data analysis, I strove to maintain the integrity of the data. I maintained a case record that included verbatim transcripts of the interview. The data was examined by the experienced qualitative researchers supervising the research. I also planned telephone follow-up for clarification; however, no telephone follow-up was required. Responses of the participants to the questions were comprehensive.

Finally, in order to limit ethical concerns associated with the dissemination of study findings, strategies were incorporated throughout the study to assure the protection and confidentiality of informants. Several measures were implemented so that no link could be established between the participants and their interviews. Code numbers were assigned to each participant at the time of the interview; these were then matched with the participant's taped interview and interview transcription. I maintained a record of these code assignments and kept it in a locked drawer in my home. All information, including the signed consent forms, demographic information, tapes, and the

transcriptions of these tapes were filed in this locked drawer until the project was completed. The notebook was destroyed at the end of the study. As an additional protective device, I utilized pseudonyms for all participants in the development of the narratives of the young adult women's stories.

Interview Process

I developed semi-structured interviews to obtain the data for this study. A few structured questions asked at the outset of the interview provided demographic information such as age, date of surgery, type of breast cancer, marital status, individuals with whom the young adult woman lives, and occupation. The interviews were then guided by a list of possible questions (See Appendix B: Interview Questions). In the first interview, I did not utilize the exact wording and the order of the questions, primarily because of this participant's eagerness to talk. She immediately began to talk about her current concerns at the beginning of our conversation for they were uppermost in her mind. The context and vehemence of this conversation caused her to tire by the end of the 90-minute interview. In subsequent interviews, I began with the first predetermined question. This format contributed to a sense of storytelling by the remaining four women. I often did not need to ask the other predetermined questions because, as the women told their stories, they addressed the areas of interest. The narrative flow allowed me to complete the other four interviews within 60 -75 minutes. During the interview process, I remained conscious of the sizable potential that the interviews could lead these women into areas for identifying concerns. As my primary focus was their salient concerns, I concentrated upon on the concerns they described. When I had to ask questions, I limited myself to using the predetermined questions. In my view, no additional questions were required to answer the research questions. When several concerns were described together, I subsequently followed up on each. Conversation and dialogue ensued as I tried to develop shared meaning. As the women described their concerns, I validated my understanding of their concerns with them to ensure complete

and accurate integration of their views. Participants granted permission for audiotaping of the interviews.

Data collection and its analysis is an ongoing process in qualitative case study research; I utilized several mediums in my study. Each of the interviews was audiotaped and transcribed at a later time by myself. Moreover, I maintained field notes during the interviews, which comprised my personal thoughts such as speculations, feelings, problems, ideas, hunches, impressions, and prejudices. I used these notes to guide me in restating or reflecting upon multiple concerns. I also utilized these notes to write reflective remarks and observational comments; these concerned responses by the participants and myself. Finally, these notes served as a channel for my summary of the participant's answers to the research questions. Although the notes were sketchy and did not reflect all of the actual content, they were reviewed because of their potential for stimulating critical thinking at a later time if needed; this potential was suggested by Merriam (1988) and Miles and Huberman (1994). After the interview, I converted field notes into "write-ups" for use in later analysis.

Data Analysis

The analysis of qualitative multicase study research follows the same guidelines for qualitative single case study research analysis. Merriam (1988) and Miles and Huberman (1994) noted the only difference in analysis between these two types of studies -- i.e. multicase studies produce a greater amount of data for analysis -- stems from the fact that each case in the cross-case analysis is first treated as a comprehensive case in itself. To maintain consistency with their guidelines for multicase study, I developed a unified description across the cases in this study, along with the development of themes and subthemes, upon completion of the analyses of the individual case studies

In qualitative case study analysis, the move from concrete description of observable data to a somewhat more descriptive abstract level involves the use of concepts to describe the phenomenon. This process entails the systematic classification

of data into schema such as categories. Categories describe and, to some extent, interpret the data. Analysis of qualitative single case studies generally comprises three dimensions: data collection, category development, and the development of description and explanation or theory. (Lincoln & Guba, 1992; Merriam, 1988; Bodgen & Biklen, 1992). In this qualitative multicase study analysis, I individually utilized each of these three dimensions in my analyses of the five case studies. The last dimension in this study, however, dealt with developing description and explanation rather than developing theory, as I wanted to provide thick, rich description of the women's experiences. Once the qualitative single case studies were analyzed, a cross case analysis was completed.

Since the collection of data and its analysis was a simultaneous process in this study, ongoing data analysis corresponded with data collection. As such, the field notes I kept during and after the interviews were converted to "write-ups" for the analysis.

In addition, I transcribed the tapes into text after each of the interviews. At the terminus of the simultaneous data collection and analysis, all the information was brought together, including transcripts and "write - ups." The information was organized into a case record for each of the participants.

Developing Inductive Categories

Categories and patterns were generated inductively in this qualitative case study; that is, through coding of the case data base or record. Two types of coding -- first level and pattern -- were carried out in this study. First level coding, which is also termed as descriptive coding, was used to summarize segments of data. Pattern coding provided a way of grouping these summaries into a smaller number of categories or themes and subthemes.

Descriptive coding began with a reading of the case record. I identified units of analysis as the case data base was read. These units of analysis revealed content relevant to the study that stimulated thinking on the part of the reader. Each unit comprised the smallest piece of information about something that could stand by itself, and as such was

interpretable in the absence of any additional information, other than a broad understanding of the context in which the inquiry was carried out.

Once identified, each unit of analysis was placed on a separate index card and coded with a name that represented what it described and the period of time in which it occurred. Words and phrases used by the participants themselves served as an important source of the names. In qualitative research, these are called "in vivo" codes (Strauss & Corbin, 1990).

Next, patterns and regularities were identified and transformed into categories; this process is known as pattern coding. This intuitive process was systematic, informed by the study's purpose and research questions, my orientation and knowledge, and the constructs made explicit by the participants in the study themselves. Categories were concepts suggested by the data. Lincoln and Guba (1992) described categorizing as involving convergent thinking, which determines what things fit together in a single category or theme, and divergent thinking, which fleshes out categories once they have been developed. This classification was accomplished by comparing one unit of analysis with the next. If units were similar, they were grouped together. If they were not, a new category was created. If some cards did not fit any of the provisionally established categories, they were placed in a miscellaneous pile. The pile was not discarded but retained for later review. An ongoing updated list of categories was maintained throughout the data analysis period.

The efficacy of the categories was judged according to the guidelines described by Merriam (1988). This criteria demands that the categories reflect the purpose of the research and are congruent with the research goals and questions; are exhaustive, in that all relevant data was capable of being placed into a category; are mutually exclusive, in that no single unit is placed in more than one category; are independent of each other; and are derived from a single classification principle. This evaluation proved the categories meet these standards of efficacy.

This level of coding also includes the noting of patterns in the data. Categories were related to each other and relationships were validated; themes and subthemes were developed. Further refinement and development to fill in the categories were accomplished. I also sorted out any descriptions that did not fit the schema.

I maintained memos to document theoretical ideas, insights, and interpretations throughout the process of data analysis. These memos served to describe how data analysis ensued in the study. In addition, I performed a check coding procedure as described by Miles and Huberman (1994); during this procedure, I re-coded the same data 2 - 3 days after the initial coding of 10 - 12 pages to aid in definitional clarity and to serve as a reliability check. Reliability was calculated to be the number of agreements and disagreements, divided by the number of agreements. Miles and Huberman suggested that the researcher should strive for an internal consistency of between 80 - 90% before proceeding with further analysis. I identified a total number of 99 agreements and disagreements in the reliability check on my analysis, encompassing 95 agreements and 4 disagreements. An internal consistency of 96% was noted, thereby freeing me to proceed with further analysis.

After the analysis of each of the qualitative case studies, I developed a separate descriptive account on an ongoing basis. Each case was compressed and linked together into a narrative that made sense to the reader. Each of the five stories was comprehensible on its own. Once the analyses of the five individual qualitative case studies were completed, and all narratives developed, I brought the information for cross case analysis.

Cross Case Analysis

The same procedures used in qualitative single case study analysis were used in the multicase analysis. This was because the latter form of analysis differs little from the analysis of data in single qualitative case study. In qualitative multicase analysis, researchers build abstractions across the cases. In their attempts to describe the processes

and outcomes that occur across the cases and, further, to explain how such processes were shaped by specific local contextual variables. According to Merriam (1988) and Miles and Huberman (1994), analysis is little more than a unified description across the cases; however, it builds categories, themes, or typologies that conceptualize the data from all the cases.

Verification Of Data

As described in the literature, the scientific criteria for a scholarly study have traditionally comprised determining the accuracy of the account; discussing the generalizability of it; and advancing possibilities of replicating a study. In contrast, qualitative paradigm are distinguished by the absence of a single stance or consensus on how one should address the traditional topics of validity and reliability. Miles and Huberman (1994) described the attributes of trustworthiness and authenticity of findings as more applicable terms for qualitative studies. Lincoln and Guba (1990) offered the term “verification”, which includes credibility, fittingness, and generalizability, as a more fitting term to address the issues of internal validity, reliability, and external validity in the qualitative paradigm. The latter researchers’ approach was used in this study.

Credibility

One of the assumptions underlying the qualitative research paradigm is the view that reality is holistic, multidimensional, and ever-changing, rather than a single, fixed, objective phenomenon waiting to be discovered, observed, and measured. An attempt to assess the congruence between data collected and the “reality” from which they were derived is an inappropriate determinant of internal validity, as the qualitative case study researcher is interested in perspectives rather than any attempt to claim an objective reality. At its core, the researcher’s obligation is to present an honest rendering of how informants viewed themselves and their experiences. Lincoln and Guba (1990) described credibility to be a more appropriate criterion in qualitative research than internal validity. According to Merriam (1988), judging the credibility of a qualitative case study rests

upon the investigator's ability to adequately represent the multiple constructions of the interviewees; that is, the investigator must show the constructors of the original multiple realities that the re-constructions are credible.

Several strategies for establishing credibility identified in my review of literature were utilized in this study. As recommended by Krefting (1991), peer evaluation increased the credibility of the interviews. In this study, the researcher was joined by with the experienced qualitative researchers supervising the research in the examination of the analyses. Telephone follow-up with the participants was planned as a contingency. As recommended by Miles and Huberman (1994), I maintained a case record of all the major information that was used in constructing the case studies and the multicase analyses; this information was carefully retained in easily retrievable form. Finally, the researcher's assumptions and theoretical orientation are clarified in the introduction of the study.

Fittingness

According to Miles and Huberman (1994), a study meets fittingness criteria when findings have meaning and applicability to the experiences of other audiences. I addressed this issue of applicability as recommended by Krefting (1991) by assuring that the reporting of results of this study included rich descriptive data to allow future comparison. In addition, I maintained an audit trail through memos that detailed methods used in data collection; the derivation of categories; and the formulation of decisions. In its complete form, this account could be used as an operating manual which others can use to replicate the study.

Generalizability

In this study, several techniques were used to increase the generalizability of findings. By assuring that the case analyses include rich, thick description, I increased the base of information for anyone interested in transferability. Cross-case analysis involving collecting and analyzing data from five cases was conducted. The utilization of

these techniques satisfies Merriam's criteria (1988) for establishing a range or generality of a finding or explanation and the conditions under which a finding occurred.

CHAPTER FOUR

THEIR STORIES

The young adult women in this study experienced great distress as they confronted the serious, stressful, and life-threatening illness of breast cancer. Although currently being debated, their cancers were regarded as uncommon and very virulent. They underwent aggressive treatment at a time when health care reform efforts have demanded greater accountability of all involved in health care (providers, payers, and the consumers) and decreased costs. In their stories, one could hear the unique concerns they experienced and how they dealt with treatment provided in managed care environments.

In addition, the personal meaning of cancer was evident in each of their stories. Cassell (1979) and Kleinman (1988) noted that the meaning of cancer for the individual derives from "the collectivity of meanings" engendered by losses experienced. These losses include a perceived loss of wholeness, a loss of certainty of self, a loss of control, a loss of freedom to act, or a loss of one's familiar world. In their studies, meaning is shaped not only by physical factors but also by the individual's ethnicity, culture, class, age, and gender. The stories of these five young adult women are presented in this chapter.

Angela's Story

Angela, an Hispanic woman, was 35 years old when she found out she had breast cancer. She was married and lived with her husband and their three children. Their two sons were 8 and 5 years old and their daughter was 12. Angela was a school bus driver; however, she took a leave of absence from work on the day of her initial evaluation and aspiration of her breast mass to assure time for her family. The treatment for her breast

cancer was provided through a health maintenance organization (HMO) of which both she and her husband were members.

It was Angela's husband who first discovered the lump. It was walnut-sized and located within the lower inner quadrant of the right breast. Angela recalled: "It must have grown fast. It caught me off guard!" Within two days, she was in to see a physician. At the appointment, an aspiration of the mass failed to obtain fluid. Since a mammogram was also positive, the need for a biopsy was identified. During that time, Angela described herself as upset but not wanting to think the worst. She described her faith as getting her through this period of time:

I believe my faith held me up. God is a Healer. If He wants to heal me, He'll heal me. If He doesn't want to heal me, then I'm just going to go through the stages and He'll walk it out with me. So that's how. I prayed. I asked Him to help me. It helped. It helped.

Angela underwent a biopsy one week later. At the time of the biopsy, the physician gave her information about surgery and treatment. She stated: "He just wanted to let me know all that stuff. I didn't read up on everything that he gave me. I just wanted to know what my case was and what the possibility was for cancer."

Angela recalled that the results of the biopsy came within five working days. She remembered being worried having to wait for the results "because you don't know. If someone told you it might be or it might not be, you're worried with it". She recalled that she would stop and think to herself:

If I'm worrying, it is just going to make it worse for me. If I was worrying, I'd say be positive. You have to be positive all the time. If you're not positive, then you're not going to make it. It's up to you. If you're going to be down, you're going to be down but it's all in your head. You have to be positive.

Angela thought that she didn't have breast cancer because she "didn't know anything about it!" She only knew about self breast exam and she only "did it every so often." For her, self breast exam wasn't a regular routine but after having her experience

with breast cancer, she thought that a woman needed to make self breast exam a regular routine at the start of breast development. She described:

It's important to be familiar with your breasts. I did not know that you had to check all around. I did not know that when you're doing self breast exam, you need to go all the way around and into your armpit and around there. Women need to be aware of that. Really aware of that.

Angela was in the physician's office when she was told she had invasive ductal breast cancer, non-comedo type. She was with her husband. She did not want to worry him. She described her response:

First, it scared me. I didn't want to be. I did tear. I wanted to tell my husband that I wanted to be a tough cookie. Maybe, I'm not open like I should be with him. I didn't want to scare him. He knows that I've always been a fighter. Even now when he sees me, he says wow, how strong!

Angela also reinforced that it is the woman who "carries the family. Once the woman falls apart, then everything else - like a domino effect." Angela didn't want that to happen.

Angela described that she worried more after she found out the results of the biopsy than before. She said: "Then, I knew. I thought, oh my gosh, I have cancer!" She remembered asking herself "what does cancer mean?" She wanted to ask the doctors a lot of questions for she described breast cancer as "in the dark" and stated: "You don't know nothing until you experience it."

Angela related that it was "prayer and the need to maintain her family" that got her through this period. She stated: "You have to keep your goals. You have to keep your appointments. Keep positive. Pray."

On the day that Angela and her husband received the biopsy results, the decision for a modified radical mastectomy was made. She was told that a partial mastectomy "would not look good. . . it would not hold up". Her husband suggested that the entire breast be removed since she could get reconstruction. Angela's initial thought was "the

whole breast - oh wow! I know my husband is a breast man!" She decided to have a modified radical mastectomy. Later, she stated that she was happy with that choice for she did not want any cancer to be left behind. Angela described that she was informed about surgery, chemotherapy, and possible radiation that day. A second opinion was recommended but she refused. She did not want to wait any longer for the surgery and increase the likelihood of cancer spread.

Angela's modified radical mastectomy was two weeks later. She recalled that the time from finding out the results of the biopsy to the day of surgery "went really fast." Her main concern during that time was not to worry her family. She stated: "I did what I was supposed to do. I took care of my kids."

In the morning of her modified radical mastectomy, Angela's thoughts focused on her husband: "How was he going to feel towards me was my concern." A part of me would be missing. She knew however, that it depended on how she felt about herself.

Angela recalled being positive to deal with that concern but she described that it was her husband's response that helped her that morning. She stated:

He said to me, don't worry about me! You're going to get another breast and it will probably be bigger and better and firmer. I said, wow. When he told me that brought me up because that's true. I had to think about that. It may take a while but I will get another breast.

Angela had her surgery around 7:00 a.m. Following her surgery, her greatest concern was associated with an early discharge. She was discharged home at about 2:30 p.m. that day. Angela did not feel that she was ready to go home. She couldn't move her arm and she was physically weakened. She recalled being fearful during this period of time because this was her first surgery. She described her husband as very disappointed about not having the care. Care of the drains was needed. Since Angela was unable to use her arm, her mother and husband had to provide the care.

Angela spoke to several of the recovery room nurses about not being ready to go home but they responded that "this is the procedure."

Angela stated that the hospital did give her papers with directions and numbers to call if there were any problems. In addition, a nurse called about a month after the surgery to see how she was feeling. Angela remarked: "That was a surprise to me. That was nice of her to see how I was doing." Angela described that she "needed help about one week, maybe actually two weeks" following surgery. She stated that her mother stayed with her for "a good week. I didn't let that get me down." Angela was "physically weakened the first day" with discomfort being "more psychological the second and third" postoperative days. The drain was not painful but she had difficulty moving her right arm. She ate with her left hand. Her mother had to help her for at least four days.

Angela had difficulty with movement of her shoulder. She stated:

The doctor wanted me within ten days to lift my arm all the way up as far as my other arm. I had a problem with that. I said ten days, are you crazy? You can't. I had never had surgery before but you do have less movement. You've got to move it. He said you got to do exercises. I was scared to move my arm. He said you don't want to go through the rest of your life like this.

This period of time was very difficult for Angela. She had to push herself to get through it. She recalled:

I said I have to do this. I can't be like this. I don't want to be like this. If I hadn't pushed myself, I wouldn't have gotten out of it. . . . You have to say, hey, I'm going to do it. I pulled myself through it. I did it. I don't want help but I was so out of it the first day.

Christmas was a week after her surgery. The family's Christmas was held at Angela's home. Angela described that it turned out to be good; however, she had taken a pain pill on an empty stomach. As a result, she was nauseated all day. She stated: "If I wouldn't have taken that on an empty stomach, I would have been up with everyone." She took the pain pill because her "arm was hurting" and she acknowledged that "I don't take a lot of pain pills. I'm not a crybaby."

Although Angela's surgery was around the Christmas season, she stated: "I think I would have been more down if this would have occurred during the summer because I like to go out. I want to be outside on a nice day." Angela became depressed following her surgery. She was very disappointed in herself that she had developed an axillary contracture. She was required to go for physical therapy. She had pain in her shoulder and under her armpit. The physical therapy was helpful. She was told that the numbness in the back of her shoulder and down the back of her arm would probably decrease over time.

But it was the loss of her breast that was truly overwhelming for Angela. She stated: "Not til maybe January did it hit me to go out and talk to someone. I said you got to get out of this panic state. Stand up. Go out there and talk to a woman who has had it." Angela did go and talk with a family friend of her mother-in-law. This was very helpful to her. This older women showed Angela her incision and reinforced that it was all right to get breast reconstruction. Angela felt encouraged by the visit.

In addition, Angela called the American Cancer Society. A Reach to Recovery volunteer came to Angela's home about two weeks following surgery. Angela recalled the helpfulness of a visit by someone who had been through it. She stated that the visit would have been useful earlier because she was also encouraged to move her arm. She described:

She was a middle-aged woman. She encouraged me more because she gave me information, she was perky. She did what the doctor told her. She encouraged me to do the same. She told about exercises for my arm. She said, you got to get out. She said you can't stay home. Don't let anything stop you. Do as much as possible. Go do activities for whatever mood you're in; whatever you're doing. If you want to go bicycle riding, go bicycle riding. That really helped. A home visit from someone who had the surgery really helped.

Angela began chemotherapy three weeks from the date of her surgery. She had been diagnosed in Stage II breast cancer. Seven out of 17 axillary lymph nodes were

positive. Both estrogen and progesterone receptors were positive. She received six cycles of cyclophosphamide, Adriamycin, and 5FU (fluorouracil) three weeks apart. After the completion of the chemotherapy courses, Angela will undergo five weeks of radiation therapy at a facility that is away from the area. She will be provided with a room during the weekdays and transportation back and forth on the weekends.

Angela described problems she experienced with the chemotherapy treatments. Most of the problems were on the same day of their administration. She would become tired and would have to lie down for the whole day. She offered that she had no nausea but that she did have darkening of the nails. Her concern however, with the chemotherapy was with her hair loss. She described:

I have hair loss. They said that some do and some don't have hair loss. During the third week of chemo, I lost my hair. I didn't want to brush my hair. I would just run my hands through it and let it go. I did not want to do that. I did not like it. You can't help it. It's the stuff they give you. I was saddened. They told me then. I think it is best that you be told. It is best to be prepared.

Angela asked the chemotherapy nurses why she had lost her hair. Angela stated they told her it was "because of the fact that my hair cells are the fast growing ones and chemo kills them too". For Angela, losing her hair "came as a surprise" because she had thick hair. Although Angela did recall that the Reach to Recovery volunteer had told her to be prepared to lose her hair, she correlated hair loss with increasing severity of her disease. She remarked several times that she knew others who had breast cancer, hair loss, and spread of the cancer into their bones prior to their deaths.

Angela had difficulty obtaining a wig. The lists from the American Cancer Society concerning self-help, support groups, and where to buy prostheses were outdated. In addition, Angela described that the wigs "were really used" or were "not a good quality". She recommended "a manufacturer that would make a good one to build that self confidence after chemo because if you've lost your hair, you need to have that."

Angela also went to a self-help group that was recommended by the Reach to Recovery volunteer; however, she did not feel comfortable in the group. The women were all older and she couldn't identify with them. She described that it was "the Number One Maker of all the people" that got her through this difficult time. She prayed a lot. She remarked:

I couldn't do it without the will of God. He is my strength. The power of prayer. I can't die. I got my kids I got to live for. I have a family. I got to show them that He's in control but that I get strength from God. If I didn't have Him, I'd be really down. But I'm an uppity-up person. I never let nothing get me down and that everything is fine. As long as I am fine, the whole family is fine.

Angela worried if the chemotherapy was working. She needed to know if the chemotherapy was working. She wanted there to be a way to know if spread were occurring. She did not feel that her physician kept her informed of her progress. She remarked: "They only told me my platelet count." So Angela talked to family friends who were knowledgeable about it. One of Angela's friends sold nutritional supplements. She told Angela about "juicing to rejuvenate and detoxify the body" and algae-derived compounds called cryptophycins to boost the blood. On a videotape recommending the use of cryptophycins, Angela heard that cancer patients died from malnutrition. After seeing this video, reading an article in the newspaper, and after having a low platelet count, Angela began taking cryptophycins and considered "juicing". Angela wished she would have had a nutritionist consult early on in her treatment. She never did however, talk to her physicians about this.

Angela reinforced often that it was not until you experienced breast cancer that you knew what it was really like. She described: "There's the fear in 'the Big C' word. That it's cancer. It's in the stars until you get it." She described that it hit everyone in her family "like a ton of bricks". A need to understand or explain the situation was also often noted. Angela stated:

There are reasons why things happen to you. Maybe, to bring me down to my knees more, maybe, to tell my husband, hey, there is a God out there. My husband and I have gotten closer because of this. It has brought me to my knees. My husband is amazed at me. She has cancer but it doesn't look like she has cancer. She's acting almost like she doesn't have nothing.

Angela also described that there were many fears when she had "the me kind of outlook. Oh, my gosh, now I have to take care of the kids and do everything else." As she looked back, she realized she could handle it. She reinforced that women be informed about the American Cancer Society and be encouraged to utilize them early on in their illness. She stated: "It took me too long to call them. I kept saying that I could do it myself because I got the Lord inside me. Then, I thought, you know, I do need somebody."

Angela offered some suggestions for the programs of the American Cancer Society such as assistance with transportation and finances. Angela encouraged the development of support groups for men:

They need support groups for men because some men don't speak out. So that they could actually comfort them. I would say as a couple so that they could get couples to help together. We could all help each other. Having couples would be a perfect thing. Men need to be involved.

Heard in Angela's story was the importance of relationship with her husband and family as she underwent treatment for her breast cancer. The experience of breast cancer evoked a loss of certainty of self as her relationships with her husband and family were affected. For Jennifer, however, her somewhat newly found sense of independence was uppermost as she underwent treatment. Maintaining a sense of control was a motivating factor throughout Jennifer's treatment.

JENNIFER'S STORY

At the time Jennifer found out she had breast cancer, she felt she had finally achieved her independence. At the age of 30, this single, white young adult woman felt that she was becoming established in a marketing career and for the first time in her life, she was able to afford and had found what she called her "own place". Very energetic

and talented, she was also a musician and played with a band. Jennifer lived with her cat and dog in a cottage-like apartment complex where many other single young adults lived. Her place was "put-together" with overstuffed furniture and knick-knack's she had found at yard sales.

Because of the demands of Jennifer's work and her busy lifestyle, our conversation was rescheduled twice. Jennifer stated she really did want to talk to me because she wanted to tell about what she felt were "important issues concerning breast cancer for single women." She called me one weekend evening to come and talk while she ironed her clothes.

It was Jennifer who first observed a mass on her right breast. Having no health insurance, she went to a women's health center for a mammogram. This service was not provided by the agency but a list of facilities where low cost mammography could be provided was available. From this list, Jennifer located a facility and within two weeks she had a mammogram taken. According to Jennifer, "the right side of my breast looked okay but the mammogram identified something on my left breast. I couldn't even feel that one!" It was in the upper inner quadrant. She was not alarmed as the staff appeared unconcerned because of her young age; they did however feel that follow-up was needed. After the mammogram, Jennifer sought to purchase health insurance to help defray costs. Since no medical condition had been actually diagnosed, she was able to purchase private coverage. As routine follow up, she underwent a biopsy about one week following the mammogram.

About one week later, Jennifer returned to the surgeon's office for the biopsy results. She was told by him that it was positive. She was shocked by the results. She stated:

It hit me hard. I couldn't believe it! I had never imagined that it would be cancer because of my age and so did everyone else. I think if the medical people would have said to me, hey, it could be cancerous, then maybe it wouldn't have been so hard. I cried. I

cried. All I could think about was - 'I'm going to die!'

Jennifer had driven to the surgeon's office by herself that day. He asked if there was anyone he could call to come and be with her. She said that she would be all right. The surgeon also told her about options such as modified radical mastectomy, lumpectomy with radiation, chemotherapy, and reconstruction. She was asked to think about it, talk it over with her family, and to make a decision. He told her how sorry he was about the biopsy results but that it needed to be taken care. Jennifer recalled that "his genuine concern helped a lot."

Afterwards, Jennifer drove to the home of a couple who were described as "my friends". They let her cry. Jennifer did not want to tell her mother because she knew that her mother would be even more upset than she was and she didn't want that for her mother. Jennifer told her father and asked him to tell her. He did. Jennifer told her younger sister. Jennifer recalled that her family was very supportive and that her mother was very upset.

Jennifer described that having to make the decisions regarding treatment as "one of the two worst times" she experienced in dealing with her breast cancer. Jennifer's mother helped her tremendously during this time. Jennifer's mother worked with another older woman who had recently undergone modified radical mastectomy and treatment. Jennifer's mother was able to get all the written information that the other woman had received about breast cancer and its treatment. Jennifer recalled that the information was very helpful. Jennifer also contacted the American Cancer Society and received additional information. Jennifer stated: "I just remember reading so much to help me get through this".

But Jennifer recalled that it was also the support of her friends that helped her to get through the shock associated with this difficult period of time. She stated:

I have two friends who live together and one of them has AIDS. I talked with them a lot and they really understood the shock I was going through. I also have a friend who's young. She has ovarian

cancer. She's had three reoccurrences and she too was understanding of what I was going through.

Jennifer decided to undergo a modified radical mastectomy. She felt that the biopsy had left her breast disfigured. She thought that since they would have to take more tissue the next time, the breast would look even more disfigured. Because she could get reconstruction and because she didn't want radiation, she chose this type of surgery. She also remarked: "After all the reading, I was more upset with the thought of losing my hair than losing my breast!"

During this time, Jennifer had her thirtieth birthday. She underwent the modified radical mastectomy about four weeks after the biopsy. She drove herself to the hospital that morning. She did not want her parents there because she did not want to upset them but they were there to meet her. Jennifer recalled crying that whole morning because she was "so sad." When signing the consents for surgery, she said: "I became really worried that I could die from the surgery itself. I didn't want to die!" She wished they would have given her a Valium with which to relax.

Jennifer described what was helpful to her at that time:

. . . all the operating room staff were so nice. They told me how sorry they were for me to have to go through this. That helped. That helped. My surgeon took me into the room and just sat down and held my hand. He spent a lot of time with me and told me what he was going to be doing. He too said that he was so sorry that he had to do this surgery for me because of my age. I know I'm not the youngest person who has had breast cancer but lot of these people had never seen anybody so young with it. In hindsight, there needs to be lots of education about breast cancer. It is happening to all women. But with my doctor, I felt a personal touch, a personal concern and that made me feel better that I was a person who was special.

As described by Jennifer, "that day after the mastectomy was such a blur. . . because of all the drugs. . . I was so weak." The following morning her surgeon told her that her lymph nodes were negative and she was "very happy" ; however, she was very disappointed in her insurance company. She stated: "My insurance company made me

leave in twenty-four hours and I didn't like that." Since she was unable to care for herself, she could not go back to her place where she lived alone. She had to make arrangements to stay at her parents' home. She described:

My mother took care of me for a week. She helped me so much. She pampered me. I would say, 'my stomach is upset from the pain pill, would you make me some jello?' and she would. She was good to me. I didn't mind their help because I really needed it but I wanted to get back to my own place.

Jennifer described that she progressed each day. She began to move her arm better. She did however, have swelling under her upper arm where lymph nodes had been removed. She stated:

I had physical concerns really at that time. Everything healed fast. I think young people spring back from surgery faster and better than someone who is older. That's one advantage that youth has for you but then that's for all surgeries.

But as Jennifer recovered from her surgery, she found that her concerns "became more psychological". She stated: "When you're young like me, you don't think about dying and I had to deal with that I wasn't going to live forever. You just don't think about that at my age."

To help her through this, Jennifer contacted the American Cancer Society following her surgery and requested a visit by a Reach to Recovery volunteer. She recalled the helpfulness of the volunteer who visited at her place two weeks after surgery:

She was really helpful. She told me about everything that was available from the American Cancer Society. She was in her forties but she was 31 when she had her mastectomy. I appreciated that. Younger women's issues are different from the issues of older women.

In addition, Jennifer went to a support group. It was not associated with the American Cancer Society. It was offered by the same facility where Jennifer had undergone her mammogram. It was at that time when she found out about the support group. She stated:

It was okay but at that point in time, I really feel that the women weren't having the same issues as I was having. It never ever met any of my needs. They were all older. Like I asked, don't any of you think about dying? None of them did. They were all really older. Maybe a group with other younger people with different types of cancer would be better. I just think our issues are different.

And as Jennifer talked about having to deal with not living forever, she recalled the support from the staff of the social service agency where she initially sought help. They sent her cards. The physician on staff called every month to see that she was okay. As a result, Jennifer's mother made a specific pledge on behalf of Jennifer, to them through the United Way Fund Campaign.

Jennifer stated that her breast cancer was infiltrating ductal carcinoma non-comedo type. Her estrogen and progesterone receptors were negative. She stated: "because of the type of cancer that it was and because of age, I underwent chemotherapy." A great concern for her at this time was the threat of sterility because of the chemotherapeutic drugs. Her oncologist talked about fertilized egg banking for her consideration. Jennifer refused to talk to a fertility specialist. She "was not going out and ask a male friend for his sperm. She decided that she would take the chance. There was a 50-50 chance that she would stop ovulating and would become infertile. She continued with her menstrual cycles following chemotherapy treatments. Now a trial of tamoxifen was being considered. Jennifer stated: "I'm still thinking about it. The decisions which had to be made were really hard to make. This one's difficult for me. I've read so much about it." She said that her physician had given her information to read and so did the American Cancer Society. She remarked: I'm not ready yet. I need more time to think about it.

As Jennifer talked about this situation, it was evident that she had spent time thinking about the threat of sterility and had identified other options. She said:

I'm really not sad about not being able to have children. That isn't an issue for me. I don't have a relationship with a guy right now. . . My sister said that she would give me one of her eggs later on if I wanted

one and probably the only thing that would be different from my egg is that the baby would be tall! My sister is tall and I'm not. We laughed. Also, I know that I could adopt if I wanted children. So I do have some options.

Jennifer described that it did upset her but there was nothing she could do about it so "it doesn't do me any good to worry about it." It was hard for her to talk about it because she was uncomfortable.

Jennifer returned to work two weeks following surgery. Even though she had just begun her six cycles of cyclophosphamide, Adriamycin, and 5-FU (fluorouracil), she went back to work because according to her, "I wanted to keep my own place". Being the only person in the marketing department, she was busy and worked long hours. After the third treatment, she had become increasingly tired. She described that she couldn't work and get through chemotherapy because she was so tired. She went on disability. She stated:

I thought it was best because I had to spend time on me and take care of me. I couldn't physically keep up with the work. Stopping working really did help me. I was able to get by and keep my place. They let me keep my lessons. I teach some flute lessons. I couldn't do everything I wanted to do like going to the health spa but I got by.

Jennifer's last chemotherapy treatment was three weeks ago. She experienced side effects but she did not lose her hair. Each time they gave her higher doses and each time she experienced something different. Once she vomited 8 hours straight. It took her longer and longer to get over each dose but she was so happy that she didn't lose her hair. Each time the oncologist asked her if she had lost her hair or her menstrual period.

Jennifer relied on her friends to help her with the chemotherapy treatments. She described that "one of my friends would take me to chemo and then pick me up. I would rotate who I would ask so I wouldn't take advantage of them. " A friend would stay with her the night of the chemotherapy in case she needed anything. She stated that they were so helpful; however, she recalled quickly: "Everybody said I looked so great. I would

say, how can you say that? I need your sympathy. I did think if I would have lost my hair, I would have gotten more sympathy!"

Jennifer went to the "Look Good, Feel Better Program" sponsored by the American Cancer Society early on when she had felt badly following the chemotherapy cycle. She described that the experience did make her feel better. She hadn't lost her hair but it really helped. She was really glad she went. She got three wigs there like a Marilyn Monroe one and a red one that she could use if she needed them. She remarked: "They were so in to it. They thought I looked so great in them. I thought I'm not wearing them only maybe at Halloween!" Jennifer had long hair before chemotherapy. She got it cut before the chemo so the loss wouldn't be so terrible for her but she never lost her hair. She stated: "I felt rebellious by getting my hair cut! I'll get rid of it before you take it away from me!"

But as Jennifer coped with the chemotherapy cycles, she also was dealing with the loss of her breast. There was "a certain amount of sheer will power" that she was going to be okay through all of this. She stated: "I spent the time taking care of me. I did things to make me feel better. If I wanted to go up to the mountains, I went up to the mountains. I played my flute." Jennifer talked to her girlfriends about it. She thought she should talk about it. Jennifer described her girlfriends as uncomfortable talking about her mastectomy but that they didn't want to upset her. She told them what the scar looked like. It didn't look like what she thought it would look like. She stated: "It doesn't look so good. The scar goes across and then all the way up towards my arm. They need to give you real pictures and not drawings to look at. Then it wouldn't come to such a shock to you when you look at it." Jennifer described that she pulled out the prosthesis for her girlfriends but she shocked them. She remarked: "I don't think they were ready for that." Jennifer really didn't like the prosthesis. She described that she just had to watch how her shirts and blouses closed in the front. She stated: "I know I can get reconstruction."

Jennifer discussed her thoughts about getting through the loss of

her breast and the side effects of the chemotherapy: "I don't know if I really know how I got through it. I don't think I have an answer. Probably being brave." She did write a couple of letters to her friends. She had never ever done that before. She told them what she was going through. It helped her. She planned on writing a third one now that chemo was finished. She stated: "I think overall the feeling that I was positive got me through it but this certainly isn't the time to learn to be positive. You can't learn to be positive with this experience." Everything she learned prior to this helped. She felt she had developed "pretty good coping skills prior to this." At times, she thought it would have been better if she would have been with someone and then other times she would think "you still have to go through it yourself." She thought it was maybe better not having to worry about how the other was going through it because she "had time to concentrate on me."

But as Jennifer progressed in her chemotherapy and as she worked to deal with the loss of her breast, she lost her disability status. As she prepared to return to work, she found out that her position no longer existed. She described this period as the second most difficult time she experienced as she dealt with her breast cancer. She felt awful. She thought everything bad that could happen was happening. While she was off, her employer lost funding for the position so she no longer had a job. Jennifer felt horrible. She thought she would probably lose "my place." She probably would have to move home with her parents. She became reminded that if she didn't have them, she could become a homeless person! She was very sad. She had to go on unemployment. It was really hard. There wasn't anything she could do about it. She couldn't start a new job right away. She was still going through chemo. She couldn't tell them that she couldn't start for about ten weeks. She was afraid. She wanted a life like everybody else did. It was "really stuck" in her mind though that everything would be okay. Even her oncologist said the disability claim was questioned. He had never had one questioned before. She stated: "They had no concept of the kind of work I do. I talked to the

disability people. They said that they have charts that say I should be okay. So I lost it. So I had to go on unemployment."

Jennifer started looking for a job because she thought she would not be able to find a job quickly. She sent out letters. She recalled:

My friend told me about a job at this place. They want to hire someone temporary but after three months it will become permanent. I got offered the job and it's a lot of money. I'm so lucky but I had to start it last week, two weeks after I finished chemo. It is tiring. The days were long last week. Now, I don't have insurance but I will in three months. I'm thinking that I will get hired into the position.

With a job in hand, however, Jennifer continued to focus on "I'm not going to live forever!" She described her feelings:

I feel it's hard not to think about it all of the time. It is pretty unlikely that I'll get a local occurrence. It is much more likely that I will have metastasis. From my reading, I feel that I'm right there in the middle between Stage I and Stage II. I think that the chances are there. I am afraid and I don't like being there. My doctor doesn't blow it off either.

To cope with this threat, Jennifer has become a "vegetarian". She described:

I've pretty much become a vegetarian because that is something that I can control. I eat fish but I don't eat meat, chicken, or dairy products. I make myself eat broccoli and cabbage which I don't like. I know they are good for me. I watch what I eat.

Related to her concern about not living forever is the fact that Jennifer doesn't know enough of young adult women who have breast cancer. In addition, her very close girlfriend with recurrent ovarian cancer has a poor prognosis. Jennifer described her thoughts:

The only young person I know who had breast cancer was 31 and now is 42. She has lived ten years. My friend has ovarian cancer and she's probably not going to. I know that's different from me but that's hard for me. For her, unless she has a miracle she probably isn't going to live five years. That's hard for me. Here I am thinking 10 or 20 years and she can't even think 5. I know older women like

my mom's age who are fine but I don't know anyone my age and that would help.

Another concern focused on the probability of her being able to develop a relationship with a guy. Jennifer stated:

Would they be serious with a girl who has breast cancer and who doesn't have a breast? Would that matter to them? I've asked my male friends and they are so uncomfortable to talk to me about it. They say it really wouldn't matter and in my mind, I say, sure! We get into big discussion about it. We say it would matter to some people and not to other people. Basically, if they like you, it wouldn't matter, we hope. They really wanted to say the right thing to me. I think about that.

Jennifer described that ultimately, she will get breast reconstruction although she is "grateful" that she can't get it right now because she doesn't have health insurance at this time. She is "afraid of surgery." She described that the associated stress of her breast cancer "has been hard". She looks in the mirror and sees "how I've aged! I have all these wrinkles now around my eyes and my mouth."

Jennifer's present concerns were also the concerns about her future. In addition, she worried if she was going to be able to keep her place and have enough money to live and have health insurance. She felt lucky to have found a job. She described: "In order to have good insurance, I do have to work for a bigger organization or a governmental agency."

Recently, Jennifer was asked by a volunteer of the Reach to Recovery Program to talk to a girl in her twenties who has just undergone a modified radical mastectomy. She needed to talk to someone. Jennifer told the volunteer that "I wouldn't know what to say to her" but she got her number and did call her. Jennifer stated:

All I could say was that she sounded good. She was sounding like she was doing good. I told her it just takes time. She needs to give it time and it will get better. I really couldn't tell her anything else.

Jennifer was happy to have been asked to help another young adult woman. Although she really didn't know what to say to her, Jennifer knew that it was important to know that others have gotten through it. Jennifer remarked:

There isn't much out there for young adults and when you're single, there's even less. We need to spread the word about breast cancer. I ran in the Revlon Walk for Breast Cancer yesterday. Others need to know about it. We need to know more to fight it.

Jennifer also verbalized the need for printed information such as that which comes from the American Cancer Society to apply to more women. She found that it applied to older women who were married or who had children. She described:

The needs of the single woman and those with alternate lifestyles such as gay and lesbian women are not addressed. They give suggestions on how to deal with things, like have your spouse do this or have your children do this for you, but they don't give you suggestions for having your friends help you and saying thank you. There needs to be things for more people.

For Jennifer, her strong need for independence was challenged by her experiences with breast cancer. Her need for control provided a strong sense of motivation to get through this difficult period of time. For Staci, her experiences with breast cancer also challenged her strong need for control; however, she also experienced a loss of familiar world.

Staci's Story

Staci, an African American, was 33 years old when she was diagnosed with breast cancer. Married, she lived with her husband, their 11 year old son, their 10 year old daughter, and her mother. She underwent a modified radical mastectomy for "adenocarcinoma of the left breast." She was diagnosed in Stage II breast cancer having 4 out of 32 lymph nodes positive for malignancy. Both estrogen and progesterone receptors were positive. All of her health care was provided through her HMO. Staci

was eager to talk with me about her concerns. She met with me the day following my call. She said that she knew "this would be good for me. Everything has been really hard." A senior customer service representative, she had recently gone on a medical leave of absence and state disability.

Staci found the lump in her left breast upon awakening one morning and stretching her arms upward along her body. She had no concerns at that time. She felt she had none of the typical risk factors. There is no breast cancer in her family. She didn't know anybody with breast cancer. She thought it's not supposed to be there. It's probably a cyst. She thought that she'd get it checked, probably cut out, and then go about her business. She has lupus as well. She had a "prescheduled" appointment in a couple of weeks with her internist, her regular doctor. She waited until she went in to see him. He told her to go to her gynecologist. She saw the gynecologist two weeks later. The gynecologist felt the lump. It was very evident. Susan got a mammogram first. By the end of the week, she had an ultrasound. It was there on the mammogram but the ultrasound identified it as a solid mass. It needed to be removed.

The gynecologist referred Staci to a surgeon. She underwent a biopsy at the facility's surgery clinic. As requested, she was awake for the biopsy. Staci stated that she really had no concerns. Although the surgery itself was a concern, the concern of it being anything "never" entered her mind. She stated that it took two weeks to get the results. She was a little anxious at that time. Not knowing was the scary part.

When the results were back from the laboratory, an appointment was scheduled. Staci's daughter had broken her finger that day. Staci had taken her daughter to see the pediatrician. His office was in the same building as the surgeon. When it was time for the appointment for the biopsy results, Staci recalls: "I ran up the stairs to his office. I took my daughter with me so this tells you where my mind is." Staci stated:

...very calmly he says, 'the pathology report is back. You have breast cancer.' I cried. What are you supposed to do? He said, 'are

you okay?' I said 'sure, I'm okay.' Then, he asked if anyone was here with me. I said 'no'. Then he said, 'are you okay?' He was concerned about my face. I said: 'Would you rather me sit here and tell you everything is okay or be truthful and cry a little bit and then tell you, it will be okay?' He looked at me and said, 'you have a choice between a lumpectomy or a mastectomy?'

Staci recalled that she got a copy of the pathology report that day and in addition, he explained it "the best that he could." Staci was told of the options available to her. She was told about surgery, reconstruction, and the type of cancer it was. She was told that she would probably need chemotherapy because of lymph node involvement.

Staci's decision was made at that time. Staci described:

Immediately, I said mastectomy. There was no thought in my mind about a lumpectomy. If it's there, cut it off and get rid of the whole thing and that way we don't have to worry about it and I can get on with my life. I am a pretty good-sized woman, ample breasts. What good is a piece of breast? Just get rid of it.

The surgery was scheduled for three weeks later. Staci requested to have the time to "get everything lined up." Her boss's wife was having surgery so he had taken time off. She stated: "With a job even if your health is important, what is another week or two? It didn't matter at this point. I thought so." Staci got things lined up at work and at home. She described what she did: "You've got to get the house prepared, the family prepared. You've got to put things in order before you go." To Staci, "it made the world to be able to do that." It helped her feel "a lot of control over what goes on in my life."

Staci described the support she received during that time before surgery. She had a lot of support from family and friends but there was "no need" for support between the time of biopsy and the report because she felt that there was nothing wrong. She stated: "I absolutely refused to think the worse. That was not an option for me."

Staci described that she dealt with it by telling everybody:

"I told everybody. . . because if it could happen to me, a 33 year old black female, that is not even a category for which it could happen, I am the most least prospect for anybody you want to meet, it could

happen to anybody. Most the people I know are over forty. I don't know too many people my own age. Most people are older than I am. Get your mammograms, people. I was very open and free. Look at me. I was only 33 years old. If it happened to me, it could happen to you!

On the morning of surgery, Staci described herself as "fearful of surgery." She described this concern as with the hospital. "What's the hospital's credential?" Signing the consents before surgery "that say if you die, will you want extraordinary means?" was very profound for Staci. She had never thought of it as dying. It was "mind boggling" to her. Having surgery bothered her. She stated: "The cancer's not going to kill me, the surgery's going to kill me." Staci coped by writing notes to her children. She told them that she loved them. A friend of hers was going to be watching them for a week after surgery. She asked them to "be good for me." It was picture day at school. She asked them to "smile really big for your pictures. . . Be good for your aunt. . . Be good because mommie can't be there for you."

Staci had another concern the morning of surgery. She didn't see the surgeon that day. She described the surgery nurse as "very friendly, very jovial. They quell the fears you have."

Staci described that she "didn't see him at all" that day and not until the next day after lunch. He told her to "go home." Staci told him that she didn't want to go home. She had barely gotten out of bed and it hurt to move. She told him: "I wasn't sure on my legs, how I felt. I'm not ready to go home yet." He responded: "Well there is a lady who is older than you and she had the same surgery and she is going home today." Staci stated very plainly: "I'm not her!" He told her that once "you get home and get into your own house and environment, you'll be comfortable." But Staci said: "I know my own home and my own environment and I'm not ready to go home." He told her that he didn't know if the insurance company would allow another night. Staci thought he was angry because she threatened his authority. He did let her stay another night. Staci felt she had "won that battle then he said to her: "You better get your butt out of this bed and get

out around and see how things feel." Staci was upset. She stated: "I just didn't want to stay in that hospital. I needed that." The next morning though the nurses woke her up at six o'clock and taught her how to empty her drains and how to measure them. Then they "kick you out by 8 o'clock." Staci described:

That above all else angered me more than anything else - not being there before my surgery, coming a day and a half later, and saying good-bye. I felt like herded cattle and I know that's his job and he has to be that way because he can't put all of his emotions into every case and I understand that. But this was a lack of anything good - that bothered me.

Before surgery, Staci tried to talk with other women who had breast cancer. After surgery, she spoke with her father's third wife who had breast cancer two years ago. She underwent a modified radical mastectomy. She had no lymph node involvement. Staci had lymph node involvement. Out of 32 lymph nodes, four were positive. Staci's step mother did not undergo any further treatment. As described by Staci, "her experiences were definitely totally different from mine because mine involved lymph nodes." Staci talked to others, some of which had lymph node involvement.

Staci told that at the hospital, another lady she had talked to, had a sling on her arm at discharge from the hospital. Staci asked the nurse if she should have had one because she could not lift her arm and had limited movement. The nurse said no. Staci said: "They know you're not going to do much because they know you're in too much pain!" When Staci saw her physician at her follow-up appointment, he told her about exercises for her arm. At her second appointment, she was to be able to put her arm above her head.

Staci described that the first couple days at home after surgery as "different." It was hard for her to get out of her waterbed with one arm. She had help at home. Her mother was there. Staci's children stayed with a friend but they came home after school

from 3 to 5 o'clock to see her. Staci said that she "saw them for a few hours but I could deal with that."

Staci called the American Cancer Society upon her discharge from the hospital. A brochure had been left at the bedside. It "bugged" Staci that the person didn't stop and speak to her. She stated: "maybe a lot of people don't want to talk to you."

A Reach to Recovery volunteer came to visit Staci in her home a day or two after surgery. Staci remarked: "You need somebody who can tell you something and I called her because I was reaching." Staci described that she was doing what they wanted her to do - "to reach to someone who had been there who could tell you and that is something that I wanted to do." The brochure from the American Cancer Society was helpful to her. Staci described that they didn't make a presentation or anything so that it really didn't look inviting to her. "If you didn't want to do it, you wouldn't."

For Staci, the volunteer's visit was helpful. The volunteer was friendly. She was older. Knowing that she had gone through it too was helpful. She stated: "For her to be there, done that, helps me with the emotional part of it. I told her about what had happened with my surgeon - not seeing me until the day after surgery and then wanting to push me out and she said, 'that's a surgeon for you!'"

Staci developed an infection of her incision. That made her "so mad." She called at the beginning of the week and told her surgeon that it was infected and that "it stunk." They gave her an appointment at the end of the week. Staci told them "that wouldn't do" and got in that day. She had to take antibiotics. That made her mad. She remarked: "Here I have lupus and have problems with my immune system. Don't you think he'd give me an antibiotic to prevent infection? No! I had to go through that and the smell."

"Going through chemo" was a major concern for Staci following recovery from surgery. She wanted to wait until after Christmas to start it. She stated: "My concern was that the drug they were going to be giving me would cause hair loss. If I lose my hair, what am I going to do?" That was her main concern at that time. She was told that

she had a 95% chance of losing her hair because of the drug Cytosan. Staci had taken Cytosan before for her treatment of an exacerbation of her lupus. It had thinned her hair then so she was pretty sure that she would lose her hair because it was now a larger dose. Staci described the difficulty she had in getting her wig:

I said, now when I lose my hair, what are you people going to do about it? I know I can get a wig for this. I want the wig before I lose my hair and not after and that was my next major project - the wig thing. I talked to the oncologist. He said my insurance would cover that. They said, I have to go through the chemo and if my hair falls out, then I can get a wig. I said, can I get it now before the hair falls out? I said I can't wait a month.

Staci completed the paperwork ahead of time. She lost her hair three days following her first chemo treatment. When she called about the wig, she was told it would be another week. Staci exclaimed:

I'm not going to wait another week. You've done all that you can. Thank you very much. Meanwhile, can I talk to this department...I told this particular 'supervisor A' that I am a very upset patient who filled out paperwork several weeks ago and isn't happy with next week as an answer.

Staci went to the wig shop before she lost her hair so that the salesperson could see, according to Staci, "her hair, her texture, her hair color, and how I wore my hair." Staci asked: "How can you fix a person, if you'd never seen them together?" Staci wanted to buy the wig that day and then ask for reimbursement from the insurance company. The insurance company supervisor said that couldn't be done. Staci stated she "was really feeling bad." The supervisor finally was able to make the arrangements for Staci to purchase a wig at the shop. Staci described that she was the first patient who had ever come to her in which the insurance company had paid for it first, up front. The next time she went to the oncologist's office, the brochure for the wig shop was there. The clinic had made her their official person for wigs. Staci described:

That made me so happy, feel good. I'm hoping that they let people go

there ahead of time. Hey, you're going through a lot emotionally, physically. Why do you have to wait til? And vanity is thy name for women, for men too. You can only deal with so much and then to be completely bald or your hair coming out in clumps? And here, you're looking like a ragamuffin. You're physically impaired now and you're going to make a person go through that? That's not right.

Staci underwent 10 cycles of chemotherapy. She had 4 cycles with adriamycin and then 6 cycles with Cytosan, Adriamycin, and 5FU (fluorouracil) three weeks apart. She has one more cycle to undergo. Staci experienced side effects. The Adriamycin made her vomit and nauseous all the time. Her sense of smell was affected. Everything smelled. Roses smelled. Nutmeg in the kitchen. Her husband couldn't wear cologne. She couldn't stand it. Coffee, the smell of bacon, everything! Everything tasted bad and smelled bad. It lasted for about a week after the treatment. A week of being tired followed and then a week of being okay. Then, she'd go back through it again. She had four courses of Adriamycin. She didn't eat much the first week after chemo. If she did, she would eat potatoes and rice. They gave her two pills but only one worked for the nausea. Now, they add it to the IV drip before she has the chemo and it helps a lot. The first two times they didn't do that.

Another concern that Staci faced was associated with radiation treatments. The oncologist thought that she should go through radiation but the surgeon didn't think so. With four affected lymph nodes, it's "right on the border." Her concern was not with what the oncologist or surgeon said. Her thoughts were that the one being swollen and involved tipped the scale to five. She wanted to fight this with everything there was now as opposed to waiting three or four years and saying "we should have, could have." She would rather overkill it than underkill it although she really wanted it to be over. She stated: "I just want to go back to as normal as a life as possible. I really don't want to go through radiation but if I have to or need to, I'll deal with that then."

Staci described that she experienced "emotional scarring." By this she meant that going through breast cancer and its treatment was hard. She stated: "Everybody else's

life is the same. But mine will never ever be the same. My life is everything but before." Breast cancer and its treatment had caused changes in her life. Her usual routines had been changed. She thought often about her mortality. She described her world as now filled with emotions. Staci stated that she will get over it. She will deal with it because she's "a strong woman." She described her feelings: "My mother can make everybody else's life happy . . . and my world is falling apart. But on the otherhand, you guys are in your world but it is my world. So because I'm unhappy, I don't want you to be unhappy. I want you to be as happy as ever. It's a 'Catch 22'. The statement of others: "Oh and you look just fine!" drove her crazier than anything else in the world. She stated: "First of all, what am I supposed to look like? Second of all, what do you expect? So nobody can say anything but that stuff is crap!" Staci described her children as too young to understand. Her husband was too emotionally withdrawn to give her the support that she needed. Staci didn't want to put the burden on her mother and let her mother do everything for her.

Staci talked to her oncologist and told him "I can't do this. . . because I've failed. I can't do this, take care of my family, and do my job with this going on. I just can't." Staci went on disability after this. She described that she did have good days. She stated that she didn't dwell on negatives, only positives. The oncologist gave her Elavil to help her sleep but she hasn't used all of them. She stated: "if you can sleep at night, you're far more able to deal with the day ahead of you. If you're not sleeping well, then the day doesn't go well and your night is even worse."

Staci took advantage of an opportunity to review her chart when she was asked to take it from the physician's office to front desk. She stated: "There was a note he had written that said she gave me tears in the office." Staci was upset by that entry. She stated: "I didn't think that was an important thing because he didn't know how I felt."

It was "mortality" that was described as her concern about her future. She stated: "When you're younger, you feel that you can live forever. When this happens, you don't

know." Staci questioned her mortality. It made her stop and think that life did not promise anything. Anything can happen to anybody and she is not alone. She described that her hurdles in her life had become more difficult: "I used to be able to jump them but it's going to take a lot more effort to jump the hurdles than it did before."

Staci described that she's "over" the loss of her breast. She felt that she was just as much a woman with one as she was with two breasts. Although there were some clothes that she couldn't wear, she did have other options. She planned on undergoing reconstruction. She remarked: "I don't enjoy the thought that they will be cutting on me. After I'm done with the treatment and the insurance will pay for it, maybe I'll feel better after that but it's a mortality issue for me."

Staci described that she had a lot of friends with whom she could talk. She also stated: "My husband doesn't talk much at all so I don't talk with him about it at all. He can't grasp it. He just can't. You can't get blood from a stone." Staci talked about her colleagues from work.

There's a network of people I can talk to - hey, I'm having a bad time.
Let's go to lunch and cry. . . And I know they care and that helps.
But they haven't been through it. I don't know anyone my age who
has had breast cancer.

Staci described that the mortality issue was there too when she had her "bout" with lupus but her "kids were a lot younger and I didn't have time to dwell on myself. For Staci, breast cancer was more of a threat. She described that "nobody understands lupus anyway so you don't know what to expect." With breast cancer:

It's the 'C' word meaning cancer. When people hear the word
cancer, it means death. That's what a lot of people have said to me.
That's what I have thought myself. To me, the 'C' word is a lot more
terrifying, is a lot more terrifying.

Talking with her oncologist has helped her somewhat in dealing with her issues concerning mortality. She asked him what was her prognosis. He responded "in the best way that he could" that "on a scale of 1-10. A person who doesn't have cancer has a one.

A person who has it ravaging through their body with bone cancer has a ten. There is a big range in the middle. . . Yours is at a five."

The numbers that Staci saw made her feel that hers "was not that bad." That helped her feel "I'm not going to die." Staci described dying as "not an option" but "that lingering little shadow is there."

In addition, Staci's husband's five year old nephew died of bone cancer prior to Staci's modified radical mastectomy. Staci stated:

. . . if cancer can take the life of a young boy, so can it with me. But his was a lot worse than what I have. I've seen cancer take the life of a five year old boy right at the time I'm dealing with this. He's been a catalyst for me. I've drawn strength from that little body. I got strength through that to fight it hard.

The Reach to Recovery volunteer told Staci about classes and support groups available through the American Cancer Society. Staci described she hasn't been able to attend any of them because of time. She also described that they were offered between 7-9 p.m. which was "a peak hour" for her children. She described her husband as "useless." He didn't do anything with them.

Staci described that it has been she herself who has helped her to get through this difficult period of time. Not having to work because she is on disability was helpful. She had one less thing to worry about. "Just not having to drive to work every day, deal with work," was helpful. But Staci stated: "I think I helped me deal with a lot. I am a person with my beliefs and my strengths and they've helped me a lot." She stated: "God didn't let this happen to me. I realize that I live in a sinful world. . . I just happened to have one of those bad things happen to me. I did nothing wrong. The Lord did nothing to punish me. Things happen. I am not of this world. I am in this world."

Staci described a need to gain strength from within to deal with breast cancer and its treatment. She stated:

You have to find the self within yourself to deal with this because you're going to have to deal with it. No one can tell you how you can deal with it. You have to find out for yourself. You cannot ignore the problem nor will it go away on its own. It has to be dealt with. You have to find it within yourself and with the help of others to deal with it.

After recalling some of the difficulties Staci experienced with her breast cancer, she concluded:

Today, western health care is a business, it's not health care. They really aren't focused on prevention like they should be. My infection could have been prevented. I had to fight for the wig. They really don't work to prevent things. I shouldn't complain too much because they have paid for everything. I haven't had to pay for anything. I've been lucky. You just have to stick up for yourself!

For Staci, although she experienced losses of her familiar world because of her experiences with breast cancer, her strong need for control was helpful to her in recovery. Karen also had a strong need for control which also was helpful to her in maintaining a sense of independence during her treatment for early breast cancer.

Karen's Story

Karen was 38 years old when she found her lump. A Caucasian woman, she was a wife, a mother of a six year old daughter, and a payroll clerk. She wanted to talk with me about her concerns, especially those about lumpectomy. We scheduled a time to meet that would be "after" her camping weekend with her family.

When laying on the floor with her arm supporting her head and watching television, Karen felt the lump in the upper inner quadrant of her left breast. It was the size of a quarter. She was not able to get it checked until a month later. Since she and her family were moving, she wanted to change her HMO to get care closer to her new home. She located a physician and changed her health insurance to a primary physician network of which the new physician was a member. The physician was on vacation at the time. Karen waited until her return.

After the physician examined her, Karen was scheduled for a mammogram and then a follow-up ultrasound. Because of the findings, Karen was referred to an oncology surgeon in the medical group. Two weeks later she had a biopsy and within three days, she and her husband were asked to come in together for the biopsy results. Karen stated: "I knew then that it was malignant."

At the office visit, the oncology surgeon confirmed that Karen had breast cancer. Karen described that visit:

He told us that I had breast cancer. He went into the background of breast cancer and the history of its treatment. He then made recommendations for my treatment which was a modified radical mastectomy which was totally unacceptable to me! He was an older doctor. I didn't personally like him. When I asked him about treatment, he would only say one thing, a modified radical mastectomy.

Karen had read about lumpectomy from the newspaper. She proposed that to the surgeon and told him that lumpectomy was also an option but according to Karen, "he said there wouldn't be enough left to support the breast. I was small breasted - a 36B. He said that there wouldn't be enough left."

Karen pursued another opinion but she stated: "I couldn't go out of the group." She did see another surgeon and oncologist in the group. They were all on the same tumor registry board and Karen stated: "They all said the same thing, a modified radical mastectomy." Karen called the American Cancer Society and got a list of recommended surgeons in her area. One of the doctors ran the Breast Center for the area. Karen described:

I felt more comfortable with him because he was younger and more up to date. I like what he said. He told about options - the modified radical mastectomy and the lumpectomy with radiation. We paid for that fourth medical opinion ourselves. I decided to go with him.

However, this required that Karen change her health coverage. With her health plan, she could change options annually and once a year for personal reasons. She had

changed her insurance when she moved her residence. They wouldn't let her use a personal reason because they felt that she was undergoing ongoing care. She had started chemotherapy before surgery. To make the change, Karen told them she had moved again and she gave them her friend's address.

Karen read so much during this time and talked to as many people as she knew, who knew about it. She wanted to get as much information as she could so she could get a grasp on it. She went to five different libraries. She read books and articles on diagnosis, treatment, and the subject. The Breast Center had a nice resource library and she went there too. She got lots of information from the American Cancer Society. She spoke to a volunteer there who was very helpful. The Breast Center also had information from the American Cancer Society.

Karen sought to understand. She had never experienced a serious illness in her family - not her mother, not her sister. Her dad's mother did die of stomach cancer but there was nothing on the maternal side. She had thought that her daughter was now at risk but that was described by her as immaterial now for "they don't know the cause of it." Karen evaluated her risk factors. She did give birth to her daughter after she was 30. She had other risk factors like the environment, stress - lots of stress! She stated: "I've had stress with my job. In fact, I just switched jobs in March. I had been working at this job for two years and I was doing payroll bimonthly. That was too much. I worked lots of overtime. I worked on the weekends. I didn't even quit work to do the chemo treatments."

Karen had surgery 13 weeks after she had found her lump. She took two weeks off of work for her surgery. On the morning of surgery, her concerns focused on her husband. She stated: "I wanted my husband there. My mother-in-law took me. My husband has a pretty high stress job and he needed to be there. I just felt abandoned. I needed a lot more support from him."

Karen described that "the surgery wasn't bad." There really wasn't anything that her husband could have done. His mom was there for her. She had come from a neighboring state. In addition, the surgeon was thorough. She explained everything she was going to do. Karen's fears were allayed.

Karen stated that she only told her sister early on that she had breast cancer. Karen thought she should know just for family history. Karen didn't feel like having the rest of family coming out from the East and "bombarding" her. She also didn't want them to worry. She did tell them right before the surgery. Karen stated that she was glad that she didn't ask for them to come out because "it really wasn't bad."

Postoperatively, Karen experienced only a problem with the drains. They became clogged and had problems draining. Additionally, she said:

I had never had surgery before so I don't know if it was difficult. It was hard for me to wake up after surgery. The anesthesiologist really doesn't know what dosages to give you. Well, it felt like I was hit by a truck. It took me awhile to get over that. I went in around 7 in the morning and got home around 5 p.m. I didn't do much around the house for the first couple days. I had swelling in my arm. His mom helped me.

Karen was happy with the appearance of her breast. She remarked: "It (my breast) looks fine now (after the surgery). I think I do need to go back and see my surgeon because this is just pulling the nipple a little."

However, Karen's concerns did change as she recovered from the surgery. By the time she returned to work two weeks after the surgery, she described: "I had lost my hair now. It was about three weeks after the start of chemo". Karen had three chemotherapy treatments before the surgery. She received cyclophosphamide, Adriamycin, and 5-FU (fluorouracil). She had them for about five months following the surgery also. She recalled:

I did pretty well. I did have concerns with the chemo. I needed to know about the drugs. There was a very, very helpful nurse over

there who answered my questions. She was very good. She told me to drink lots of water. The more water you drink, the faster it gets out of your system. She told me about all of my prescriptions but I only used them four or five times.

Karen stated that she had been told that she would lose her hair. She had received a business card of a wig shop at the physicians office. She stated that the salesperson was very helpful. Karen got the wig before she went back to work following surgery. She stated: "I didn't know how the staff would take it." Although her boss was aware of her breast cancer, Karen decided to tell her whole department at a meeting. Everybody knew that she had been going to see doctors. They thought that she was pregnant. Once they found out and knew what was going on, Karen felt that communication was opened. She felt supported; however, hair loss continued to be a concern for Karen. She remarked: "Even now, with my new job, it's just my wig. I wished I didn't have to wear it. I can't wait 'til my hair gets a little bit longer."

Immediately after surgery and when Karen was losing her hair, she called the American Cancer Society again. The Reach to Recovery volunteer came to see Karen right away. Karen recalled: "She was really nice. She gave me a lot of helpful suggestions and told me about all of the programs offered." Karen found out from the volunteer about the 'Look Good, Feel Better' program and she participated in it before she went back to work. She recalled: "It helped me a lot. . . . The lady at the Look Good, Feel Better program was so nice."

Karen also underwent two different types of radiation therapy. She was hospitalized for three days to receive brachytherapy. Radioactive implants were placed in her breast for 24 hours and were then removed. Karen stated "it was easy. The only problem we had with it was that I was hospitalized and our daughter couldn't see me but she called me on the telephone several times each day." Following that, she had eight weeks of external radiation, Monday through Friday. Karen would go to work. She used her lunch hour for the treatments. Each would take about an hour and a half. Karen

reported that she didn't have any problems with radiation. Her skin did get red like a sunburn but the red was now gone. She stated: "I lost a good layer of skin. It's still a little bit swollen but he said that it would be like that for a while."

Karen described her present concern as "recurrence, of course!" She is "also concerned if anybody else in her family will get it, like her daughter." She also has "a lot of concern for other women out there who are getting mastectomies recommended instead of lumpectomies." She would like to go to work for the American Cancer Society because Karen believes that "they can really help people. Women should not be getting maimed when they don't have to be!"

A sense of optimism was communicated by Karen. She stated: "My doctor thinks that they've done a really good job in arresting the cancer especially in the lymph nodes. He's going to be monitoring me closely for the next 2, 4, 6, 8 months with mammograms." However, Karen seeks to understand her situation. She confided that excessive worrying such as with her job "was part of the cause behind it (her breast cancer)." She made a job change during this time to make a difference in her stress level. She stated: "I can sit for maybe 20 minutes at work and not do a thing. I can get used to it! In my other job, I couldn't do that." Karen made the job change because she "wanted to make more time for family and help out other women in making their decision in the type of surgery and what they go through."

Karen described that her family and life has become more meaningful since she has experienced breast cancer. She and her family did more things together and she got more involved with them now; however, she'd like for them to do more. Having breast cancer has caused her to see things that she needed to do differently. She hasn't made all of the changes in her life that she wanted to make. She wanted to start going to church because she felt she needed to reset her priorities. She felt she needed to learn to worry less. Even her husband asked her why she worried and why she buried herself in the

ground about it? Karen described that she paid attention to particulars and that was important to her but it was also hard on her.

But Karen described concerns about her relationship with her husband. Their relationship had become somewhat better since she was diagnosed with breast cancer. He had concerns of his own such as the financial concerns of the family and on several occasions, she had talked to him about it. She stated however, that she needed him to be more supportive of her. People told Karen that the experience of breast cancer was hard on him. He read the paper to the husband from the American Cancer Society on how he could help her. Although Karen thought it was a little bit better, she felt that he really didn't understand. He's not as supportive as she'd like him to be. She thought it was because they needed to find some time to be alone by themselves. They were isolated from their families and friends with the move to their new home and they were feeling it more. Karen felt that they just needed some more time together and needed to make friends with new neighbors to help them "get back on target."

Karen thought in the beginning that having breast cancer would change the way she felt about herself but it really hadn't. She had done really well. She stated that people she knew said that she went through this so much better than the other people they knew who had gone through it. Karen recalled that she didn't take advantage of any support group of the American Cancer Society because she was busy with the treatments. She also crossed over three counties everyday for work and that took a lot of time but she had forgotten about the young adult support group in this area. She stated that she could have used those and still could.

To cope with the threat of recurrence, Karen confided that she found herself checking her breasts every time she showered. She stated she's doing a much more consistent job of checking her breasts. She's trying to keep on top of it by making sure she gets mammograms as often as she needs to and keeping to appointments. She stated:

"I found my breast cancer. It was the size of a quarter. I know about it. I think I can play a role in checking for recurrence if I can be on the lookout for it."

Karen communicated a genuine concern for self and other young adult women with breast cancer. She was very concerned about the poor care of the young women who lived nearby with breast cancer and who had received nationwide attention. She stated: "I thought that could be me. Make people more aware of those things. It seems like its rampant when you have it. When you don't have it, it's like somebody else's problem. So you just have to make people more aware of it. It can happen to anybody." Looking forward to the upcoming walk and run for breast cancer, Karen stated: "They are so important in increasing awareness. I'm going!"

For Karen, her strong need for independence although it was challenged by the experience of breast cancer, was also a motivating factor in her recovery. To Susan, her need for control helped her to endure the experiences of breast cancer; however, she suffered from losses in certainty of self. With an infant and seven year old son, her mothering role was greatly threatened by a diagnosis of cancer.

SUSAN'S STORY

At the age of 36, Susan, a Caucasian housewife and mother, underwent treatment for breast cancer. She lived with her husband and their seven year old son and 1 year old baby boy. Susan was eager to tell her story because she "needed to talk about it." She met me at the Y.W.C.A. the day following my call. She had planned to go shopping with her sister at the nearby mall. She thought that "it would be convenient to meet there" since she would be in the area and lived in the "outskirts of the city". She described her health insurance as 'private insurance.' She arrived at the Y.W.C.A. on time. She had been "dropped off by her sister".

It was Susan who found the lump in the upper inner quadrant of her left breast. After breastfeeding her baby who at that time was about 8 months old, her breast began to hurt and she felt that somehow it had been bruised. She called her physician. He wasn't

really concerned unless she could feel lumps. Since she hadn't checked, she sat down and checked. She found a lump. She was "a little concerned about it being cancerous but at the same time, it didn't act classically. It was painful, movable, and not hardlike." Since her mother had undergone treatment for breast cancer two years previously, she decided to see a nurse practitioner "just in case". Susan stated that the nurse practitioner "didn't think it was any big deal" and told her to "watch it." Susan's husband asked Susan to have somebody else look at it so within two weeks, Susan got in to see her OB/GYN physician.

The OB/GYN physician was concerned and sent Susan for an ultrasound of the breast. Two masses that were not cystic were identified. A referral to see a surgeon was made. Susan saw the surgeon between two to three weeks later. Her concerns at that time were:

... if it's something, at what point does it spread? ... You need to see somebody in my opinion as soon as you can and you know how busy they are. ... You don't know how big it is. You don't know how far it spreads when it does spread. If it was something, waiting wasn't something that I wanted. If my husband wouldn't have said anything, I would have waited for the routine OB/GYN appointment which was in about two weeks.

The surgeon told Susan that she "should have found it when showering" but Susan disagreed. She said: "Even though it was there, it was not obvious. Not unless I was checking, would I have found it!" The results of an ordered mammogram identified calcium deposits which according to Susan, "concerned them." For Susan, it was at that point that she decided that she "probably had it" but her husband said she "probably didn't." In her mind, she thought, "that's probably what it is."

About two weeks later, Susan had a breast biopsy as an outpatient. Her "biggest concern was living through the biopsy." She explained: "I had never had surgery. It scared me more to have surgery than to have breast cancer at that point. I thought I am going to die under anesthesia." She had general anesthesia for the procedure.

But Susan had an additional issue that she had to deal with at this time. She had to stop breast feeding her baby. Even though "he wasn't a good breast feeder" and her "first son weaned himself at around eight months", she had some difficulty with this. She said: "When somebody tells you have too, that bothers me more than if I decided it on my own. I thought he had made it through the first eight months which is the most important." Susan got through this period of time by continuing with her daily activities which included her water aerobics. She thought: "I have to do it so I said okay. I can go through it and not worry about it."

The actual biopsy itself went well for Susan. Her pastor was there and sat with her husband. She stated: "It really wasn't so bad. When I came out of it, I was elated not even thinking of the cancer." Susan was glad that she had come through it okay; however, she was told at that time that the biopsy "was cancerous." Immediately, she thought, "I'm probably going to die!" She became very scared. Her greatest concern focused on her children. She stated: "Them not knowing me really bothered me. If I die in a year, my baby wouldn't know who I was."

Although Susan was able to talk with her husband about her feelings, she described that "I got this feeling that it would be okay." From that point on, she stated she didn't worry. She described prayer as helping her through it. She attended church regularly. For her, the thought of how she found it "was sort of strange." If she would not have bruised it, she probably wouldn't have found it. Finding it when she did was "something religious." She stated: "I figured someone meant for me to find it. . . someone was telling me, it was going to be okay. I didn't worry a whole lot about it from then on."

But Susan worried about her lymph node status. There were two lumps and her surgeon was not optimistic. She stated: "He did not have a ray of sunshine, in fact he told me which I don't think he should have told me from the beginning that in the future, I will probably die of cancer someday!" This was very upsetting. For her, waiting for

the lymph node status became the worst part because her surgeon thought that they were going to be positive for cancer. Even though they were small, one was 1.2 cm and the other was 1.6 cm, he thought she was at least in Stage II ductal breast cancer.

Susan recalled that she really didn't learn about breast cancer from her mother's experience with breast cancer. Her mother lived out of state and it was difficult to talk with her. Susan however, received a lot of information from a woman in her church who was in her fifties. This woman had found out at about the same time as Susan, that she too had breast cancer. This woman who worked in a pharmacy, shared all of the information that she had obtained with Susan. Susan stated: "so that's how I learned about spreading, lymph nodes, and this type of cancer" and "it was helpful but confusing because where she got her information was oh, you don't get a modified radical mastectomy for they can do a partial!"

But Susan was not given the option of a lumpectomy. She stated: "My doctor said no, we use the modified." Susan stated: "I'm just the type of person who wants to be told that this is what is successful to use and this is what we should use rather than me having to decide." So Susan did not appreciate the difference in opinion offered by the woman from her church. In the long run, Susan thought that a modified radical mastectomy was the best route for her since it was the recommendation of members of the Tumor Registry Board. A modified radical mastectomy was recommended along with chemotherapy and radiation depending on lymph node results. In addition, Susan and her husband spoke with a plastic surgeon preoperatively to discuss reconstruction options. Susan thought: "... at my age, it would be easier to feel normal to a degree so at that point they decided that if I didn't need radiation, they would put this tissue expander in so I wouldn't have two surgeries especially how I felt about surgery."

During the time between biopsy and surgery, it was caring for her baby that was helpful to Susan. She described: "When you have a baby, it really keeps your mind off of things because you are busy. You're trying to do as much as you can with a baby."

But Susan was also concerned about having to make it through the surgery. Although she described removal of the breast as "no big deal," she became more concerned with the chemotherapy and losing her hair. For Susan, how she looked and felt were more important after the surgery than before.

Other things were helpful to Susan during this period. She called the American Cancer Society one to two days after the biopsy. She spoke with someone over the phone about the surgery and was forwarded helpful information in the mail. She had been referred to the American Cancer Society by her friend whose husband had testicular cancer. Susan also called the National Cancer Institute but she received a recording so it was not helpful for she "needed to talk to someone at the time and not later." In addition, she received support from the group of ladies she has lunch with every month. She also received lots of cards and letters from the people in her church everyday. She felt supported.

On the morning of her surgery, "making it through the surgery" was described as her concern that morning. She had to wait at least one or two hours for surgery. There were people ahead of her. There were emergencies. It was scary for her. She observed other people who had more problems than she did. She thought that seeing them helped her get through it along with believing that so much of cancer was curable. She had got that from the information she had read. She stated: "If you catch it early, your prognosis was very good."

Susan recalled that it felt good to make it through the surgery but that it did hurt. All of the 22 lymph nodes were negative. She described: "I was more concerned about the pain. I was concerned about the drugs." Susan didn't like the drugs that she had been given. According to her, "Tylenol would have been fine!" She described the care provided by a nurse:

In the morning I was having a panic attack. I was getting really scared. The drugs were making me feel really odd. . . . I asked her to

sit down with me which she did and then they gave me drugs to try to calm me down. . . . It was more about the drugs. I thought I was going to die in the hospital. . . . The nurse was very good.

Susan was happy that she had stayed overnight in the hospital. Her physician had told her: "if I hadn't had children, he would have sent me home after the surgery but I needed time to rest so I was to stay overnight." Susan remarked:

I think it was a good idea to stay at the hospital. You don't know the things that come up. You got people there who do know what's going on, how you're feeling, and they can get the things you need immediately. That makes you feel more secure. If you're home, if they did have nurses who went with you, that would be better. As long as there's somebody there who knows what is going on in case something happens, you can know if it's normal.

Upon discharge from the hospital, Susan described that things went well. It was a couple of days until she was doing normal things. She immediately quit the drugs. She was really tired. For Susan, the tissue expander hurt and the drain was described as "awful." Susan's husband took care of it for her. Susan didn't go out because of her physical discomfort.

During the month following surgery, Susan's two sisters stayed with her to help her with cleaning, cooking and watching the kids. "It was helpful." As described by Susan: "when you're not feeling great especially when you like things clean and you wake up and everything is a mess and you don't feel like cleaning, having somebody there to address those needs and make it mentally easier on yourself helps." Additionally, Susan described her sisters and mother as "up people." They were supportive and "they said everything was going to be fine. They were going to take care of everything."

During this time, Susan called the Reach to Recovery Program but no one returned her call. She had no trouble with her arm. She was able to move it ten days after surgery. There were no special precautions for her tissue expander; however, she did follow the safety precautions for her arm. She became more careful when gardening

and being with her cat so that her arm wouldn't get scratched and develop a problem with infection. She received written instructions concerning the arm precautions.

Susan underwent chemotherapy treatment. Because she had heard of chemotherapy causing tiredness and since she had no lymph node involvement, she requested starting chemotherapy after the Christmas holidays. She joined a study based on the recommendations of the physicians whom she described as "kind of like God." Her chances of getting cancer again would be reduced from 50% to 5%. Susan felt that six weeks of "feeling crummy" was worth it to minimize risk.

In this study, the group of participants to which she was randomly assigned received six courses of the drugs with stronger dosages each time. The other group's treatment schedule for the individuals included four courses of treatment in which the drugs were given on successive days with additional blood work required. Susan was happy to be assigned to her group. She did not like to get blood draws.

Susan stated: "I didn't get any information to prepare me for chemotherapy." She received six courses of Adriamycin and cyclophosphamide every three weeks. Her last dose was received a week prior to this conversation. She stated: "Having chemo is not wonderful. . . . It doesn't make you feel great!" She described that first two cycles "weren't bad" but she didn't realize that it was not the same everytime. It "became harder each time on the body." She did not feel as good as the first couple of times. The nausea wasn't bad but she just didn't feel good. She got headaches which lasted a long time. She got back pain with the neupogen shots. She tired toward the end of each cycle.

Susan also developed associated nausea in which everything she correlated with the clinic where she went for chemotherapy made her feel nauseous. She continued to become nauseous when she saw 'Jolly Rancher's' candies because they were on the counter of the clinic even though she never ate them. She also developed nausea when her port-a-catheter was used for intravenous access. It had a rubbery smell.

Susan also lost her hair. It started falling out two weeks after the first cycle of chemotherapeutic drugs. She described it "raining hair" when she shook her head. She found it depressing to slowly watch her head get smaller and smaller. Her wig came in three weeks after she started chemotherapy so she dealt with hair thinning for one week. Once she had her wig, she shaved her head. She had ordered it when she had talked to the doctor and he had said that she was probably going to lose her hair. She went in immediately so they would know what she looked like before so they could cut the wig similar to her usual hairstyle. The doctors had given her a couple of names of people to see for the wigs. She wanted to do something so that she wouldn't have a gap and feel uncomfortable going out.

Susan felt prepared for losing the hair on her head. They had told her that she had a 99% chance of losing it; however, she was not prepared to lose her body hair. She remarked: "My eyebrows and eyelashes went before too long. I just wanted prepared for that. I haven't had to shave my legs so he was off on that one."

Susan wasn't able to keep up with things at home while undergoing chemotherapy. She liked to cook but when she didn't feel like eating, she didn't feel like cooking. She felt guilty about that. Preparing food did not make her feel good. At times, she felt like an awful mother. She didn't want to feed her baby. She did it but she didn't feel good about it. She didn't feel like spending time with her children. That made her feel bad. She felt that her children weren't getting the time that they needed especially the seven year old. She thought that her seven year old had more of a problem coping with mom not spending time with him.

The threat of neutropenic fever was also a concern to Susan especially after she experienced it following the third cycle of chemotherapy. When she went in for the fourth cycle, the staff didn't see any parameters for reducing the dosage. They were going to give it to her straight again. She thought they noticed that she looked panicked. She said, "you've got to be kidding!" She became very upset so they double-checked her

chart. When they came back, they said, yes there was something in there that they had missed for decreasing it which made her feel a lot better. Even though they tried to reassure her that this didn't necessarily happen, she had it in her mind that it was going to happen. She was really concerned about it. They had told her in the beginning and had put the fear of God in her; that is, when you get a temperature, you come to the hospital because people die of temperatures in a day or two if they don't.

To cope with these thoughts and feelings, Susan talked to her husband about it. He was very supportive. He would tell her that it's normal and not to worry about it. Talking to the doctor helped a little bit. He said, you're going to get tired, you need to take time for yourself. Don't worry about it. The kids will make it. They'll do fine. Susan made arrangements for her mother or one of her sisters to be with her for each of the remaining cycles. They helped especially with the children. For example, on spring break, her little sister took her seven year old son to Disneyland for Susan. After have neutropenic fever, Susan's physician preferred her to stay home.

In addition, the people in Susan's church were available to help. Although Susan felt "a little guilty taking people up on things", she knew that if she needed somebody, she could have called them and they would have been there and would have taken the children. She would have also had their support if her family wouldn't hadn't been able to help her or if she hadn't had a family.

However, Susan communicates great concern about her future. She has become focused on the threat of cancer spread. Her mother is undergoing testing for metastatic bone cancer. Susan thought that when her chemotherapy treatments were done, she would "be done with it." But with her mother's threat of metastatic breast cancer, Susan has developed a fear of "maybe it's not over." She described that fear as having become a part of her. She stated that her fear may be part of the doctor's fault for he told her, "you probably will die of cancer." He reinforced the thought that once you got cancer in your system, it's in the body. She stated: "At some point later, it may be 20, 40, or 60 years

later, it will pop out and you'll get it again." Susan worried that it might be soon. She stated:

I want to be around for my children. I want to have an influence on how they are raised. . . . Once you go through cancer, I know it's the old theory but you associate death and cancer together. Now with all the things they've been doing and all the people who live, grow up, and live through it, there is still the fear that you will die from it. It's always in the news.

Susan recalled a negative experience when she was on the "cancer unit" for her neutropenic fever. She saw other women with terminal breast cancer. Watching the care of them bothered her a lot. She didn't think that they were well taken care of. She remembered telling her husband about the woman next to her who had advanced breast cancer. She told him: "If I get to that point, don't do to me what they did to her - extend it and leave her." Seeing that type of thing upset Susan. She stated: "I do not want to die from cancer especially when you see people at the end. It is really awful."

To deal with the threat of spread, Susan described that being informed has been one of her "biggest allies." Although she didn't like being overinformed, she described that it was important to know things ahead of time. There were many decisions that needed to be made. She needed to be comfortable with her decisions. She also stated that she needed to be able to actually tell the doctors things and show that she was participating.

Susan described several other things that have helped her to cope. Watching comic shows such as "I Love Lucy" was helpful. Laughing made her feel good. It helped her feel positive. She also tried not to think about it. She stated: "When I do, I get scared and I sort of talk to myself, kind of you'll be fine. This type of thing. Eventually I get myself out of it. I just work it out myself. Talking it through to myself is one of my best things." Susan also talked to her husband. She stated: "He's probably the person I

talk about it with the most. He's a very optimistic person. He helps me get through it the most."

Susan described that she doesn't take things for granted anymore. She quipped: "That's something that old people talk about." She tries to enjoy her children a little bit more. When she gets mad at them, she now feels guilty. She thinks she shouldn't be mad for she could be gone tomorrow. She stated: "I want at least 10 years with them. Should my husband remarry after I die, I want my children to have been loved enough. I'm not sure another woman could love them enough."

Susan has not attended any support groups. She hasn't felt well enough to go because of chemotherapy treatments but she has thought about going. Her family has been very supportive to her. When she feels "really awful", she calls one of her sisters and talks to one of them over the phone. She feels lucky to have such a supportive family; however, Susan does feel that talking to people who have gone through it, have children, and have the same fears, would be helpful to her. She described: "Even though I'm almost done with chemo, the fears really never go away. They come back once and awhile. I think talking to people who have gone through it - they may know something that I didn't know about."

Susan described that her whole outlook on life has changed by her experience with breast cancer. She stated: "Death is something that's not there and now you realize it. So you have to start coping with it. I don't know if I've completely coped with it. I think it's a long process."

CHAPTER FIVE

FINDINGS

In the stories of the five young adult women, I identified three themes in their journeys through the treatment of early breast cancer. For these women, their experiences with early breast cancer and its treatment involved dealing with "I'm going to die!" reassessing self, and seeking help from others (See Figure 1).

"I'm Going To Die!"

"I'm going to die!" was a central theme as these young adult women experienced early breast cancer and its treatment. When Angela was told that the biopsy results were positive, she thought: ". . . oh my gosh, I have cancer!" Staci cried when she heard that her biopsy was positive for breast cancer. Jennifer described being shocked by the results: "I had never imagined that it would be cancer because of my age and so did everyone else. . . I cried. All I could think about was I'm going to die!" When Susan was informed, immediately she thought, "I'm probably going to die." Because she had two lumps, she stated that her surgeon was not optimistic. Susan recalled: "He did not have a ray of sunshine, in fact he told me which I don't think he should have told me from the beginning, that in the future, I will probably die of cancer someday!"

As the young adult women progressed through treatment, they dealt with "it's the 'C' word". Several worried about living through the associated surgical experiences and dying from complications of chemotherapy. The threats of recurrence and metastasis were uppermost in their minds as they contemplated "not living forever".

It's The 'C' Word

Although finding a lump was accompanied by "little" or "no concern" for the young adult women participating in this study, when they heard that their biopsy results were positive for breast cancer, the thought "I'm going to die!" was engendered. Staci

said that this was because "it was the 'C' word, meaning cancer." She described that when you hear the word 'cancer', it means death. She said that a lot of people had said that to her and that's what she thought herself. To her, "the 'C' word was terrifying!"

Jennifer related her concern of not knowing someone close to her own age with breast cancer. This made it more difficult for her not to correlate breast cancer with death. She stated: "I know older women like my mom's age who are fine but I don't know anyone my age and that would help."

Living Through Surgery Itself

For several of the young adult women, having to undergo surgical experiences evoked fears of dying. For Susan and Staci, "living through the biopsy" became the major concern as they underwent their biopsies. Susan described: "I had never had surgery. It scared me more to have surgery than to have breast cancer at that point. I thought I'm going to die under anesthesia." When she awoke following the biopsy, she stated: "I was elated not even thinking of the cancer!" For Staci, the biopsy itself was the concern but the lump being cancerous "never" entered her mind.

"Making it through the surgery" was also Susan's concern as she prepared for her modified radical mastectomy. She described that this surgery was more involved and she had more time to think about it. When signing the consents for surgery, Jennifer stated: "I became really worried that I could die from the surgery itself. I didn't want to die!" She wished they would have given her a "Valium" with which to relax.

Staci also talked about her fear of the surgery itself. She stated: "You just don't know a lot when you go into surgery. . . You have to sign all these papers that say if you die, will you want extraordinary means? . . This was mind boggling for me!" Staci wondered about the hospital and its credentials.

While, the thought of breast reconstruction was helpful to the young adult women in dealing with the loss of their breasts, the threat of dying from the surgery itself lingered on in their minds. Susan had breast reconstruction at the time of her modified radical

mastectomy since her lymph nodes were negative and because her surgeons were aware of her feelings about dying from surgery. Jennifer described that because of her new job, she didn't have health insurance now. Breast reconstruction was postponed. She stated: "A part of me is a little grateful that I can't get it right now because I'm afraid of surgery. Maybe in a year!" Staci described that she would be getting breast reconstruction. She stated: "I don't enjoy the thought that they will be cutting on me. After I'm done with the treatment and the insurance will pay for it, maybe I'll feel better after that but it's a mortality issue for me."

Dying From Chemotherapy Complications

Two of the young adult women feared dying from the complications of chemotherapy. Susan experienced neutropenic fever following her third cycle of the chemotherapy drugs. Although she knew she had contributed to its development by going to her water aerobics class when she had a cold, she still developed a fear of dying from neutropenic fever. She stated that her physician had "put the fear of God in me. When you get a temperature, you come to the hospital because people die of temperatures in a day or two if they don't." And as Susan was hospitalized for neutropenic fever on an oncology unit, she witnessed several other women dying from breast cancer. Even the other woman in her room had advanced breast cancer. Susan told her husband: "If I get to that point, don't do to me what they did to her - they extended it and they kind of left her."

Additionally, Angela viewed an advertisement video concerning the use of the nutritional supplement, blue green algae. In the video, she saw and heard that individuals undergoing chemotherapy die from malnutrition. She started taking the supplement blue-green algae that day and considered "juicing to rejuvenate her blood and detoxify her body" to prevent dying from malnutrition in herself. She wished she would have had a nutrition consult prior to the start of her chemotherapy.

"Not Living Forever!"

For the young adult women, "not living forever" emerged as they recovered from their surgeries and progressed through chemotherapy treatments. The threats of recurrence and metastasis were uppermost in their minds as they contemplated their futures.

Karen described her present concern as "recurrence, of course!" To deal with this threat, she planned to undergo routine mammogram follow up and also perform self breast exam. Susan spoke of recurrence as her greatest fear. Since metastatic bone cancer was suspected in her mother diagnosed with breast cancer two years ago, Susan did not feel that her experience with breast cancer would be over as she had hoped at the end of her chemotherapy cycles. She stated that she had come to worry that "it will pop out" with recurrence "being soon." She stated: "Death is something that's not there and now you realize it. So you have to start coping with it. I think it's a long process."

Hearing about others whose breast cancer had spread into their bones, Angela spoke about a fear of the cancer "coming back." She stated: "I have a 60-70% chance that it could come back in my other breast." She identified the need for her cancer to be tracked more effectively. She wanted there to be a way that the physicians could tell if the cancer was spreading. She felt that she and other patients should be kept better informed. She was fearful of dying from malnutrition. She planned to maintain a nutritious diet.

Staci stated: "When you're younger, you feel like you can live forever. When this happens, you don't know. You question your mortality. . . it makes you stop and think and rethink things that life does not promise you anything." Jennifer also remarked: "I'm not going to live forever. I feel it's hard not to think about it all the time." She described that it was unlikely that she would get local recurrence. It was more likely that she would have metastasis. She described herself in the middle between Stage I and Stage II of

breast cancer. She stated: "I am afraid and I don't like being there. My doctor doesn't blow it off either."

Reassessing Self

As these young adult women were changed by confrontation with their mortality, each sought to find herself again. Each struggled to find inner strength to endure the difficulties they encountered. Each had "to stick up for self" as issues concerning receiving prompt treatment, deciding between treatment options, being prepared, and dealing with early hospital discharge were confronted. Each sought to rebuild body image and regain a sense of focus in her life.

Finding Strength From Within

Each of the five young adult women spoke about finding inner strength to help her get through the difficult experience of early breast cancer and its treatment. As described by Staci:

You have to find the self within yourself to deal with this because you're going to have to deal with it. You have to find out for yourself. You cannot ignore the problem nor will it go away on its own. It has to be dealt with. You have to find it within yourself and with the help of others to deal with it.

Having faith, being positive, and being hopeful helped these young adult women to find strength within themselves to deal with the experience of early breast cancer and its treatment.

Having faith in God. For Angela, Karen, and Susan, it was their faith in God that helped them to find inner strength. As described by Angela:

I believe my faith held me up. God is a Healer. If He wants to heal me, He'll heal me. If He doesn't want to heal me, then I'm just going to go through the stages and He'll walk it out with me. So that's how. . . I prayed. I asked Him to help me. It helped. It helped.

Angela recounted often that she got her strength from God through prayer. Karen described her faith as more meaningful to her as she completed her treatment. She worked toward going to Church with her family more often.

Susan also identified the helpfulness of prayer during this time. Through prayer, she would develop the thought that "everything would be okay." For her, the thought of how she found her breast cancer "was strange." She stated: "I figured someone meant for me to find it. And the feeling that it was going to be okay because I am on the whole a pessimist. I think God figured, someone was telling me, it was going to be okay." She found herself not worrying after prayer.

Being positive. Several of the young adult women identified that being positive also helped them to gain the inner strength to deal with the experience. Angela described that when she was worrying:

. . . I'd say be positive. You have to be positive all the time. If you're not positive, then you're not going to make it. It's up to you. If you're going to be down, you're going to be down but it's all in your head. You have to be positive.

She described that she did not let anything get her down because she did not want her family to see her down. She wanted to communicate that everything was fine for she believed that as long as she was fine, her whole family would be fine.

Jennifer stated: "Overall, the feeling I was positive got me through it but this certainly isn't the time to learn to be positive. You can't learn to be positive with this experience." Susan also reinforced that need of being positive. She stated: "I try to be positive. This changes your whole outlook." She discussed the use of laughter in helping her to feel positive. She stated: "I love to watch comic shows such as 'I Love Lucy' and ones that are funny and you know that helps. Laughing - it makes me feel good. I feel it works. It helps you feel positive." In addition, Susan also described: "I sort of talk to myself, kind of you'll be fine. . . Eventually I get myself out of it. I just

work it out myself. Talking it through to my self is one of my best things" in becoming positive.

Being hopeful. Being hopeful was also instrumental in these young adult women in finding the inner strength to deal with their experiences. Because they did not know other young adult women who had been through it, hoping that everything would be fine was often hard. Angela described: "I thought that all I can do is hope that everything is fine." Susan stated: "I just sat there and hoped to make it through the surgery." Staci remarked: "I absolutely refused to think the worst!"

Being hopeful was very important to Susan. She worked hard to regain hopefulness after her surgeon told her that in the future, she would probably die of breast cancer. "Thinking so much is curable" especially if the breast cancer was caught early helped Susan to find the strength within to get through this time. She also compared her situations to other people's situations and realized that there were others who had more problems than she.

The need to have hope was noted in the struggles of several of the young adult women to determine their prognosis. Angela needed to know from her physicians if the chemotherapy was working. All they told her about was her platelet count. Staci asked her oncologist to try to explain "as best as he could" her prognosis. On a scale of one to ten, he placed her at a five. Staci stated: "the numbers that I saw made me feel that I'm not going to die. It's just not an option for me but that lingering little shadow is there." The death of her young nephew from bone cancer was described by her as a "catalyst." She stated: "I've drawn strength from that little body. I got strength through that to fight it hard." Karen communicated hopefulness when her physician stated that he thought that "they've done a really good job in arresting the cancer especially in the lymph nodes."

Each of the young adult women talked about not knowing someone young who had been through it. Staci stated: "Knowing someone similar who has gone through it, would tell me everything would be okay." Jennifer related her concern of not knowing

someone closer to her own age with breast cancer which made it difficult for her to look into her future. She stated:

The only young person I know who had breast cancer was 31 and now is 42. She has lived ten years. My friend has ovarian cancer and she's probably not going to. I know that's different from me but that's hard for me. For her, unless she has a miracle she probably isn't going to live five years and she can't even think five. I know older women like my mom's age who are fine but I don't know anyone my age and that would help.

Getting A Grasp On It

Each of the young adult women spoke about the need for "getting a grasp on it" as they were diagnosed with breast cancer and underwent treatment. Angela described breast cancer as: "It's in the dark! Angela described a need "to ask the doctors all these questions." Others identified a need to get information so that they could understand more fully what was happening to them. Each spoke about not knowing someone young with breast cancer. Staci had the need to tell everyone. Karen and Angela sought to understand and explain their breast cancers.

"It's in the dark!" Angela described breast cancer as: "It's in the dark! You know nothing about it until you experience it. When it came to me with the lump, I thought I don't have cancer. I don't know anything about breast cancer!" Several of the young adult women talked about the usefulness of information to them at this time.

Karen described what she did at this time:

I read so much during this time and tried to talk to as many people I knew, knew about it. I wanted to get as much information as I could so I could get a grasp on it. I went to the libraries. I read books and articles on diagnosis, treatment, and the subject. I went to five different libraries. The Breast Center has a nice resource library and I went there too. I got a lot of information from the American Cancer Society. I remember talking to a lady there and she was really helpful. The Breast Center also had information from the American Cancer Society.

Jennifer described "reading so much to help me get through this period of time" to get a grasp on it. Besides getting information from a friend of her mother, she too contacted the American Cancer Society. She stated: "The information was so helpful." Susan described that information was also important to her at this time. She, too, called the American Cancer Society. They answered her questions over the phone and also sent her information. She also called "NAPCO" but she received a recording. She stated: "I didn't pursue that again. I needed to talk to someone at the time and not later."

However, two of the young adult women did not identify the usefulness of information to them during this period of time. Angela stated that her physician gave her information about surgery and treatment; however, she remarked: "I didn't read up on everything that he gave me. I just wanted to know what my case was and what the possibility was for cancer." Susan received information from a woman in her church. She stated: "it (the information) was helpful but confusing because where she got her information was oh, you don't get a modified radical mastectomy for they can do a partial." Susan described herself: "I'm just the type of person who wants to be told that this is what is successful to use and this is what we should use rather than me having to decide."

Not knowing someone young with breast cancer. Each of the young adult women spoke about not knowing someone young with breast cancer. This made it difficult for them to imagine that someone young like themselves could develop it. Jennifer stated that even the medical staff she came in contact with when she sought follow up and treatment for her breast lump "weren't concerned about it because of my age, so I too was not concerned!"

Staci told everybody about her diagnosis of breast cancer. She found that "telling everybody helped to get a grasp on it." She stated: ". . . if it could happen to me, a 33 year old black female, that is not a category for which it could happen . . . it could happen to anybody." Most of the people she knew with breast cancer were over 40 years of age.

She stated: "Look at me. I was only 33 years old. If it happened to me, it could happen to you!"

Making sense of the experience. Karen and Angela described a need to understand and explain the cause of their breast cancers. Karen "had never experienced serious illness!" No one in her family had ever been ill. She reviewed her risk factors for breast cancer. Although, she had given birth to her daughter at the age of 30, she felt that it was the "environmental factor of stress" that caused her breast cancer. She was experiencing great stress in her job as a payroll clerk. She worked lots of overtime and weekends to get the payroll out every two weeks. Staci stated that her diagnosis of breast cancer had made her stop and think that "life did not promise anything. Anything can happen to anybody and I am not alone." She did not feel that she was at risk for breast cancer. She described herself as the "most least prospect" for breast cancer. She remarked; "If it could happen to me, it could happen to you!" She also stated: "God didn't let this happen to me. I realize that I live in a sinful world. . . I just happened to have one of those bad things happen to me. I did nothing wrong. The Lord did nothing to punish me. Things happen. I am not of this world. I am in this world."

Angela sought to understand her breast cancer. She stated:

There are reasons why things happen to you. Maybe, to bring me down to my knees more, maybe to tell my husband hey, there is a God out there. My husband and I have gotten closer because of this. It has brought me to my knees. My husband is amazed at me. She has cancer but it doesn't look like she has cancer. She's acting just like she doesn't have anything.

She also recounted often: "I did what I was supposed to do" thinking that this would influence the course of her disease.

Sticking Up For Self

As the young adult women sought follow up and treatment of their early breast cancer, they advocated for themselves. Staci remarked: "Today, western medicine is a

business, it's not health care. They really aren't focused on prevention like they should be. . . I shouldn't complain too much because they (her HMO) has paid for everything. . . You just have to stick up for yourself!" Jennifer described that one had to be brave in dealing with treatment issues. The young adult women confronted issues concerning seeking prompt treatment, deciding between treatment options, being prepared, and dealing with early hospital discharge.

Seeking prompt treatment. Each of the five young adult women participating in this study identified the need to seek prompt follow up of their breast masses but only Angela received prompt follow up. She was able to have her lump checked by a physician within two days. Susan called her physician immediately but he was not concerned unless she could feel lumps. When she rechecked her breast, she found a lump but she wasn't concerned because "it didn't act classically." It was painful, movable, and not hardlike. Since her mother had undergone treatment for breast cancer two years previously, she decided to see a nurse practitioner the following day. According to Susan, the nurse practitioner "didn't think it was any big deal" and told her to "watch it." Susan's husband asked Susan to have somebody else look at it so within two weeks, Susan got in to see her OB/GYN surgeon. She saw the surgeon between two to three weeks later.

Staci had a routine appointment with her internal medicine physician in two weeks, she waited until that time to get her lump checked. She was referred however at that time to her OB/GYN surgeon and waited two weeks longer for evaluation of the lump. Although Karen made an appointment to have her lump checked within two days, she waited a month because of insurance reasons associated with her family's move to a new area. Having no health insurance, Jennifer went to a social service agency for a mammogram. This service was not provided by the agency but a list of facilities where low cost mammography could be provided was available. From this list, Jennifer located a facility and had a mammogram taken. About three weeks later, she underwent a biopsy.

Although each of the young adult women knew to get the lump checked, prompt follow up of their lumps was not realized. Each had to advocate for herself to assure that their lumps were followed up.

Karen had to deal with changing her health care coverage to get the care she wanted. Another had to seek health care coverage and had to deal with lapses in coverage due to change in employment. Each had to find a way to deal with the situation at a time when each was facing a diagnosis of breast cancer. Each strove to assure that they got the level of care they wanted.

Initially, Karen sought to change her health care coverage because she and her family were moving to a different area. They decided to change their health insurance so that she could get health care close to where they would be living. Karen selected a primary care network in order to get a specific physician.

However Karen wasn't satisfied with the care offered by surgeons in that primary care network. She did find a surgeon, but he was located in another area. This required another change in her health coverage. She experienced difficulty in making this additional change. She stated:

I wanted to take my option although I had taken one option when I had moved. You can change options annually but then you can change your option once a year for personal reasons. They gave me a hard time. They wouldn't let me use my personal reason because they felt that I was undergoing ongoing care. You see, I started chemo right away even before surgery. At first, they wouldn't let me. So I told them I had moved again and I gave them my friend's address. They use a perimeter in that area and she lived in that perimeter.

Karen changed her health care coverage by giving her friend's address.

Jennifer's situation was different. Although she worked full time, she did not have health insurance. Highly motivated to be independent and aware that the suspicious area on her mammogram needed follow up, she purchased private health insurance through

her place of employment. She was able to get it at this time because no diagnosis had been established by the date of purchase. She felt fortunate.

When Jennifer's job was terminated as she underwent chemotherapy treatments, she lost her insurance coverage. With the help of her oncologist, she went on disability but this was short lived also. According to Jennifer, "I talked to the disability people. They said that they have charts that say I should be okay. So I lost it." As a result, Jennifer went on unemployment. She felt demoralized. As chemotherapy cycles ended, she searched for a new job in order to maintain her level of "independence." Although she found a position with health insurance as a benefit, it was three months until that benefit became available. Jennifer looked forward to that day and realized that she would always need a job with health benefits. According to Jennifer, her breast reconstruction was placed on hold.

Each of the young adult women underwent biopsy within one week following surgical consultation. Results were obtained immediately for one of the young adult women. Three knew results within three to seven days. One waited two weeks for results. The time from finding a lump to mastectomy for these young adult women was 4, 7, 7, 10, and 13 weeks. It was Karen who had surgery 13 weeks after finding her lump. She sought four "second opinions" until she was able to find a doctor who would perform a lumpectomy. She changed her health care coverage twice.

Deciding between treatment options. For these young adult women, once the diagnosis of breast cancer was confirmed, treatment was discussed. Each of the participants was told about modified radical mastectomy, lumpectomy with radiation, chemotherapy with radiation, and reconstruction. Only two of the young adult women spoke of surgical options between modified radical mastectomy or lumpectomy with radiation. For three of the young adult women, decisions regarding the type of surgery were made quickly with modified radical mastectomies selected due to cosmetic purposes as recommended by their surgeons. One of the young adult women selected a modified

radical mastectomy immediately due to fear of cancer spread. Karen was the only young adult woman to receive a lumpectomy. She had to advocate for herself to accomplish this.

When Karen was told that she had breast cancer, the recommendation of modified radical mastectomy was unacceptable to her. She was told that a lumpectomy was not a consideration for her because according to the surgeon, "there wouldn't be enough left to support the breast. Karen pursued another opinion but she stated: "I couldn't go out of the group." She did see another surgeon and oncologist in the group. They were all on the same tumor registry board and Karen stated: "They all said the same thing - a modified radical mastectomy."

Karen was not satisfied. She called the American Cancer Society and got a list of recommended surgeons in the area. One of the doctors ran the Breast Cancer Center in a nearby area. Karen described:

I felt more comfortable with him because he was younger and more up to date. I like what he said. He told about options - modified radical mastectomy and the lumpectomy with radiation. We paid for that fourth medical opinion ourselves. I decided to go with him.

Dealing with early hospital discharge. Each of the young adult women experienced significant weakness immediately following their mastectomies. They were unable to care for themselves. They had surgical drains that needed care but they were unable to do so. They had pain and limited movement in their arms because of the lymph node dissection. Each had to deal with the experience of early hospital discharge. Staci called it "a battle." Three of the young adult women complained about their early discharge from the hospital. One spoke to the recovery room nurses to no avail. Only Staci confronted her doctor about the unreasonable expectation of being discharged at a time when she "wasn't sure on her legs."

Karen was discharged in the afternoon after having surgery earlier in the day. She felt like she had been "hit by a truck." She was happy that her mother-in-law had come to

be with her through the surgery. Because she needed rest but had two small children at home, Susan's surgeon had her remain in the hospital the first night following surgery. Susan was happy that she stayed that first night. She experienced an adverse drug reaction and needed a nurse to be with her. She also spoke about being fearful because she had never really experienced this level of surgery before. She was happy to have staff available who knew what to expect. She felt ready the following morning to go home although she needed help even in caring for herself. Her two sisters stayed with her and her family for the month following her surgery to provide assistance. But Jennifer didn't share Susan's sentiments. She stated: "My insurance company made me leave in 24 hours and I didn't like that." She "ended up" going to the home of her parents for a week to get the help she needed since she lived alone.

Angela described that she and especially her husband were disappointed in having to leave the hospital early in the afternoon on the day of her surgery. Weakened, she was barely awake. They were fearful, not knowing what to expect. This was her first surgery. Although they gave her instructions on how to care for her drain, she was unable to care for it. Her husband and mother had to do it for her. Angela stated that she questioned early discharge but the recovery room nurses told her "that was the procedure."

When Staci saw her physician the morning following surgery he told her "to go home." She told him that she had barely gotten out of bed, that her left arm hurt, that she "wasn't sure on her legs," and that she wasn't ready to go home. He told her about an older woman who had the same surgery who was going home that day. Staci responded: "I'm not her!" Her surgeon told her that she would be more comfortable in her own home environment. Staci replied: "I know my own home and my own environment and I'm not ready to go home." Her surgeon gave her permission to stay another night but he said to her: "You better get your butt out of this bed and get around and see how things feel." Susan described that she didn't want to stay in the hospital. She needed it. The next morning the nurses woke her up at six o'clock. They taught her how to empty her drains

and measure the drainage. She stated: "They kicked me out by eight o'clock." Staci was angered that she didn't see her physician before her surgery, he spoke to her a day and a half after the surgery, and then when he did see her, he said good-bye. She felt "like herded cattle." She described her hospitalization as "a lack of anything good!"

Dealing with treatment effects. Only Staci received information about the Reach to Recovery Program during her hospitalization although Angela's surgeon encouraged her to find others who had been through mastectomy and to talk with them about it. Each of the other young adult women called the American Cancer Society on their own. They had heard of some of the services of the American Cancer Society from friends and advertisements. As the young adult women progressed in their treatment, they advocated for self to get prompt treatment.

Staci developed a suture line infection following surgery and she was angry. She felt that since she had a history of lupus, she should have received prophylactic antibiotics. She had to call and demand an appointment with the surgeon the day she noted that she had drainage from her suture line that smelled. The office nurse thought she could wait until the end of the week. Susan developed neutropenic fever following her third cycle of chemotherapy. At that time, the oncologist had told her that the next chemotherapy dosages would be reduced. When Susan went in for the fourth cycle, the staff prepared full drug dosages. She said, "you've got to be kidding!" She became very upset so they double-checked her chart. They missed the new orders for decreasing the dosages. She received reduced dosages. If she wouldn't have gotten upset with them, she would have received the higher dosages.

As treatments progressed, "chemotherapy became harder on the body" and they experienced difficulty in carrying out daily routines. Two of the young adult women talked to their oncologists about these hardships. For Staci, she told her oncologist: "I've failed. I can't do this, take care of my family, and do my job with this going on!" He arranged medical disability that day. He also gave her five Elavil tablets to help her get

some sleep. He wrote in her chart "she gave me tears in the office." Staci was upset by that entry. She stated: "I didn't think that was an important thing because he didn't know how I felt." Jennifer was also placed on medical disability during this time.

The young adult women advocated for self in procuring wigs. When Susan was told that she would probably lose her hair on her head, she went immediately to get a wig so that it would look and be cut to her usual style. It was her own thought to go immediately. Her physicians had given her a list of names to see for the wigs. Although Susan experienced little difficulty in obtaining a wig, two of the other young adult women confronted difficulties. Angela called the American Cancer Society for loan of a wig but she was not satisfied with its quality.

Staci called having to get a wig, "the wig thing!" This was described as "the next major project" she had to undertake in dealing with the treatment for her breast cancer. Staci was aware that her insurance would cover the cost of a wig. She wanted the wig before she lost her hair rather than afterwards. She spoke with the oncologist. He told her that first she had to lose her hair and then she could get a wig. Since she didn't want to wait, she completed the paperwork ahead of time. She also went to the wig shop so the salesperson could see her hair texture, color, and style. She remarked: "How can you fix a person if you'd never seen them together?" Staci wanted to purchase the wig that day and then request reimbursement from the insurance company. The supervisor told her that it couldn't be done.

Staci lost her hair three days following her first chemotherapy treatment. When she called the insurance company about getting the wig, she was told it would take another week to finish the paperwork. Staci spoke to the supervisor and told her: "I am a very upset patient who filled out paperwork several weeks ago and isn't happy with next week as an answer." The supervisor made the arrangements for Staci to purchase the wig and later be reimbursed. Staci got the wig that day.

Being Prepared

Although each of the young adult women received information concerning surgery and the availability of breast reconstruction, not all of them received instructions to prepare them for surgery and chemotherapy treatments. Angela was given information at the time of her biopsy. The information concerned breast cancer itself, its stages, and surgical treatment. She stated that she didn't read all of the information. She "just wanted to know my case and what the possibility was for cancer." Susan talked about needing to control the amount and type of information she received. Her physician had informed her about modified radical mastectomy and she did not appreciate hearing and reading information about lumpectomy with radiation. Staci sought to talk with other women who had undergone mastectomy to become prepared for surgery.

Being prepared for surgery. None of the young adult women spoke about receiving preoperative instructions. Although each stated that they were informed at the time of hospital discharge how to empty their drains and measure the drainage, only Susan spoke of learning about arm care to prevent the development of lymphedema. Two of the young adult women experienced complications of surgery. Angela developed axillary contracture and Staci developed a suture line infection. Angela was required to undergo physical therapy. She wished she would have sought the guidance of the Reach to Recovery volunteer either before surgery or the week following surgery. She would have become more aware of the need to push herself to do arm exercises.

Being prepared for chemotherapy. Three of the young adult women spoke of being informed about the side effects of the chemotherapy drugs. Karen was the only one to talk about interventions to take to minimize the common side effects of the chemotherapeutic agents of nausea, vomiting, and weakness. She was the only one who did not experience increasing difficulties with the progression in treatments. She attributed this to the helpful instructions of the chemotherapy nurse. She stated: "She told me to drink lots of water. The more water you drink, the faster it gets out of your

system." Susan stated that she received information about the chemotherapy drugs but that she needed more. Jennifer spoke about the threat of sterility. She was relieved that her menstrual cycle continued throughout chemotherapy treatments. Although her breast mass was estrogen receptor negative, she was asked to consider treatment with tamoxifen. She was aware that sterility would result from this treatment. She had received information from the oncologist and the American Cancer Society.

As three of the young adult women underwent chemotherapy, they were plagued with problems of nausea, vomiting, and an altered sense of smell. Receiving medications helped them cope at times with these side effects; however, they did not always receive antiemetics at the time of the administration of the chemotherapy drugs.

Not all of the women described being prepared to lose their hair. Staci was told that she had a 95% chance of losing her hair because of the drug cyclophosphamide. She had taken this drug before for her lupus treatment. It had thinned her hair then so she was pretty sure that she would lose her hair this time because it was a larger dose. Karen stated that she was prepared for hair loss. She lost it three weeks after the start of her chemotherapy. Susan lost her hair two weeks after the first course of chemotherapy. She described it as depressing to slowly watch her head "get smaller and smaller." Susan stated she felt prepared for losing her hair on her head. She was told that she had a 99% chance of losing her hair; however, she stated that she was not prepared to lose her body hair. She remarked: "My eyebrows and eyelashes went before too long. I just wasn't prepared for that. I haven't had to shave my legs so he was off on that one." Angela stated that she wasn't told that she would lose her hair. She lost it three weeks after the start of chemotherapy. She was deeply saddened. She stated: "They told me then. I think it is best that you be told. It's best to be prepared."

Rebuilding Body Image

For the young adult women in this study, rebuilding body image was essential to recovery. Angela described that she needed "to build that self confidence after chemo."

For the young adult women in this study, loss of hair was considered the greatest worry prior to the start of chemotherapy and was considered to be even greater than the loss of a breast. Only Jennifer did not lose her hair. Angela also correlated hair loss with severity of illness and death. She spoke several times about individuals she knew or had heard of who had "cancer in their bones, throughout their body, and hair loss." Each of the young adult women who had loss of hair obtained a wig.

Although hair was considered the greatest concern prior to chemotherapy and even more than the loss of a breast, as the young adult women progressed through chemotherapy, they grieved the loss of the breast as well. Jennifer also talked about having to deal with the threat of sterility. She was 30 years old and the youngest of the young adult women. She also was the only one who did not have children.

Dealing with hair loss. Loss of hair was the greatest emotional concern the young adult women had regarding chemotherapy. Susan found it "depressing" to slowly watch her head get smaller and smaller. Staci experienced great difficulty in obtaining a wig. She stated: "You can only deal with so much and then to be completely bald. . . you're looking like a ragamuffin. You're physically impaired now and you're going to make a person go through that? That's not right." She reinforced the importance of obtaining a wig before the loss of hair so that the salesperson can see hair texture, hair color, and style. Staci remarked: "How can you fix a person, if you'd never seen them together?"

When Angela and Karen experienced the loss of hair following the first chemotherapy treatment, they attended the 'Look Good, Feel Better' Program of the American Cancer Society. Each wanted to know more about cosmetic application and wearing a wig. During the two weeks that Karen was off work following her lumpectomy, she participated in the program. Karen found out from the Reach to Recovery volunteer about it. She stated: "It helped me a lot. . . . The lady at the 'Look Good, Feel Better' Program was so nice." Karen purchased her own wig.

Angela wasn't satisfied with the program. She had planned to rely on the American Cancer Society for a wig. The wigs that they had "were used and not of good quality." She recommended that a manufacturer be selected who would make a good one. Angela went out and purchased one on her own.

Jennifer also went to the 'Look Good, Feel Better' Program. She described: "It really did make me feel better. I hadn't lost my hair but that really helped. I was really glad I did it. I got three wigs there like a Marilyn Monroe one and a red one that I could use if I needed them. . . They thought I looked great in them."

"Something is missing". Only Karen had undergone lumpectomy with radiation treatment. She was "happy with the appearance of the breast." She remarked: "It (my breast) looks fine now (after the surgery). I do think I need to go back and see my surgeon because it is just pulling the nipple a little." Susan was relieved that she had gotten a tissue expander at the time of her mastectomy and would need no further surgery. The concerns for the other young adult women focused on "something is missing!" but it would take time before they would undergo breast reconstruction.

For Angela, losing her breast was difficult. The extent of difficulty is described in her statement: "I said you got to get out of this little panic state. Stand up. Go out there and talk to a woman who has been through it." She recalled that it took her a month seek help from another. She stated: "After you've lost a breast, you do feel that there is something missing there." She looked forward to breast reconstruction.

Staci described a similar feeling. She stated: "The breast was a part of me. You know our breasts are for display. Let's face it!" She planned on breast reconstruction although she was afraid of undergoing surgery once again. She stated: "I'll feel better after that."

Jennifer stated: "It didn't look good!" The incision went across the chest wall and up toward her arm. She described: "They need to give you real pictures and not drawings to look at. Then it wouldn't come to such a shock when you have to look at it!"

She too remarked: "I know I can get breast reconstruction. . . A part of me is a little grateful that I can't get it right now because I am afraid of surgery."

Regaining A Sense Of Focus

As these young adult women were changed by confrontation with mortality, altered body image, and inability to carry out their daily routines and responsibilities, they sought to regain a sense of focus. Each spent more time on self. For those who were mothers, the importance of their children and their mothering roles was reinforced. Feeling connected with others brought meaning and a sense of purpose to their experiences of breast cancer.

Taking time for self. Jennifer spent more time taking care of herself. She became a vegetarian and exercised more. She did things to make herself feel better. She stated: "If I wanted to go up to the mountains, I went up to the mountains. If I wanted to play the flute, I played the flute." Wanting to keep her "own place," she went on unemployment after she had lost her job and medical disability. She found a job that would offer health insurance while completing her chemotherapy treatments.

The need to take care of self was reinforced by the breast cancer experience for the other young adult women. Susan continued with her water aerobics but then had to reduce her activities because of her decreased susceptibility to infection. Angela began taking a nutritional supplement "to rejuvenate her blood and detoxify her body." Karen changed jobs in order to reduce the amount of stress at work. Although she "felt like a failure" because she couldn't work, take care of her family, and undergo chemotherapy treatments at the same time, Staci went on disability to have more time to take care of herself.

Caring for children. For the young adult women who were mothers, their roles as mothers helped them cope with their experiences of breast cancer. Breast cancer reinforced the importance of their children to them. Karen was happy that she had more time to spend with her family after she changed her job. Angela quit her job the day of

her mammogram in order to have more time for hers. "Not worrying her family" was her main concern when she was diagnosed with breast cancer. She did not want to scare her husband. She stated:

He knows that I've always been a fighter. Even now when he sees me, he says wow, how strong. As a woman, we have to carry the load, the family. The man is the head of the house. It is the woman who does it. Once the woman falls apart, then, everything else. Like a domino effect. I didn't want that to happen.

Being a mother was also important to Staci. She waited three weeks to have her surgery so that she would have time "to put things in order." She stated: "You have to get the house prepared, the family prepared. You've got to put things in order before you go. . . To me, it meant the world to be able to do that." In addition, Staci wrote notes to her children the morning of her surgery. She told them that she loved them and what she wanted them to do that day. She stated: "It was picture day at school. I want you to smile really big for your pictures. . . Be good because mommie can't be there for you!" For Staci, not being able to keep up with her mothering role, her work, and chemotherapy treatments elicited a sense of guilt.

Susan kept up with "her basic activities." Being a mother was of paramount importance. She described that her greatest concern "was the kids. Them not knowing me really bothered me." She wanted them "to be loved enough." Her emotional concern as she went through chemotherapy was her feeling that she was "an awful mother." When she was physically sick following her chemotherapy treatments, she felt guilty that she didn't want to feed her baby or spend time with her children. She and Staci "waited until after Christmas" to begin chemotherapy treatments. They did not want to disrupt their family holiday.

Telling their children about the diagnosis of breast cancer was not a voiced concern for these young adult women. One child was an infant. The other children were between the ages of five and twelve. Each of the older children was told about the

illness. Staci described that her children knew but they were too young to understand. All four of the mothers strove to maintain their children's usual routines through the help of others.

Staying connected to others. For each of the young adult women, as they went through treatment, their connectedness with others was noted. This brought additional meaning and a sense of purpose to their experiences with breast cancer. Staci was proud that the stress she underwent in obtaining a wig paved the way for other women not having to experience what she had endured. Women with her health care coverage could now get a wig before they lost their hair and be reimbursed at a later time. Karen voiced "concern for other women out there who are getting mastectomies recommended instead of lumpectomies." She planned to volunteer at the American Cancer Society because she too wanted to help others. She reinforced: "Women should not be getting maimed when they don't have to be."

Jennifer also wanted to help others. She suggested that there be individual support groups to meet the special needs of the younger individual. She found that printed information applied to older women who were married or had children. She felt that the needs of the single woman and those with alternate lifestyles such as gay and lesbian women were not addressed. She remarked:

They give suggestions on how to deal with things, like have your spouse do this or have your children do this for you but they don't give suggestions for having your friends help you and saying thank you. There needs to be things for more people.

Angela also had many suggestions that she felt were needed so that other women wouldn't experience what she had experienced. She felt that women needed to be told of the services of the American Cancer Society before or soon after their mastectomies. She voiced concern about the quality of wigs available through the American Cancer Society and the need for updated lists of support groups and groups for younger women. She suggested support groups for young couples so that husbands could become more

involved in the experience. In addition, Angela felt that there needed to be more information concerning nutrition and chemotherapy. She wanted more communication between the oncologist and client concerning the threat of cancer spread.

Each of the young adult women spoke about the need for increasing the awareness of breast cancer. As described by Karen: "It seems like its rampant when you have it. When you don't have it, it's like somebody else's problem. So you just have to make people aware of it. It can happen to anybody." Two of them had already gotten involved by participating in the Revlon Run For Breast Cancer.

Seeking Help From Others

As described by Staci, these young adult women had to find the strength within themselves to deal with the diagnosis and treatment of early breast cancer but they also needed the help of others. Relying on family and friends, searching for the understanding of others, and reaching out beyond family and friends were instrumental to these young adult women in dealing with their experiences with early breast cancer and its treatment. The need for spousal support was noted.

Relying On Family and Friends

Each of the young adult women talked about the help from family and friends during the difficult periods following their mastectomies and chemotherapy treatments. They described great weakness following their surgeries and difficulties in caring for self. For three of them, the chemotherapy treatments became harder to endure as they progressed. The help they received from family and friends was described as supportive. Susan stated: "They said that they would take care of everything." They communicated "that everything was going to be fine."

Karen waited until just before the surgery to tell her mother about her breast cancer. By that time, Karen's mother-in-law who lived closer had made arrangements to stay with the family. Karen's mother-in-law extended her stay from one to two weeks to stay with Karen and her family "until she knew that everything was straightened out and

that I wasn't having any problems with anything." Karen was the only young adult women who did not experience the problems of vomiting and increasing difficulties with chemotherapy treatments. She attributed this to the teachings of the chemotherapy nurse. Karen was told to "drink lots of fluids with the chemo to rid the body of the drugs."

Jennifer also did not want to worry her mother about the diagnosis of breast cancer. She had her father inform her. Because of weakness following her surgery, Jennifer stayed with her parents for a week. She described the care given to her by her mother:

She helped me so much. She pampered me. I would say, 'my stomach is upset from the pain pills. would you make me some jello?' And she would. She was good to me. I didn't mind their help because I really needed it but I wanted to get back to my own place. I progressed each day.

In addition, Jennifer received help as her chemotherapy treatments progressed. She stated: "Each time they gave me higher doses and each time I experienced something different. Once I vomited eight hours straight. It just took me longer and longer to get over each dose." Jennifer relied on her friends for help following chemotherapy treatments. She stated: "One of my friends would take me to chemo and then pick me up. I would rotate who I would ask so I wouldn't take advantage of them." A friend would stay with her that night in case she needed anything. She described that they were so helpful.

Angela's mother stayed with her and her family for one week. Angela stated that she actually needed help for two weeks. Although her mother stayed for just a week, Angela remarked: "I didn't let that get me down." She developed axillary contracture and required physical therapy. Although she regained movement of the shoulder, numbness in the back of her shoulder and arm remained. She also grieved the loss of her breast. She stated: "I said you got to get out of this little panic state. Stand up. Go out and talk to a woman who has had it. It took me about a month. . . you do feel that there

is something missing there. . . . Not until maybe January did it hit me to go out and talk to someone." She turned to a friend of her mother-in-law who gave her encouragement.

Staci also relied on her mother to help during this time. She too was weakened following surgery and her arm hurt. In addition, she developed a suture line infection that required antibiotic therapy and dressing changes. Staci's children stayed with a friend but they came home afterschool from three to five o'clock to see her. Staci said that she "saw them for a few hours but I could deal with that."

Susan's mother and sisters stayed with her to help her with cleaning, cooking, and watching the two children for the month following her surgery. "It was helpful." Susan said:

When you're not feeling great especially when you like things clean and you wake up and everything is a mess and you don't feel like cleaning, having somebody there to address those needs and make it mentally easier on yourself helps.

And after Susan experienced neutropenic fever and as the chemotherapy treatments became "harder each time" on her body, one of her sisters or her mother was always with her to be of help especially to her children. Susan also had the support of church members during this time. Although she felt a "a little guilty taking people up on things," she described:

I knew that I needed somebody, I could have called them and they would have been there and would have taken the kids. . . . I would have also had support if my family wouldn't have been able to help me or if I hadn't had a family.

Searching For The Understanding Of Others

Each of the young adult women identified the understanding of others as helpful to them as they faced diagnoses of breast cancer and experienced difficulties with treatment. Sympathy from others reinforced that the extent of their plight was understood. Karen spoke about the support of her surgeon just prior to her surgery. She stated: "The surgeon was pretty thorough. He explained everything he was going to do.

He allayed my fears." Jennifer described the operating room staff as "so nice." She stated: "They told me how sorry they were for me to have to go through this. That helped." In addition, her surgeon sat with her that morning and told her what he was going to do. She remarked: "He too said that he was so sorry that he had to do this surgery for me because of my age. But with my doctor, I felt a personal touch, a personal concern and that made me feel better that I was a person who was special."

After hearing that she had breast cancer, Jennifer drove to the home of a couple who were described as her "friends" They let her cry. She described:

I have two friends who live together. One of them has AIDS. I talked with them a lot and they really understood the shock I was going through. I also have a friend who's young. She has ovarian cancer. She's had three recurrences and she too was understanding.

Jennifer also wrote letters to her other friends. In her letters, she told them what she was going through. She stated: "It helped. And I'm going to write a third one now that chemo is done." Jennifer also reinforced her need for sympathy from others. She needed others to know the hardship she was experiencing. She stated that she did not like it when "everybody said I looked so great. I would say, how can you say that? I need your sympathy. I did think if I would have lost my hair, I would have gotten more sympathy."

Jennifer also talked with her friends about the loss of her breast. She remembered that they were uncomfortable in talking about it. Her girlfriends became shocked when she pulled out her prosthesis to show them. She stated: "I don't think they were ready for that!" She also spoke to her male friends about developing a relationship with a woman who had breast cancer and had lost a breast. Jennifer wanted to know: "would it matter to them?" They told her that "it would matter to some but not to others." Jennifer described them as being "nice" with her.

Understanding from friends was helpful to Susan during this time. She continued to have lunch with a "group of ladies" who met monthly. One of the women encouraged

her to call the American Cancer Society for assistance. The American Cancer Society was helpful to her husband as he dealt with testicular cancer. In addition, Susan voiced her gratitude for the numerous cards and letters she received from the members of her Church every day. Receiving cards each day was meaningful to her.

Staci searched for understanding from friends. She had colleagues from work with whom she talked. When she was "having a bad time," she would call them. They would go to lunch and she would "tell them what's going on and cry." She stated she knew that they cared and that helped; however, she reinforced: "they haven't been through it."

Staci used the words "emotional scarring" to describe the changes in her life brought about by her experiences with breast cancer. She stated: "Everybody else's life is the same but mine will never be the same. . . . My mother can make everybody else's life happy . . . like you guys (her family) are living your life as normal. . . and my world is falling apart." She described it as a "Catch 22" situation. She wanted her family to be happy yet she needed them to share her pain. She also remarked that comments from others such as "You look just fine!" drove her "crazier than anything else in the world." She stated: "First of all, what am I supposed to look like? Second of all, what do you expect?"

Reaching Beyond Family And Friends

Each of the five young adult women also called the American Cancer Society during the two weeks following surgery to speak with a volunteer of the Reach to Recovery Program. Susan called early on but no one returned her call. Staci called the agency upon her discharge from the hospital. A brochure concerning the Reach to Recovery Program had been left at her hospital bedside. A Reach to Recovery volunteer visited Staci in her home "a day or two" after surgery. Staci described: "You need somebody who can tell you something and I called her because I was reaching. . . Getting

that brochure was helpful. . . . For her to be there, done that, helps me with emotional part."

Karen also contacted the American Cancer Society immediately after surgery. This was during the time when Karen was losing her hair. The Reach to Recovery volunteer came to see Karen "right away." Karen recalled: "She was really nice. She gave me a lot of helpful suggestions and told me about all of the programs offered".

Angela found the visit of the Reach to Recovery volunteer to be very helpful too. She called the Agency itself. She had heard their advertisements and had read about them in the paper. She described:

She encouraged me more because she gave me information. She was perky. She did what the doctor told her. . . She said you can't stay home. . . Don't let anything stop you. . . . That really helped. I said I didn't mind that she was older. She came a couple weeks after I had surgery. Coming before or a week after would really help motivate.

Jennifer also described the helpfulness of the Reach to Recovery volunteer who visited at her place two weeks after surgery:

She was really helpful. She told me about everything that was available from the American Cancer Society. She was in her forties but she was 31 when she had her mastectomy. I appreciated that. Younger women's issues are different from the issues of older women.

Jennifer was appreciative of talking to someone who was closer in age for she had gone recently to a support group. It was not associated with the American Cancer Society. It was offered by the same facility where Jennifer underwent her mammogram. She stated:

It was okay but at that point in time, I really feel that the women weren't having the same issues as I was having. It never ever met any of my needs. They were all older. Like I asked, don't any of you thinking about dying? None of them did. They were all really older. Maybe a group with other younger people with different types of cancer would be better. I just think our issues are different.

Angela attended a support group sponsored by the American Cancer. Each of the women participating in the group were older. Angela found that attending the group was not helpful. She "could not identify with the women because they were all older."

Seeking Spousal Support

Susan identified her husband as the person with whom she talked about her fears and inadequacies the most. She stated: "He's a very optimistic person. He helps me get through it the most." Angela's husband was helpful to her also. When going into surgery for her mastectomy, she wondered how her husband was going to feel about her following the surgery. She described: "A part of me is missing. We all come with two boobs and I'm going to have one. How was he going to feel towards me was my concern." Although she described that she knew that it depended on how she felt about herself, she talked to him about it. He said to her: "Don't worry about me. You're going to get another breast anyways." Angela stated: "When he told me that, that brought me up because that's true. I had to think about that. It may take a while but I will get another breast."

But several of the young adult women spoke about their need for reestablishing intimacy with their husbands. Staci spoke with disappointment about talking with her husband about her breast cancer. She stated: "My husband doesn't talk much at all so I don't talk with him about it at all. He can't grasp it. He just can't. You can't get blood from a stone." Karen also identified this need. On the morning of her lumpectomy, her concerns focused on her husband. She stated: "I wanted my husband there. My mother-in-law took me. My husband has a pretty high stress job and he needed to be there. I just felt abandoned." However, Karen described that her relationship with her husband "became a little bit better as treatment progressed." The letter for husbands of women with breast cancer from the American Cancer Society was helpful but she said: "he really doesn't understand." She remarked: "We just need some more time together and to meet some more friends who live around here to help us to get back on target."

Angela reinforced the sentiments of Staci and Karen. Although she felt supported by her husband, Angela communicated a need to increase his involvement in what she was going through; however she identified that he too needed support. She stated: They need support groups for men because some men don't speak out." She felt that they could provide comfort to their wives during this time. She suggested that perhaps couples get together to talk and help one another. She stated: "Having couples would be a perfect thing. Men need to be involved."

CHAPTER SIX

DISCUSSION

Although the experiences of the young adult women who shared their stories in this study were very personal and unique, there were concerns that were experienced by each of them in some way. The manner in which they dealt with these concerns focused on dealing with the threat of dying, inner strength, and ability to connect with others. Although the research focusing on the experiences of young adult women with breast cancer is somewhat limited, the stories of these young adult women and the resultant themes are consistent with the findings of some related studies but differ from others. In this chapter, the results of this study are discussed in relation to other studies that have dealt with the experiences of women diagnosed with early breast cancer and undergoing treatment.

Dealing With The Threat Of Dying

"I'm going to die!" was a theme as these young adult women were diagnosed with breast cancer and underwent treatment. In this study, finding a lump was accompanied by "little" or "no concern." This differed from the emotional reactions of the majority of women described in the literature by Payne, Sullivan, and Massie (1996) and Massie and Holland (1991). For the majority of women, finding a lump evoked terror, "shock," and panic followed in minutes or days by emotional numbness, denial, or disbelief. These researchers noted specific fears upon finding a lump such as "I may die! I have given breast cancer to my daughter(s)! My husband deserves better than this!" These emotional reactions were not described by the young adult women in this study upon finding a lump. It was not until they became diagnosed with early breast cancer and

underwent treatment that they dealt with "It's the 'C' word," dying from the surgical experiences and chemotherapy complications themselves, and "not living forever."

In this study, only Angela and Susan expressed increased concern after receiving the results of mammography. Angela stated: "I was upset but I didn't want to really get scared. . . I didn't want to think the worst;" however, when the young adult women heard that their biopsy results were positive for breast cancer, it was then that the thought "I'm going to die!" was engendered.

None of these young adult women experienced shock and panic was not demonstrated at the time of finding a lump in these young adult women. Four of them never imagined that the lump would be positive for breast cancer because of their young age. Denial did not seem to be involved. For Jennifer, this belief was reinforced by the health care personnel with whom she came in contact. They did not act concerned although they reinforced the need for follow-up of the lump. A nurse practitioner told Susan just "to watch it!"

The description of breast cancer as one of the most feared and devastating illnesses faced by women occurs throughout the literature. The findings of this study supported this description. The most commonly occurring cancer, it is the second leading cause of cancer deaths among women in the United States (American Cancer Society, 1995). As described by Massie and Holland (1991), the thought of breast cancer elicited fears of death, disfigurement, disability, life disruption, and dependence on others for care and support. Its treatment was emotionally charged because it involved the partial or total removal of the breast which was intimately tied to the woman's sexuality and reproductive and nurturing capacity.

From qualitative studies, Toombs (1993) described living with cancer as not necessarily related to the extent of physical signs and symptoms of disease experienced, but to the manner in which the cancer affected the individual's life situation. He described cancer as a global sense of disorder characterized by perceived losses of

wholeness, certainty of self, control, freedom to act, or one's familiar world. Cassell (1979) and Kleinman (1988) described that the meaning of cancer derived from the "collectivity of meanings" engendered by these losses. In this study, a loss of control was heard in each of the young adult women's stories. For Angela, the experience of breast cancer also evoked a loss of certainty of self. She worked hard so that her relationship with her husband and family would not be affected. For Jennifer, her strong need for independence was challenged and provided a strong sense of motivation for her to get through this difficult period of time. Staci's strong need for control was helpful to her recovery although she experienced losses in her familiar world. Karen also demonstrated a strong need for independence and it was motivating to her in her recovery. Susan's need for control helped her to endure the experiences of breast cancer, however, she suffered from losses in certainty of self. With an infant and a seven year old son, her mothering role was greatly threatened by the diagnosis of cancer. Her mothering role was important to her in her recovery.

For three of the young adult women, having to undergo surgical experiences evoked fears of dying. As described by Susan, "It scared me more to have surgery than to have breast cancer at that point." Both Northouse et al. (1995) and Payne et al. (1996) identified emotional distress as women underwent biopsies. Northouse et al. identified the factor that had the strongest association with the level of distress as the amount of concurrent stress.

Shaw et al's. (1994) qualitative study identified uncertainty regarding the outcome of the biopsy as the main contributor to the feelings of increased distress. In this study, two of the young adult women did voice concern about biopsy results. Angela stated: "If someone told you it might be or might not be, you're worried with it." She and Staci talked about "just the not knowing" as the scary part. However, three of the young adult women never imagined that their biopsies would be positive! They worried about dying from the surgical experience itself.

Two of the young adult women feared dying from the complications of chemotherapy. After Susan had experienced neutropenic fever, she stated her physician had "put the fear of God in me." She was to go to the hospital if her temperature elevated "because people die of temperatures in a day or two if they don't!" After Angela viewed an advertisement video which talked about individuals dying from malnutrition while undergoing chemotherapy, she began taking the nutritional supplement, blue-green algae.

This finding was reinforced in the descriptions of psychological reactions to chemotherapy by Payne et al. (1996). Women with breast cancer took drugs that were described as "poison" by some individuals. This was at a time when the public was concerned about food additives, air and water quality, and ridding the body of harmful substances. The names of the drugs themselves sounded foreign and ominous. Vinokur et al. (1990) correlated fears with the level of information received or the operation of psychological processes within the woman which distorted the meaning of the objective threat such as denial and illusion of control. The need for guidance and support for the woman was reinforced.

For the young adult women in this study, "not living forever" began to be heard as they recovered from their surgeries and progressed through chemotherapy treatments. The threats of recurrence and metastasis became uppermost in their minds as they contemplated their futures. This finding was supported in the literature. Oktay and Walter (1991) found that young adult women described "not living forever" as they were confronted by the fact that they were not invincible. This was a belief that came a lot earlier for them than it did for other young adult women and was devastating to them. The researchers however, identified the experience of breast cancer as helping the young adult woman to transition more quickly into a new world view that was more functional for dealing with the later phases of life.

Reassessing Self

As the young adult women were changed by confrontation with their mortality, the need to find oneself again was noted. Each sought strength from within to endure the difficulties they encountered. They had "to stick up for self" when confronting treatment issues. Each sought to rebuild body image and regain a sense of focus in her life.

Finding Strength From Within

Each of the five young adult women spoke about an inner strength that helped them to get through the difficult experience of early breast cancer and its treatment. As described by Staci:

You have to find the self within yourself to deal with this because you're going to have to deal with it. You have to find out for yourself. You cannot ignore the problem nor will it go away on its own. It has to be dealt with. You have to find it within yourself and with the help of others to deal with it.

Having faith, being positive, and being hopeful helped these young adult women to find the strength within themselves to deal with the experience of early breast cancer and its treatment. Support for Northouse's (1989) findings from his study on 35 women with early breast cancer and their husbands. The factors that patients reported helpful were emotional support, religious faith and beliefs, information, positive attitude, distraction, and tangible aid.

In Morse and Doberneck's (1996) study, the illness experience of breast cancer was described by women as one in which they had to fight continuously to "keep the negative thoughts out." They described dealing with the devastating treatments for breast cancer and the constant threat of recurrence as a continuous process of hoping to get through different barriers that repeatedly emerged, revealing a pattern of hope they described as "hoping against hope." (p. 283). This study supported this finding. Susan described "talking it through to myself" as one of her "best things." Angela stated: "You have to be positive all the time!."

For the young adult women in this study, faith in God was described as a coping strategy. This finding was supported by Shaw et al. (1994). In addition, Benedict et al. (1994) found concepts of spiritual and hopeful in their study on women undergoing breast biopsy. Jarret et al.'s (1992) finding of positive reappraisal as a coping method following treatment for breast cancer parallels the findings of positive attitude and hopefulness in this study.

The results of this study supported the findings of Mickley and Soeken's (1993) study which identified cultural differences in religiosity and hope among Hispanic and Anglo American women with breast cancer. Hispanic women had a significantly higher mean level of intrinsic religiosity (religion as the "master motive" in their lives) than Anglos; however, neither intrinsic nor extrinsic (religion as practiced to achieve goals such as social status or emotional security) religiosity was a more important predictor of their religious well-being or hope. For Anglo women, intrinsic religiosity was a stronger predictor of hope and of the religious and existential components of spiritual well-being than was extrinsic religiosity. In this study, intrinsic religiosity was sensed in Angela, an Hispanic, and Susan, an Anglo. Their intrinsic religiosity helped them during this difficult period of time. Karen, also an Anglo, wanted to make more time for going to church. Her religiosity could be described as extrinsic and was not reported as a major support to her during this period of time.

Getting A Grasp On It

Each of the young adult women spoke about the need for "getting a grasp on it" as they were diagnosed with breast cancer and underwent treatment. Angela described breast cancer as: "It's in the dark! You know nothing about it until you experience it. When it came to me with the lump, I thought I don't have cancer. I don't know anything about breast cancer." Each of the young adult women described a need to get information so that they could understand more fully what was happening to them. Each of the young adult women spoke about not knowing someone young with breast cancer. Staci had the

need to tell everyone. An African American woman, she did not consider herself "even a category for which it (breast cancer) could happen. I am the most least prospect." She stated: "Look at me. I was only 33 years old. If it happened to me, it could happen to you!" Karen and Angela sought to understand and explain their breast cancers. Karen came to believe that it was the "environmental factor of stress" that caused her breast cancer. Angela stated: "There are reasons why things happen to you. Maybe, to bring me down to my knees more, maybe to tell my husband, hey, there is a God out there."

"Getting a grasp on it" correlated with the level of shock and disbelief experienced by these young adult women; however, "it's in the dark" also reflected a "just world view" that is common to young adults. As described by Oktay and Walter (1991) in young adulthood, beliefs from childhood are confronted as young adults enter the real world. Young adulthood is a time of life when individuals struggle with "unfairness" issues. For instance, young adults learn during the course of their lives that working hard does not always bring success; if one does all the right things, one will probably not be rewarded; and it is not important that you try for you have to succeed. For these young adult women, breast cancer brought the wish to believe in a just world into focus. Angela and Susan often remarked that they did what they were "supposed to do" with the hope that everything would work out for them. Staci described that the experience of breast cancer "made her stop and think that life did not promise anything." Although studies on informational needs of women with breast cancer were identified in the literature, none of the studies found the issues that my study participants described as "getting a grasp on it" (Shaw et al., 1994; Luker et al., 1995).

Sticking Up For Self

Payne et al. (1996) described the considerations women newly diagnosed with breast cancer faced. These considerations included such things as "how to adjust to the loss of the breast versus how to adjust to living with a breast that became diseased," "how to find a surgeon 'I can trust'," and "how to sort through conflicting pieces of information

given by different medical and professional books, journals, friends, and coworkers" (p. 91). For the young adult women in this study, they were concerned about conflicting information they encountered; however, they talked about other kinds of issues. These issues included: receiving prompt treatment, deciding between treatment options, dealing with early hospital discharge, and dealing with treatment effects.

Each of the young adult women sought prompt medical evaluation of the breast lump. This demonstrated an awareness that each lump needed checked. Although each of the young adult women in this study demonstrated an awareness of the need to get a breast lump checked, none of them practiced self breast exam routinely. Four of the lumps were found inadvertently. One of the lumps was found by a husband.

Each of the five young adult women participating in this study identified the need to seek prompt follow up of their breast masses but only Angela received prompt follow up. A nurse practitioner told Susan just to "watch it." Susan was encouraged by her husband to have someone else look at it. It took about five weeks until she had a surgical evaluation. Karen waited a month for surgical evaluation because of insurance reasons associated with her family's move to a new area. For the others, it took between two to four weeks to get a surgical referral.

Each of the young adult women underwent biopsy within one week following surgical consultation. Results were obtained immediately for one of the young adult women. Three knew results within 3 to seven days. One waited two weeks for results. The time of finding a lump to mastectomy for these young adult women was 4, 7, 7, 10, and 13 weeks. It was Karen who had surgery about 13 weeks after finding her lump. She sought four "second opinions" until she was able to find a doctor who would perform a lumpectomy. She changed her health care coverage twice. The last time this was accomplished by giving her friend's address. Jennifer purchased health insurance prior to follow up of her mammogram through her place of employment to help defray costs. This caused a two week delay. She was happy that she had requested health insurance

prior to a diagnosis of breast cancer or it would have been denied. As described by Henderson (1995), with some breast cancers doubling in size within a few days with others taking >2,000 days (average 100 days) and metastasis thought to occur after the first twenty doublings, the delay in treatment in these young adult women was alarming. Only Susan voiced concern about her seven week wait for surgery. She asked: "How fast does it spread?" Delay in treatment was identified by Sariago et al. (1995) as a consideration in the treatment of young adult women. The findings in this study lent support for this consideration.

As more information became available concerning surgical options in the treatment of breast cancer, Pierce (1993) identified less need for special counseling in decision-making. Most women were able to make a choice regarding treatment once options were identified. Pierce identified three patterns of decision-making. They included deferring, delaying, and deliberating. The deferring style was characterized by a decision to choose a treatment that as perceived as safe, easy, and quick. This was frequently the treatment option recommended by the physician deferring to his or her expert judgment. The women using this style were older (mean age of 56 years). Women who used the delaying style vacillated between the alternatives until difference between the options was noted or until one option became clearly preferred. These women were younger (mean age of 45 years) than the deferrers. Women using the deliberative style (mean age of 40) had specific strategies, considered risks, and were confident about their decision-making process; however, they were uncertain about the outcome of their choices and felt they might later regret the choices they made. In this study, all three patterns of decision-making could be noted.

The studies by Ward et al. (1989) and Wilson, Hart, and Dawes (1988) identified that women who chose modified radical mastectomy expressed more concern about efficacy and side effects, inconvenience, or disruption by radiation as well as the uncertainty of whether they would later need a mastectomy. Women who chose

lumpectomy with radiation were significantly younger. They reported that their concerns were primarily based on concerns of bodily integrity and to a lesser extent on physician's or significant others' opinions and other's negative experiences with breast cancer surgery. They gave a significantly higher importance to survival rates for the two types of surgery, concern about losing a breast, and breast reconstruction feasibility than compared to the women who chose modified radical mastectomy. The findings of this study were not fully supported. Only one of the young adult women chose lumpectomy with radiation.

For three of the young adult women, treatment decisions concerning the type of mastectomy to be performed were made on the same day that the diagnosis of breast cancer was confirmed. Each was told about modified radical mastectomy, lumpectomy with radiation, chemotherapy with radiation, and reconstruction. Only two of the young adult women, however, spoke of surgical options being offered to them between modified radical mastectomy or lumpectomy with radiation. One of these young adult women searched for a surgeon who would give her that option. This required four "second opinions" and two changes in health care coverage. For three of the young adult women, decisions regarding the type of surgery were made quickly with modified radical mastectomies selected due to cosmetic purposes as recommended by their surgeons. One of the young adult women selected a modified radical mastectomy immediately due to fear of cancer spread. For the young adult woman who searched for surgical options, she was the only one who chose a lumpectomy.

As described by Payne et al. (1996) waiting for the pathology report was the most stressful time during the preoperative period with the preoperative period being the second most stressful time. In this study, the initial period of recovery (postoperative period) was more difficult than the preoperative period. This was different from what Massie and Holland (1991) described. They described that most women found hospitalization comforting following mastectomy. The expert nursing staff provided

emotional support and were well informed about the women's needs for education, reassurance, and understanding.

For the young adult women in this study, there were many concerns. "I was so weakened!" was a common statement heard in each of the young adult women's stories. Fear because "this was my first major surgery" was also a common sentiment. Help in the care of their drains and in their activities of daily living for the first two to three days following surgery were needed. Two complications were experienced by two of the young adult women.

The descriptions of short stay surgery for these young adult woman differed from the findings of studies concerning patient satisfaction with short stay surgery for mastectomy in the literature (Clark & Kent, 1992; Hunt et al., 1995). Eighty to 85% of elderly women and older women interviewed stated that they were ready for discharge. They were discharged the day following surgery. About 10% of the participants required extended hospitalization for the management of postoperative nausea and vomiting, pain control, and a variety of social factors. Complication rates were unchanged. Hemorrhage rate remained within 1-3% and was seen within 4-6 hours. The infection rate remained at .8 - .9% with the development of seroma at 4.2 - 3.5% and axillary contracture at 0.7%.

Palsson and Norberg's (1995) study identified that nursing care improved the sense of control perceived by women experiencing mastectomy. They reinforced the need for adequate information about medical treatment and more "confirming" relationships. A "confirming relationship" was experienced when nurses and physicians showed understanding. It was characterized by positive feedback, a showing of interest and respect for the woman as a human being, and a permissive tone of conversation whereby the women felt free to ask questions and show feelings.

Only Susan in this study described a "confirming relationship" during this time with a nurse or doctor. Susan had a "panic attack" the morning following her surgery in the hospital because of the pain medications. A nurse stayed with her until the other

medication that were given to help her worked. However, several of the young adult women described a lack of supportive relationships with the surgeon and hospital staff.

Absent in these descriptions was an understanding of the influence of culture at this time. Angela, an Hispanic, expressed to the recovery room nurses that she did not feel that she was ready to go home. She did not pursue it further when the nurses responded: "This is the procedure." Angela's feelings were not acknowledged by these nurses nor was the possible influence of her Hispanic culture on communication with health care professionals addressed. Sue and Sue (1990) described that religious beliefs in the Hispanic culture often contributed to difficulty in behaving assertively because of a common belief that difficulties were meant to be and could not be changed.

Staci expressed her upset feelings concerning early discharge but she had to become confrontational with the surgeon to be heard. This was upsetting to her surgeon. The nurses also reacted abruptly to Staci the following day. The possible influence of her culture on her behavior was not realized. Sue and Sue (1990) described that because of past experiences with racism and prejudice, African Americans learned that they often times had to speak out in order to be heard. They identified four sets of interactive factors that needed considered in working with the African American client. These included the individual's reaction to racial oppression, the influence of African American culture on the individual's behavior, the influence of the majority culture on the individual's behavior, and the personal situations they had experienced.

Studies have been undertaken to identify factors contributing the disparity in survival outcomes among differing cultural groups of women in the United States. In 1992, breast cancer accounted for 8.3% of the cancer deaths in white women , 8.2% in African Americans, 7.1% in Native Americans, 6.3% in Asian and Pacific Islander women, and 8.5% in Hispanic women in 1992 (Parker et al. 1996). Baquet, Horm, and Gibbs (1991) identified that after controlling for socioeconomic differences, cultural practices and levels of acculturation and education were factors needing serious

consideration in outcome statistics. They reinforced the need to study cultural differences. They highlighted cultural practices dictating marriage and reproduction, diet, and gender roles as factors needing consideration. The need for attention to cultural differences in the care of young adult women with breast cancer was suggested by the findings of this study.

Lerman et al. (1993) identified a need for client advocacy. They identified that the women with breast cancer who were most likely to report communication problems were those with more distress and who were less optimistic and felt more hopeless about their disease. Their findings identified that perceptions women have of communication with their providers contributed to their psychological adjustment. Accordingly, the researchers suggested that interventions which enhanced communication between women with breast cancer and their providers also enhanced the women's adjustment to treatment. They suggested that health care providers give greater attention to the development of their communication skills. They also identified the need for bolstering women's skills in asking questions to address their concerns.

Palsson and Norberg's (1995) study, identified the district (community health) nurse as a central support for the women upon discharge and during rehabilitation. In Suominen et al's. (1995) study, it was the comforting support of the nurses the women with breast cancer came in contact with that was viewed as most important to their recoveries; however, several of the nurses were viewed as not adequately prepared to recognize their psychological or social distress. In this study, there were few instances of the development of a meaningful relationship with a nurse. Only Karen spoke about a nurse being helpful to her during chemotherapy treatments. A need for confirming relationships was identified with family and friends.

As three of the young adult women underwent chemotherapy, they were plagued with problems of nausea, vomiting, and an altered sense of smell. Receiving medications helped them cope at time with these side effects; however, they did not always receive

antiemetics at the time of the administration of the chemotherapeutic drugs. To prevent the nausea, Staci didn't eat much the first week. If she did, she would eat potatoes and rice. Jennifer arranged a friend to stay with her the night following chemotherapy in case she needed anything. She had previously vomited 8 hours straight following chemotherapy.

As treatments progressed, "chemotherapy became harder on the body" and the three young adult women experienced difficulty in carrying out daily routines. Several studies have correlated chemotherapy treatments with decreased quality of life. Packer (1988) found no significant decrease in the women's perceptions of activity, daily living, health support, or outlook; however, there was a significant decrease in the quality of life while on therapy. The instrument to measure quality of life focused on loss of attractiveness, fatigue, physical symptoms, inconvenience, emotional distress, and feelings of hope and support from others. Ganz, Polinsky, and Schag (1989) found significant differences in the number of psychologic problems, mood states, and several quality of life indices between women receiving and women not receiving chemotherapy. The chemotherapy group had more reports of worry about recurrence, anxiety, depression, anger, and being overwhelmed with emotions regarding the cancer. They also had more worry about success of therapy, difficulties with interactions in the health care setting, anxiety over diagnostic tests and waiting for results, communication difficulty with nurses and doctors, and concerns about financial impact. Both groups however, had concerns regarding job performance and ability to work. Trief and Donohue-Smith (1996) found that women who underwent chemotherapy identified counseling needs during and after treatment significantly more often than women who did not receive chemotherapy.

Being Prepared

Although each of the young adult women received information concerning surgery and the availability of breast reconstruction, not all of them received teaching to

prepare them for surgery and chemotherapy treatments. Although Angela was given written information about the surgeries, she didn't read it all. She "just wanted to know my case and what the possibility was for cancer." Susan talked about need to control the amount and type of information received. Her physician had informed her about modified radical mastectomy and she "did not appreciate" hearing and reading information about lumpectomy with radiation. This finding was supported by Shaw et al. (1994). Two of the young adult women utilized information management to control the amount and type of incoming information. Additional support for this finding was gained from Luker et al. (1995). Information about the likelihood of cure, the spread of the disease, and treatment options were found to be the important items of information at the time of diagnosis. Information pertaining to sexual attractiveness such as breast reconstruction was also important.

None of the young adult women spoke about receiving preoperative instructions. Although each stated that they were informed at the time of discharge how to empty their drains and measure the drainage, only Susan spoke of learning about arm care to prevent the development of lymph edema. The lack of preoperative instruction was not described in the literature. Massie and Holland (1991) found that in preoperative classes, the women learned not only about anesthesia and care of drains but also the importance of early postoperative rehabilitation and the availability of group or individual emotional support. Hunt et al. (1995) described that in managed care environments, educational programs were shifted from the postoperative to the preoperative period. This was not the case for these young adult women.

Only three of the young adult women spoke about side effects of the chemotherapy drugs; yet, each one of them underwent this treatment. Karen was the only one to talk about interventions to take to minimize the common side effects of the chemotherapeutic agents. She was the only one who did not experience increasing difficulties with the progression of treatments. She attributed this to the helpful

suggestions of the chemotherapy nurse. She stated: "She told me to drink lots of water. The more water you drink, the faster it gets out of your system." Susan stated that she received information about the chemotherapy drugs, but that she needed more.

From their studies, Payne et al. (1996) described that when nausea and vomiting was not controlled following chemotherapy, women came to face the chemotherapy sessions with dread. Love, Leventhal, and Easterling (1989) found that the type, intensity, and number of side effects directly contributed to increased distress. The number of side effects was predictive of greater disruption of social life and work. Nausea, vomiting, and anticipatory nausea were the most predictive individual side effects. When side effects proved to be resistant to coping efforts, emotional upset and physical disruptions were even more pronounced.

Jennifer was informed about the threat of sterility and was relieved that her menstrual cycle continued during chemotherapy. She had refused follow up with a fertility doctor about embryo banking for she was not involved in a relationship with a guy during this time. Even though her breast mass was estrogen receptor negative, the initiation of tamoxifen therapy was being discussed.

Rebuilding Body Image

The importance of sexuality to young adult woman was described throughout the literature. Young adulthood is the time when many women reach their peak of sexuality. In this study, the young adult women sought to rebuild their body image.

For the young adult women in this study, the loss of hair was considered the greatest worry prior to the start of chemotherapy and was considered to be even greater than the loss of a breast. Only Jennifer did not lose her hair. Payne et al. (1996) described the loss of hair for the majority of women undergoing chemotherapy as "the most visible and loathed side effect of chemotherapy" (p. 91). They reported that after the loss of the breast, hair loss came next and was perceived as another assault against their femininity. According to Payne et al., hair loss reinforced the perception of being

"mutilated" and different. It was an outward sign of the inward conviction that they were emotionally scarred and forever vulnerable. In this study, this finding by Payne et al. was supported although loss of hair was described as a greater concern than the loss of a breast. For Angela, hair loss was correlated with severity of illness and death. She spoke several times about individuals she knew or had heard of who had "cancer in their bones, throughout their body, and hair loss."

Each of the young adult women who had loss of hair obtained a wig. Two of them had difficulty in obtaining a wig. One of the difficulties was associated with insurance protocols. The other difficulty was associated with a perceived lack in the quality of wigs of the American Cancer Society by one of the young adult women. These kinds of difficulties associated with wigs were not identified in the literature.

Although hair was considered the greatest concern prior to chemotherapy, even more than the loss of a breast, as the young adult women progressed through chemotherapy, they grieved the loss of the breast as well. Karen who had undergone lumpectomy with radiation treatment, was "happy with the appearance of the breast." The concerns of the other young adult women focused on "something is missing!" They had undergone modified radical mastectomy.

Schain et al. (1994) found that breast conservation surgery protected women's perception of their bodies although it did not contribute over time to positive sexual adjustment. This seemed supported by the findings of this study. Schover et al. (1995) identified that although a specific advantage of partial mastectomy over breast reconstruction in terms of maintaining pleasure and frequency of breast caressing during sexual activity was noted, women who had undergone chemotherapy had more sexual dysfunction, poorer body image, and more psychological distress. Although this finding was supported throughout the literature (Massie and Holland, 1991; Oktay & Walter, 1991; Payne et al. 1996), it could not be supported by this study. None of the young adult women identified sexual intimacy as a specific concern.

The young adult women in this study also experienced increased psychological distress following surgery. Hughes (1993) found that the perceptual uncertainty and functional status (physical, social, and role functioning) of women following lumpectomy with radiation and modified radical mastectomy declined over the initial course of recovery from surgery but that quality of life was unaffected. Treatment did not affect patients' satisfaction with respect to their health and functioning or psychological and spiritual well-being. Treatment was also unrelated to patients' satisfaction with their family situation. This finding was not supported by the results of this study. The quality of life for the young adult women was affected by the surgical experiences.

Regaining A Sense Of Focus

Changes were made in the lives of the young adult women which reinforced deeply held values. Consistent with the findings of Gilligan (1982) and Miller (1986), development in these young adult women's lives was guided by attachment and care. Each of the young adult women spoke about a need to take care of self. Jennifer became a vegetarian and Angela started taking a supplement "to rejuvenate her blood and detoxify her body." Jennifer played her flute. Susan enjoyed water aerobics. The importance of her career and keeping her "own place" were reinforced. Four of the young adult women made changes in their jobs in order to have more time available for themselves and for what they considered important in their lives.

Descriptions of a reassessment of self that occurred with a sense of urgency as women newly diagnosed with breast cancer dealt with an uncertain future (Massie & Holland, 1991; Payne et al, 1996) were found in the literature. For young adult women, this reassessment occurred at a time when they were already refocusing on who they were and redirecting their lives. Oktay and Walter (1991) found that reassessment in young adulthood resulted in a powerful and creative sense of self. The diagnosis of breast cancer had a profound impact on the young adult's career and family plans. It provided a legitimate reason for changes in one's life. Young adult women experienced personal

growth, enhanced self-esteem, and increased self confidence, which allowed them to make desired changes in their lives. In this study, Karen had made significant change in her life. She had changed her job to limit the amount of overtime she worked and to have more time for self and family. Karen was the only young adult woman to undergo lumpectomy with radiation and not experience chemotherapy side effects except for hair loss. Two of the young adult women had changed their eating habits. Jennifer became a vegetarian. Staci hadn't begun to make any changes in her life. She still felt that others didn't understand what she was going through. Oktay and Walter reinforced that young adult women needed to learn to accept dependency needs and build more support into their lives.

For the young adult women who were mothers, the importance of their children and their mothering roles were reinforced by the experience. Each of the young adult women strove to maintain the children's daily routines and accepted the help of others. Caring for children was one of ways in which the young adult women coped with the difficult experiences. They experienced great emotional distress when they were unable to care for their children. Each of the older children were told about the illness. Staci described that her children knew but they were too young to understand. Only Jennifer sorted through thoughts and feelings about future childbearing. She was single and the only one who did not have children. She had identified options available to her should she develop sterility and want children in the future. She also contemplated the development of a relationship with a man. Karen was concerned about the development of breast cancer in her daughter but she realized that "the cause of breast cancer was not known."

These findings were supported in the literature. Oktay and Walter (1991) described that breast cancer interfered with the tasks of mothering in many ways. Breast cancer resulted in self-absorption and the women were less able to be there for children. Emotional reactions and the time needed for treatments and their recovery exhausted

mothers and made them less able to care for children. These researchers identified several factors which contributed to how and what children were told. These included: the age of the children, the type of coping methods of the mother (such as denial), and the communication patterns in the family. They found a range of not telling children at all, telling about the disease but minimizing its meaning, to being completely honest even about the possibility of death. They too identified that young adult women often felt guilty about the possibility of passing breast cancer on to their daughters.

Each of the young adult women demonstrated a connectedness with other women as they underwent treatment for their breast cancer. Concern for others brought additional meaning and a sense of purpose to their experiences with breast cancer. They did not want others to experience the difficulties they had endured. Each of the five young adult women identified specific interventions to help other young adult women during this time. In their suggestions could be heard the need for recognition of the unique needs of young adult women and the availability of services for "the majority of women" - older, white, married women without children. Oktay and Walter (1991) also identified more time being devoted to the development of relationships with others in young adult women as they dealt with a diagnosis of a breast cancer.

In this study, Karen described that she planned to become a volunteer for the American Cancer Society to tell others about the option of lumpectomy with radiation. She had "a lot of concern for other women out there who are getting mastectomies recommended instead of lumpectomies." As Jennifer and Karen made plans to participate in the Revlon Run For Breast Cancer, increasing the awareness of breast cancer in other young adult women had become valued in their lives.

Seeking Help From Others

These young adult women also sought the help of others to deal with their experiences with breast cancer diagnosis and treatment. Receiving help from family and

friends, being understood by others, reaching out beyond family and friends, and seeking help from husbands were instrumental in dealing with the experiences.

Relying On Family And Friends

One of the findings by Roberts et al. (1993) on women with early breast cancer was that ego strength and past psychological functioning were better predictors of patient adaptation to disease than perceived social support. This was supported by the findings in this study on young adult women. Although finding the strength from within self was essential in coping with the experience of breast cancer, these young adult women also needed the support of family and friends. Staci stated: "You have to find the self within yourself to deal with this because you're going to have to deal with it. . . You cannot ignore the problem nor will it go away on its own. . . You have to find it within yourself and with the help of others to deal with it." Susan described the help from her family as supportive: "They said everything was going to be fine. They were going to take care of everything." In the study by Suominen et al. (1995), social support of family was not identified as an important factor in "good recovery;" rather, it was the comforting support of the nurses they came in contact with which was helpful. Perhaps these differences could be correlated with health care now being provided in managed care environments where contact with professional nurses is limited and where the individual is asked to assume a greater role in her or his own health care. Weakened by surgery and chemotherapy treatments, these young adult women needed others for physical assistance.

Each of the young adult women talked about the help from family and friends during the difficult periods following their mastectomies and chemotherapy treatments. They experienced great weakness following their surgeries and had difficulties in caring for self. For three of them, the chemotherapy treatments became harder to endure as they progressed. The help they received from family and friends was described as supportive.

Susan stated: "They said that they would take care of everything . . . that everything was going to be fine."

Jennifer and Karen did not want to tell their mothers about their diagnoses of breast cancer. They did not want to worry them. As reinforced by Oktay and Walter (1991), young adulthood was characterized by the movement from dependency on mothers and fathers toward autonomous independence. Not wanting to tell mother was consistent with a threat of slipping back into a dependent role. Jennifer had her father tell her mother. She worked hard to minimize the support she needed from them and relied more on friends. Karen accepted the help of her mother-in-law when it was offered before she told her own mother.

Sue and Sue (1990) described the value of extended family in Hispanic American families. Family members often sought help first from family members and then from friends of family members prior to use of services outside the family. This consideration was supported in this study. When Angela, an Hispanic, was "in a panic state" following her surgery, she sought out a friend of her mother-in-law's for guidance. Although this woman was older, she encouraged Angela to get breast reconstruction. After speaking with her, Angela contacted the Reach to Recovery Program for help. In addition, as chemotherapy treatments became more difficult for her, Angela sought the help of a woman in her church who sold nutritional supplements. Angela began taking the supplement, blue-green algae, that day.

Sue and Sue (1990) also reinforced the African American family as a strong extended family network of relatives and close friends. Strong support was often provided. African Americans also utilized services outside the family if a sensitivity to cultural differences was perceived. In this study, these considerations were also supported. Staci relied on family and friends for support. Although she communicated a sense that her friends did not understand what she was going through, she did not seek outside services. Staci however, had also experienced a lack of sensitivity on part of the

physicians and nurses with whom she had come in contact in her treatment of early breast cancer.

Searching For The Understanding Of Others

Understanding from family and friends was instrumental to the coping of the young adult women. The need to be understood by others was consistent with what Palsson and Norberg (1995) termed "confirmation." Confirmation communicated understanding, showing interest/respect for the woman as a human being, and creating and maintaining a climate of free discussion by allowing the expression of feelings and the asking of questions. Zenmore and Shepel (1989) identified emotional support as the type of support most helpful to women undergoing treatment for early breast cancer and found that emotional support was positively correlated with adjustment.

Jennifer and Staci also identified the need for sympathy from others as they experienced the difficulties associated with treatment. In social psychology, sympathy was defined as a "heightened awareness of the suffering of another person as something to be alleviated" (Wispe, 1987, p. 318). When used, it communicated a desire to reach out to another in feeling and in action. It was motivated by compassion for another. Devalued in nursing because it has been associated with pity involving overidentification, the importance of sympathy in the development of justice and community was noted in ethics literature (Ricoeur, 1992).

Reaching Beyond Family And Friends

Each of the young adult women called the American Cancer Society themselves for follow-up with a Reach to Recovery volunteer. Only Staci got information about the program during her hospital stay. The other young adult women got the information from newspapers and hearing about the helpfulness of the American Cancer Society from others. No return call was made to one of the young adult women by the American Cancer Society.

The Reach to Recovery volunteers were helpful to the young adult women. They communicated a sense that "every thing would be okay." Jennifer was happy that the woman she spoke to was 31 years old when she was diagnosed with breast cancer. She stated: "Younger women's issues are different from the issues of older women." Both Angela and Jennifer attended support groups. Neither of them found them helpful because the women were older. Jennifer stated that she asked the members of the group: "Don't any of you think about dying?" They stated that they didn't! Staci stated that she thought about attending a support group but they were held in the evening which was "peak hour" for her children. Angela also identified having problems of transportation to the groups.

The helpfulness of the volunteers and support groups of the American Cancer Society was identified in literature (Massie and Holland, 1991; Palsson and Norberg, 1995; Payne et al.1996); however, the increased importance of someone close in age to the young adult woman was not identified in the literature. In Palsson and Norberg's study, talking with other women with newly diagnosed breast cancer was also identified as helpful. Kawaga-Singer (1995) reinforced that the projects funded by the American Cancer Society in 1989 to reach the underserved, demonstrated that if services are available, accessible, and delivered in a culturally sensitive, humane, and caring manner, the people will come. A need for available, accessible, and individualized programs for the diverse young adult women was noted in this study.

Seeking Spousal Support

Susan identified her husband as the person with whom she talked the most about her fears and inadequacies the most. Angela described the helpfulness of her husband in dealing with the loss of her breast. Three of the young adult women spoke of their need for more supportive relationships with their husbands. Jennifer, who was single, wondered about a relationship with guy. She stated: "would it (breast cancer and the

loss of a breast) matter to them?" Angela identified the need for support groups for couples because husbands needed support too!

This finding was supported in the literature. Roberts et al. (1993) studied the effects of perceived social support from friends, family, and spouses on the psychological adjustment in women with breast cancer. In their study, when the effects of social desirability were controlled, the correlations between social support and psychological distress dropped with the exception of the correlation between spouse support and psychological distress. Spousal support demonstrated "stress-buffering value" (p. 163). Oktay and Walter (1991) described that in breast cancer, the capacity for intimacy was affected by the need for self-absorption to meet physical needs. Partners often distanced themselves because of fear that the other might die and they would be abandoned. Young adult women and their spouses needed assistance in communicating thoughts and feelings.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

Within the descriptions of these young adult women's concerns and experiences, I was able to transcribe individual and joint narratives that related the meaning of cancer to them and the ways in which they coped with their illness. These descriptions may encourage other young adult women recovering from mastectomy to reflect upon their own strategies, and perhaps adjust or augment their existing tools to include some of the strategies related by their peers in this study. Consistent with the practices currently characterizing managed care, the young adult women were asked to assume a greater role in their health care but without a corresponding expansion of resources to address their singular psycho-social and physical needs. Although these five women experienced great disruption in their lives, in the final analysis their inner strength operated as the central resource that helped them endure the treatment process required to survive this life-threatening illness.

Strengths And Limitations Of The Study

Extremely little extant information in cancer research literature addresses the concerns of young adult women and their experiences with breast cancer and the treatment of this population in managed care environments. The use of qualitative multicase study research methodology in this study therefore provided an ideal structure to provide a holistic description of the concerns of these young adult women and in doing so, afforded some corresponding insight into the issues that arise in negotiating contemporary health care systems.

A limitation of qualitative multicase study research and thereby of this study, is the researcher's inability to form generalizations from five case studies in which the

participants were selected in a purposeful rather than random manner. Accordingly, this study was undertaken in an attempt to understand the phenomenon in depth rather than to know what is generally true of many. The extent to which the study's findings can be applied to other situations is directly dependent upon the variables of these subsequent situations.

Conclusions And Recommendations

The findings from this study identified areas for health care reform in managed care environments. These reforms include areas dealing with increasing the awareness of breast cancer in young adult women; facilitating early breast cancer detection; minimizing delays in treatment; and making adjustments in care. The care adjustments encompass improvements in education, early referral to the American Cancer Society, follow-up care, and the provision individualized care. These "action areas" can be used to guide funding and the allocation of scarce resources for young adult women undergoing treatment for early breast cancer

Increasing Awareness

The incidence of breast cancer in this young adult age group shocked not only the patients included in this study; health care personnel shared and reinforced this perception. This finding accentuates the importance of continuing public education regarding the incidence of breast cancer, particularly among this seemingly "atypical" population. Further, education efforts must be expanded among health professionals themselves, including physicians and nurses. For example, the evaluation of all breast lumps in women of all ages and ethnic heritage is of paramount importance; no one is "too young" or "not at risk". Breast cancer is not a disease limited to middle-aged and older white adult women. It is, instead, a disease that threatens all women and crosses all age and cultural demarcations..

Facilitating Detection

One study finding with serious implications for early detection efforts is that none of the young adult women in this study practiced routine self breast examination. The fact that their breast cancer could have been diagnosed earlier lends both credence and emphasis to the importance of routine self breast examination. Self breast examination is recommended by the American Cancer Society for all women from the onset of menses; self-examination enables women to "know" their breasts, and so increases their ability to identify the early development of a lump. In conjunction with the standard recommendation of the American Cancer Society, the health care community must redouble its efforts to inform the public of the critical value of this simple procedure.

The findings of this study also reinforce the importance of yearly clinical breast exams as recommended by the American Cancer Society. However, the American Cancer Society recently extended the recommended interval for papanicolaou (PAP) testing in women, eliminating the yearly test for women who record three or more consecutive annual examinations with normal findings. This reduction in frequency has provoked a corresponding decline in the volume of yearly clinical breast examinations, particularly among young adult women. This researcher therefore recommends that clinical breast examination be performed on a standard basis when women seek primary care services; education regarding self breast examination should be provided at the same meeting. Because of the difficulties associated with mammography in young adult women, alternatives to mammography in young adult women (such as ultrasound and transillumination) should be investigated for use in the detection of breast masses in all premenopausal women.

Minimizing Delays In Treatment

The four- to thirteen-week interval between lump discovery and mastectomy reported by the women in this study is distressing, as this finding supports an existing hypothesis that identifies delay in treatment as a possible factor contributing to diagnoses

of advanced stage cancer among young adult women. The extent of delay in breast cancer treatment could serve as an important indicator in evaluating the quality of care provided in managed care environments with abbreviated time periods established as a central goal. A similar recommendation centers upon increasing educational efforts that encourage women to demand prompt treatment. In addition, the standard use of "second opinions" is encouraged. The American Cancer Society offers a free list of recommended surgeons in all regions of the country.

Referring To The American Cancer Society

Study participants cited American Cancer Society programs such as Reach to Recovery and "Feel Good, Look Better" as extremely important factors contributing to their recovery. However, only one of the young adult women was referred to the American Cancer Society by health care providers; the other four were referred by friends, or received information about services in the newspaper. Before the advent of managed care, referral to the American Cancer Society by the Social Service Departments of individual hospitals was common practice. As well, women also were referred preoperatively by their surgeons. This valuable practice was not evident in the stories of these young adult women and should be reinstated by case managers.

It is further recommended that women be referred to the American Cancer Society at the time when they first enter the health care system for initial evaluation of the breast lump. The organization offers some valuable information for both patients and their families. This study incorporated a review of some of the most salient information, including NIH guidelines for lumpectomy with radiation for early breast cancer; the importance of "second opinions"; a listing of area surgeons approved by the American Cancer Society; treatment options; and the Reach to Recovery Program. The young adult women in this study also underscored the benefits of having Reach to Recovery volunteers within their age group; in a similar vein, they recommended developing alternative support groups for young adult women and for couples. One participant

further recommended that health care providers offer actual pictures of post-surgical breast areas so that young adult woman can gain greater understanding of what the mastectomy might look like following surgery.

Educating About Surgical Procedures

Despite being asked to assume a greater role in their health care, these young adult women did not receive sufficient education to help them in this endeavor. These young adult women related treatment histories that did not include preoperative and postoperative instructions, except for the measuring of drainage from surgical drains. The stories were characterized by frequent requests for longer hospitalization and incidents of complications such as axillary contracture and suture line infection. It is therefore strongly recommended that comprehensive educational programs be provided prior to the initiation of treatments, surgery, and chemotherapy treatments. The involvement of family and friends in the educational programs would also assist in the transferal and application of this knowledge in individual treatment programs. If managed health care systems are to increase patient responsibility, these organizations are similarly accountable for developing and disseminating adequate information to these patients.

Providing Follow-Up Care

Post-operative recommendations center upon the expanded provision of both in-house and post-discharge care. The need for longer hospitalization was consistently identified in this study. Nursing staff and case managers should be adequately prepared to recognize the psychological and social difficulties particular to young adult women with breast cancer. As client advocates, these individuals must work with surgeons to extend hospitalization or provide follow-up care in the home when appropriate..

Study findings also point to the need for ongoing education, corresponding to the aforementioned need for increased education during the treatment process. Several of the young adult women utilized information management to control the amount and type of

incoming information. The need for continued reinforcement of instruction is recommended, as well as the provision of home care options such as telephone calls, home visits, and information lines.

These young adult women also experienced great difficulties as they underwent chemotherapy, some of which could have been alleviated with educational preparation. For this reason, instruction concerning chemotherapeutic agents and interventions should be provided to minimize the development of side effects. This study also identified the need for young adult women who undergo chemotherapy treatment to receive individual counseling or to participate in support groups designed specifically to address the concerns of young adult women.

Individualizing Care

Although the American Cancer Society does provide several valuable avenues of information for cancer patients, the stories of these young women delineated a critical chasm in services and information geared to the singular needs of single and married women alike in their population group. Participants describe available brochures as directed to older women with children. While two of the young adult women did attend a support group, they did not maintain their associations with the group due to the differences in age and specific issues. In response to this void, information booklets and support groups should be developed that specifically address the unique needs of young adult women. Further, there is a need for support groups focused upon the concerns of these women and, as well, for their partners and families. Those young adult women who want to become active in helping other young women undergoing treatment for breast cancer could participate in designing programs to meet the unique needs of this age group.

This study also pinpointed the lack of culturally sensitive care within the existing health care industry, which collectively fails to adequately address the unique needs of Latina and African-American women. Patient communication with health care personnel

did not reflect an understanding on the part of health care professionals concerning the potential influences of culture upon care. While these young adult women did rely on family and close friends, the myriad components of cancer treatment often forced need to go beyond their familial and cultural circle to seek help. When this outer circle proved insensitive to their cultural concerns, they chose not to return, thereby relinquishing the search for additional resources. The provision of culturally sensitive care must be emphasized in educational programs and home care organizations. Programs and services developed for underserved populations could and should be expanded to meet the needs of culturally diverse populations. Culturally diverse young adult women comprise a large potential pool of recruits to assist in the development, outreach, and implementation of programs that would serve as a resource for themselves and other members of their cultural groups.

Areas For Future Research

The sum findings of this study present the need to replicate its data with additional studies on young adult women with breast cancer, including subject groups that are more culturally diverse. My findings identify several areas requiring additional research: among the most critical are incidents of the delay in treatment for early breast cancer in young women, with comparisons made to results produced by studies of women of other age groups. Additional studies geared toward identifying the beliefs of physicians, nurses and other health professionals concerning early breast cancer in young adult women would assist in highlighting misconceptions and gaps in professional education. Patient satisfaction concerning same day surgery for mastectomy and the development of complications represents another area requiring investigation, along with the effect of preoperative instruction on postoperative functioning.

Overall, as hospitals transition into managed care, the quality of life for young adult women undergoing treatment for early breast cancer needs to be investigated to assure that satisfactory health outcomes are achieved. The practical implementation of

the interventions suggested by this study must be validated, as well as their efficacy of these interventions for more young adult women. At the same time, the studies previously undertaken on women with early breast cancer could be replicated to determine the effect of age upon results. Finally, the subject limitations of this study, aligned with the demographic trends in the US, demand that the influence of culture be examined to identify interventions that are meaningful and acceptable to culturally diverse young adult women.

Concluding Remarks

There were two assumptions that I suspended at the onset of this study. First, this study began with the assumption that the issues surrounding health care economics were complex and included both positive and negative aspects. Hospitals have ceased to serve as the center or core of the business of health care; instead, primary care and keeping people healthy are currently the focal points in managed care and integrated health care systems. Hospitals, focused on profound cost reduction measures to survive in the competitive market, have only recently begun to evaluate client outcomes of managed care. From this scenario emerges a clear calling for nurses to address issues of quality care and the outcomes of care in the managed care environment in their roles as client advocates; they are similarly charged with the responsibility of suggesting areas for health care reform and necessary adjustments in care. The nursing profession must continue to identify and promote health care reform to ensure that standards of care are uniformly accepted and achieved, particularly for those disadvantaged groups who cannot serve as their own advocates.

The second assumption I suspended related to the importance of a therapeutic relationship between the nurse and client in meeting the psychological needs of the client. Since young adult women who undergo mastectomy for early breast cancer possess individual and significant psychological needs, a therapeutic relationship is an inescapable aspect of their care. The stories of the young adult women related in this

study included few instances that reflected this therapeutic nurse-client relationship.

While this lack must be ascribed in part to the limited presence of nurses, that factor does not absolve nurses of the responsibility to reach out to this population. "Finding strength from within" helped the young adult women to endure their difficult experiences with treatment for early breast cancer. These young adult women, however, sought to gain the support of others as well; a central element of this external support was its conveyance of a sense of empathetic understanding of these women's concerns. .

It is probably the thoughts of Staci, one of the young adult women participating in this study, that bring special meaning to the complexity associated with the current flux in health care reform and as well to the status of my assumptions. She remarked:

Today, western health care is a business, it's not health care. They aren't focused on prevention like they should be. My infection could have been prevented. I had to fight for the wig. They really don't work to prevent things. . . You just have to stick up for yourself!

Our identity, at its core, is based on a curious duality of independent autonomy and interdependence with other individuals within our community. Our selfhood is predicated upon concepts of self-image and self-esteem; breast cancer, in particular, poses a significant threat to these integral components of self. As health care providers – as patient advocates – we nurses must carve a central position in the current debate over health care reform, and argue for the development of a system that places the humane rights of the patient above cost and risk considerations.

REFERENCES

- American Cancer Society. (1996). Cancer facts and figures - 1996. Atlanta, GA: American Cancer Society.
- Baquet, C., Horm, J., & Gibbs, T. (1991). Socioeconomic factors and cancer incidence among blacks and whites. Journal Of The National Cancer Institute, 83, 551-557.
- Becker, H. (1990). Generalizing from case studies. In E. W. Eisner & A. Peshkin (Eds.). Qualitative inquiry in education. (p. 233-242).
- Benedict, S., Williams, R., & Baron, P. (1994). Recalled anxiety: From discovery of a benign breast mass. Oncology Nursing Forum, 21, 1723-1727.
- Bogdan, R. C. & Biklen, S. K. (1992). Qualitative research for education: An introduction to theory and methods. Boston: Allyn & Bacon.
- Brooten, D. & Naylor, D. (1995). Nurses' effect on changing patient outcomes. Image: Journal of Nursing Scholarship, 27, 95-99.
- Burke, C., Zabka, C., & McCarver, K. (1995). Short stay surgery for breast cancer: Patient perceptions and program evaluation. Oncology Nursing Forum, 22, 350.
- Cassell, E. (1991). The nature of suffering. New York: Oxford University Press.
- Clark, J. & Kent, R. (1992) One-day hospitalization following modified radical mastectomy. American Surgeon, 58, 239-242.
- Creswell, J. W. (1994). Research design: Qualitative and quantitative approaches. Thousand Oaks, CA: Sage.
- Dean, C. (1988). The emotional impact of mastectomy. British Journal of Hospital Medicine, 32, 30-39.

Dean, C. & Surtees, P. (1989). Do psychological factors predict survival in breast cancer? Journal of Psychosomatic Research, 33, 561-569.

Fawzy, I., Fawzy, N. & Hyun. (1994). Short-term psychiatric intervention for patients with malignant melanoma: effects on psychological state, coping, and the immune system. In C. Lewis, C. O'Sullivan, & J. Barraclough (Eds.), The psychoimmunology of cancer: Mind and body fight for survival? Oxford: Oxford University Press.

Frank-Stromborg, M. (1989). Reaction to the diagnosis of cancer questionnaire: Development and psychometric evaluation. Nursing Research, 38, 364-369.

Ganz, P., Polinsky, M., Schage, C. (1989). The quality of life of breast cancer patients receiving adjuvant chemotherapy. Recent Results Cancer Research, 115, 244-254.

Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University.

Greer, S. (1990). Psychological response to breast cancer and 15 year outcome. Lancet, 335, 49-50.

Henderson, I. C. (1995). Breast cancer. In G. Murphy, W. Lawrence, & R. Lenhard (Eds.). American Cancer Society Textbook Of Clinical Oncology. (Second Edition). Atlanta, GA: The American Cancer Society, Inc.

Hughes, K. (1993). Psychosocial and functional status of breast cancer patients: The influence of diagnosis and treatment choice. Cancer Nursing, 16, 222-229.

Hunt, K., Feig, B., & Ames, F. (1995). Ambulatory surgery for breast cancer. The Cancer Bulletin, 47, 292-297.

Jarrett, S., Ramirez, A., Richards, M., & Weinman. (1992). Measuring coping in breast cancer. Journal of Psychosomatic Research, 36, 593-602.

Kawaga-Singer, M. (1995). Socioeconomic and cultural influences on cancer care of women. Seminars In Oncology Nursing, 11, 109-119.

Kleinman, A. (1988). The illness narratives: Suffering, healing, and the human condition. New York: Basic Books.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. The American Journal of Occupational Therapy, 45, 214-222.

Lee-Feldstein, J., Anton-Culver, H., & Feldstein, P. (1994). Treatment differences and other prognostic factors related to breast cancer survival: Delivery systems and medical outcomes. JAMA, 271, 1163-1168.

Lerman, C., Daly, M., Walsh, W., Resch, N., Seay, J., Barsevick, A., Birenbaum, L., Heggan, T., & Martin, G. (1993). Communication between patients with breast cancer and health care providers: Determinants and implications. Cancer, 72, 2612-2620.

Lincoln, Y. S. & Guba, E. G. (1990). Judging the quality of case study reports. Qualitative Studies in Education, 3, 53-59.

Lincoln, Y. S. & Guba, E. G. (1992). The making of a constructivist: The paradigm dialog. Newbury Park, CA: Sage.

Love, R., Leventhal, H., & Easterling, D. (1989). Side effects and emotional distress during cancer chemotherapy. Cancer, 63, 604-612.

Luker, K., Beaver, K., Leinster, S., Owens, G., Degner, L., & Sloan, J. (1995). The information needs of women newly diagnosed with cancer. Journal of Advanced Nursing, 22, 134-141.

Mack, E., McGrath, T., & Pendleton, D. (1993). Reaching poor populations with cancer prevention and early detection programs. Cancer Practice, 1, 35-39.

Maier, S., Watkins, L., Fleshner, M. (1994). Psychoneuroimmunology. American Psychologist, 49, 1004-1017.

Massie, K. & Holland, J. (1991). Psychological reactions to breast cancer in the pre- and post-surgical treatment period. Seminars in Surgical Oncology, 7, 320-325.

Maunsell, E., Brisson, J., Deschenes, L. (1992). Psychological distress after initial treatment of breast cancer: Assessment of potential risk factors. Cancer, 70, 120-125.

Merriam, S. B. (1988). Case study research in education: A qualitative approach. San Francisco: Jossey-Bass.

Mickley, J., & Soeken, K. (1993). Religiousness and hope in hispanic and anglo american women with breast cancer. Oncology Nursing Forum, 20, 1171-1177.

Miles, M. B. & Huberman, A. M. (1994). Qualitative data analysis. (Second edition). Thousand Oaks, CA: Sage.

Miller, J. B. (1986). Toward a new psychology of women. Boston, MA: Beacon Press.

Mock, V. (1993). Body image in women treated with breast cancer. Nursing Research, 1993, 42, 153-157.

Morse, J. M. & Doberneck, B. (1996). Delineating the concept of hope. Image: Journal of Nursing Scholarship, 27, 277-285.

Nelles, W., McCaffrey, R., Blanchard, C., & Ruckdeschel, J. (1991). Social supports and breast cancer: A review. Journal of Psychosocial Oncology, 9, 21-34.

Northouse, L. (1989). A longitudinal study of the adjustment of patients and husbands to breast cancer. Oncology Nursing Forum, 16, 511-526.

Northouse, L., Jeffs, M., Cracchiolo-Caraway, A., Lampman, L., & Dorris, G. (1995). Emotional distress reported by women and husbands prior to a breast biopsy. Nursing Research, 44, 196-201.

Oktay, J. & Walter, C. (1991). Breast cancer in the life course. New York: Springer Publishing Company.

Owens, R., Aschcroft, J., & Leinster, S. (1987). Informal decision analysis with breast cancer patients: An aid to psychological preparation for surgery. Journal of Psychosocial Oncology, 5, 23-33.

Packer, J. (1988). The quality of life of breast cancer patients receiving adjuvant chemotherapy. Oncology Nursing Forum, 15, 127.

Palsson, M. & Norberg, A. (1995). Breast cancer patients' experiences of nursing care with the focus on emotional support: The implementation of a nursing intervention. Journal of Advanced Nursing, 21, 277-285.

Parker, S., Tong, T., Bolden, S., Wingo, P. (1996). Cancer statistics, 1996. CA - A Cancer Journal for Clinicians, 46, 5-27.

Patton, M. Q. (1990). Qualitative evaluation and research methods. (Second edition). Newbury Park, CA: Sage.

Payne, D., Sullivan, M., Massie, M. (1996). Women's psychological reactions to breast cancer. Seminars in Oncology, 23, 89-97.

Pierce, P. (1993). Deciding on breast cancer treatment: A description of decision behavior. Nursing Research, 42, 22-28.

Prescott, P. (1993). Nursing: An important component of hospital survival under a reformed health care system. Nursing Economics, 11, 192-199.

Recht, A. (1996). Selection of patients with early stage invasive breast cancer for treatment with conservative surgery and radiation therapy. Seminars in oncology, 23, 19-30.

Ricoeur, P. (1992). Oneself as another. Chicago: The University of Chicago Press.

Roberts, C., Cox, C., Shannon, V., & Wells, N. (1994). A closer look at social support as a moderator of stress in breast cancer. Health & Social Work, 19, 157-164.

Roid, G. & Fitts, W. (1988). Tennessee self-concept scale: Revised manual. Los Angeles, CA: Western Psychological Services.

Sariego, J., Zrada, S., Byrd, M., & Matsumoto, T. (1995). Breast cancer in young patients. American Journal of Surgery, 170, 243-245.

- Schain, W., d'Angelo, T., Dunn, M., Lichter, A. & Pierce, L. (1994). Mastectomy versus conservative surgery and radiation therapy: Psychological consequences. Cancer, 73, 1221-1228.
- Schover, L., Yetman, R., Tuason, L., Meisler, E., Esselstyn, C., Hermann, R., Grundfest-Broniatowski, S., & Dowden, R. (1995). Partial mastectomy and breast reconstruction. Cancer, 75, 54-64.
- Shaw, C., Wilson, S., & O'Brien, M. (1994). Information needs prior to breast biopsy. Clinical Nursing Research, 3, 119-131.
- Sinsheimer, L. & Holland, J. (1987). Psychological issues in breast care. Seminars In Oncology, 14, 75-82.
- Sovie, M. (1995). Tailoring hospitals for managed care and integrated health systems. Nursing Economics, 13, 72-83.
- Stevenson, B. & Coles, P. (1993). A breast cancer support group: activities and value to mastectomy patients. Journal of Cancer Education, 8, 230-242.
- Strauss, A. & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage.
- Sue, D. W. & Sue, D. (1990). Counseling the culturally different: Theory and practice. (Second Edition). New York: John Wiley & Sons.
- Suominen, T., Leino-Kilpi, H. & Laippala, P. (1995). Who provides support and how? Breast cancer patients and nurses evaluate patient support. Cancer Nursing, 18, 278-285.
- Toombs, S. (1993). The meaning of illness: A phenomenological account of the different perspectives of physician and patient. Boston: Kluwer Academic Publishers.
- Trief, P. & Donohue-Smith, M. (1996). Counseling needs of women with breast cancer: What the women tell us. Journal of Psychosocial Nursing, 34, 24-29.

Vinokur, A., Threatt, B., Caplan, R., & Zimmerman, B. (1989). Physical and psychosocial functioning and adjustment to breast cancer: Long term follow-up of a screening population. Cancer, 63, 394-405.

Vinokur, A., Threatt, B., Vinokur-Kaplan, D., Satariano, W. (1990). The process of recovery from breast cancer for younger and older patients. Cancer, 65, 1242-1254.

Ward, S., Heidrich, S., & Wolberg, W. (1989). Factors women take into account when deciding upon type of surgery for breast cancer. Cancer Nursing, 12, 344-351.

Wilson, R., Hart, A., & Dawes, P. (1988). Mastectomy or conservation, the patient's choice. British Medical Journal, 297, 1167-1169.

Wispe, L. (1987). History of the concept of empathy. In N. Eisenberg & J. Strayer (Eds). Empathy and its development. New York: Cambridge University Press.

Wong, C. & Bramwell, L. (1992). Uncertainty and anxiety after mastectomy for breast cancer. Cancer Nursing, 15, 363-371.

Yin, R. K. (1991). Applications in case study research. Washington, DC: Cosmos Corporation.

Zenmore, R. & Shepel, L. (1989). Effects of breast cancer and mastectomy on emotional support and adjustment. Social Science Medicine, 28, 19-27.

Appendix A
Informed Consent

UNIVERSITY OF SAN DIEGO

Consent to Participate in a Research Study

I give permission for Donna K. Schutte, a doctoral candidate at the School of Nursing, University of San Diego, to interview me regarding my experience with my surgery for breast cancer. I understand that the information will suggest a foundation for easing the concerns of young adult women with early breast cancer. I understand that audiotaped interviewing will last approximately 60-90 minutes and that follow up via telephone may be required within 1-2 days for clarification of areas determined to be unclear.

I understand that my participation is completely voluntary. I may refuse to answer any questions with which I feel uncomfortable. I may withdraw from the study at any time without prejudice. A decision not to participate will in no way jeopardize the support and help that can be provided to me by the volunteers of the Reach to Recovery Program and the staff of the American Cancer Society. I will be reimbursed for transportation costs to the interview site and/or child care during the interview if necessary; otherwise, I will receive no compensation. Although no physical, social, or psychological risks are anticipated from participation in this study, I understand that recalling my experiences may trigger some emotional feelings concerning aspects of the surgery on my part. I am aware that telling aspects of my story can be therapeutic for myself and can also be used to help others. I am aware of the availability of support groups of the American Cancer Society should I wish to attend.

There was the opportunity to ask questions about the study prior to signing this form and my questions were answered to my satisfaction. I am aware that I may call Donna Schutte at any time for any clarification. I understand that the information collected will remain confidential. I further understand that to preserve my anonymity, no identifying information will be transcribed into text nor used in any publication of the findings of the study. Interview tapes will be stored in a locked file and will be destroyed at the completion of the study. I will receive a summary of findings at the conclusion of the study.

There is no agreement between myself and the researcher, written or verbal, beyond that expressed on this consent form.

I, the undersigned, understand the above explanations and, on that basis, I give consent to my voluntary participation in this research.

 Signature of Participant

 Date

 Location (e.g., Riverside, CA)

 Signature of Researcher

 Date

Appendix B

Interview Questions

The following questions will be used to guide the interview. The exact wording and the order of the questions may not be followed.

1. What concerns did you have when you first discovered the breast mass? How did you deal with them?
2. Did you have different concerns at the time of your biopsy? Tell me about that experience.
3. When you were told of the need for mastectomy, what concerns did you have?
4. What were your thoughts as you went into surgery for the mastectomy? How were you able to handle these thoughts?
5. What were your concerns after the surgery?
6. What were your concerns at the time of discharge from the hospital following your mastectomy?
7. Have these concerns changed in your recovery from surgery? If so, how?
8. What concerns, if any, do you have now?
9. What concerns do you have about the future?
10. If you were asked to talk to another young adult woman who is about to have a mastectomy, what would you say to her?
11. Is there anything else we haven't talked about that you would like to tell me?

Figure 1: Young adult women's responses to undergoing treatment for early breast cancer.