

**Quality of Life of Breast Cancer Survivors in the Acute, Extended and Permanent  
Phases of Survivorship**

By

Lori Andreas

A Master's Research Thesis

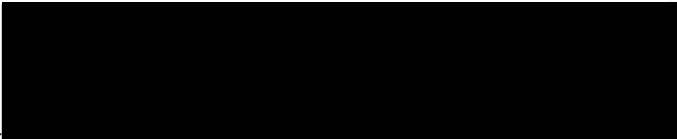
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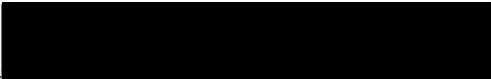
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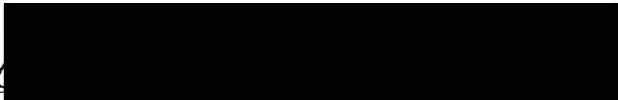
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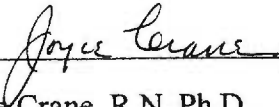
  
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## Abstract

Title: Quality of Life of Breast Cancer Survivors in the Acute, Extended and Permanent Phases of Survivorship.

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Joyce Crane, R.N. Ph.D.

Most of the women that are diagnosed with breast cancer will be survivors. There is belief that quality of life gradually returns to normal following treatment for breast cancer. However, there appears to be evidence that there are negative changes that occur long after treatment. The purpose of this study is to describe the quality of life of breast cancer survivors within the physical, psychological, social and spiritual domains. The study also describes how quality of life of breast cancer survivors differs in three phases of survivorship (acute, extended, permanent), and for breast cancer survivors in the acute phase of survivorship; the study also describes what nurses do that most impacts the survivors' quality of life. The sample size was limited to breast cancer survivors who continued to be followed by physicians at Oregon Health Sciences University. The QOL-Cancer Survivors (QOL-CS) Tool created by Ferrell and Hassey Dow (1995) was used to collect information regarding quality of life in the four domains (physical, psychological, social and spiritual). This 41 item instrument rated each item on a scale of 0-10, with 0 being the worst possible and 10 representing the best possible.

Psychometric analysis based on the administration of the QOL-CS included a test - retest reliability ( $r=.89$ ), internal consistency ( $r=.93$ ). The demographic tool gathered data to describe the sample and the QOL- Breast Cancer- Qualitative Tool was used to describe the experience of acute phase survivors. There were 56 responses: 12 in the acute, 32 in the extended and 12 in the permanent phases. Quality of life scores for this study were comparable to those found in the earlier Hassey Dow (1995) study. Physical changes

such as aches and pains and fatigue, as well as sleep changes and weight gain were undesirable outcomes for survivors. Psychologically, worse outcomes for survivors included distress associated with initial diagnosis and treatment and distress on family. The most distressing outcome for breast cancer survivors socially was the concern for their daughters or relatives regarding breast cancer. Spiritually, breast cancer survivors rated uncertainty regarding their future and degree that illness has made positive changes had the worse outcomes. The analysis of how quality of life varies in the three phases (acute, extended, permanent) demonstrated that there is no significant variation in quality of life since diagnosis. Themes in responses to what survivors thought nurses did that particularly impacted their quality of life included teaching, positive attitude, instilling hope, support and caring. Themes in responses to what survivors would have liked for nurses to do that might have affected their quality of life included operational issues such as quality of meals during hospitalization, comfort measures and supplying information. This study contributes to our knowledge of the four domains of quality of life in breast cancer survivors, and supports findings from other research related to survivors' quality of life. This study has added a dimension to the body of knowledge that exists regarding the quality of life of breast cancer survivors, by investigating how quality of life varies in the three phases of survivorship. The sample size is limited in this study, however, and further study is needed to understand how quality of life varies in each phase of survivorship. Overall, the research findings can assist oncology nurses to understand what components of quality of life are important to breast cancer survivors. Further, survivors in this study have described what they would have liked for nurses to do for them that might have affected their quality of life.

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And finally, my deepest appreciation to the brave women that this study is all about, breast cancer survivors. Thank you for giving your time, your emotions and your stories. Without these stories, this work would not exist!

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The most distressing outcome for breast cancer survivors socially was the concern for their daughters or relatives regarding breast cancer. Spiritually, breast cancer survivors rated uncertainty regarding their future and degree that illness has made positive changes had the worse outcomes. The analysis of how quality of life varies in the three phases (acute, extended, permanent) demonstrated that there is no significant variation in quality of life since diagnosis. Themes in responses to what survivors thought nurses did that particularly impacted their quality of life included teaching, positive attitude, instilling hope, support and caring. Themes in responses to what survivors would have liked for nurses to do that might have affected their quality of life included operational issues such as quality of meals during hospitalization, comfort measures and supplying information. This study contributes to our knowledge of the four domains of quality of life in breast cancer survivors, and supports findings from other research related to survivors' quality of life. This study has added a dimension to the body of knowledge that exists regarding the quality of life of breast cancer survivors, by investigating how quality of life varies in the three phases of survivorship. The sample size is limited in this study, however, and further study is needed to understand how quality of life varies in each phase of survivorship. Overall, the research findings can assist oncology nurses to understand what components of quality of life are important to breast cancer survivors. Further, survivors in this study have described what they would have liked for nurses to do for them that might have affected their quality of life.

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## **Chapter 1**

### **Statement of the Problem**

The majority of women diagnosed with breast cancer will be survivors. In 1993 breast cancer was the most commonly diagnosed cancer with 182,000 new cases. The five year survival for cancer in situ is 100 % (in situ carcinoma of the breast is characterized by the proliferation of malignant appearing cells within the ducts and lobules without invasion into the surrounding tissue), 93% for localized disease, 71% with regional spread and 18% with distant metastases. (American Cancer Society, 1994). This increasing number of women surviving breast cancer points to the need to explore the quality of life among these women.

There is belief that quality of life gradually returns to normal following treatment for breast cancer. Most quality of life studies have focused on the period of time during treatment or soon after treatment. However, there appears to be evidence that there are negative changes that occur long after treatment.

Kathy LaTour , a breast cancer survivor who wrote the book The Breast Cancer Companion, describes the year following treatment as feeling as though she had been abandoned by her doctors, and that her family was as tired of hearing about breast cancer as she was of going through it. It should be over, but it wasn't. Many of the women that were interviewed for her book said that the true emotional devastation of the disease did not begin for them until a year to eighteen months after diagnosis.

Mullan (1985), the founder of the National Coalition for Cancer Survivors, conceptualized survivorship into three categories: acute, extended, and permanent. Acute survival is dominated by treatment, i.e., medical (chemotherapy), surgical, and radiological. Extended survival is characterized by remission or termination of the basic and intense course of treatment. This is the period of "watchful waiting" with periodic

examinations and intermittent therapy. Permanent survival is the evolution from the extended phase into a period where activity of the disease or likelihood of its return is sufficiently small and that the cancer is considered to be arrested (Mullan, 1985). People in cancer remission, who are no longer coping with the acute aspects of their care, still face difficulties resulting from the chronic aspects of their disease. Psychological, social, physical, and spiritual issues all influence the individuals' overall quality of life after breast cancer treatment. These changes in quality of life occur over time and with varying degrees of intensity. (Hassey Dow, Ferrell, et al, 1995) A major concern that patients in cancer remission face is learning how to live with the uncertainty of disease exacerbation or recurrence. Uncertainty about their prognosis places additional stress on patients as they attempt to reorganize their lives in preparation for possible unpredictable outcomes.

Although all people face uncertainty in life, the uncertainty faced by persons in cancer remission is accentuated by fear of their disease returning. Lack of knowing if and when symptoms will recur affects the individual's sense of mastery and control over life (Welch-McCaffrey, et al, 1989).

### **Purpose of the Study**

The purpose of this study is to examine the quality of life of breast cancer survivors in the three phases of survivorship. The first phase, the acute phase is the time period up to eighteen months post diagnosis. Breast cancer patients undergo treatment up to eighteen months after diagnosis. The second phase, the extended period is from eighteen months to five years after diagnosis. Medical follow-up during this period is less frequent. The five year mark delineates the extended period from the permanent phase. Five years is a widely accepted time in cancer care, that patients are

considered "cured" if they have no recurrence. The third phase is the permanent survival phase. This period is five years or greater. For purposes of this study the permanent survival phase will be limited to 5 to 10 years.

Most health care professionals are actively involved with breast cancer patients during the treatment or acute phase of cancer recovery. Consequently, many health care professionals have limited exposure to survivors after they have completed treatment if the patient does not reenter the health care system, and are unaware of the adjustment problems of survivors.

The intent of this study is to describe the quality of life of breast cancer survivors in the three survival phases described by Mullan. The information from this study will enhance health care professionals' ability to improve quality of life for breast cancer survivors by focused assessment and appropriate therapy throughout the illness trajectory and survival.

### **Significance to Nursing**

Ferrans (1994) qualitative analysis of breast cancer survivors demonstrated that some survivors are troubled by problems related to breast cancer therapy. Ferrans described these problems within the four domains. The four domains described by Ferrans are health and functioning, psychological/spiritual, family and social, and economic. Carter (1993) described survivors experiences over extended periods of time. For example, one 20 year survivor interpreted the meaning of her cancer as a "traumatic loss" of her breast; she described flashing back to "thinking about surgery" during the first 4 or 5 years. "Loss of the breast" is the most difficult thing this woman had to deal with. In greater than 20 years, she had never shown her scar to her husband. She preferred that her husband maintain the image of her body before surgery and preferred to not show him her body. The quality of Life (QOL) study of long term cancer survivors by Ferrell et als., (1995) showed that the psychological well-being subscale

score was the lowest among the four domains described by Ferrans.

Nurses, particularly in the acute care of breast cancer patients, often do not have the opportunity to learn how breast cancer patients adjust to their diagnosis long after the acute intervention has ended. Lack of assessment of these problems is a critical barrier to long term management of breast cancer patients particularly when they return to the acute care setting. Nurses do not always understand the changes that occur over time with these patients. To provide effective follow-up care, nurses must identify what problems the breast cancer patient can expect so that education and support is available as the patient journeys through the different phases of survival.

It is equally important for health care providers to learn what the breast cancer survivor found to be most helpful to help her cope with breast cancer treatment and continue to cope with breast cancer over time. As well, what she would have liked to have been different in her experience that could have enhanced her current quality of life in each phase of survivorship. This information is important to improve the care of the breast cancer patient during all three phases of survivorship.

Nurses in all types of health care settings including acute, ambulatory, community, and hospice will face the challenge of caring for survivors who have moved beyond the acute phase of diagnosis and treatment. They will see individuals who are experiencing the physical, social, psychological and spiritual sequel that survivors of cancer face.

## **Chapter 2**

### **Literature Review**

For purposes of this review, the literature will be summarized according to the phases of survivorship for breast cancer patients described by Mullan (1985) and the quality of life domains for breast cancer survivors adopted by Ferrell. The quality of life domains model originated in a program of research by Ferrell and others (Ferrell et al., 1992a, 1992b; Ferrell, Grant et al., 1992; Hassey Dow et al, 1995) which reported four domains of QOL for patients with cancer: physical, psychological, social , and spiritual well-being.(see Figure 1). The phases of survivorship will be described first followed by the quality of life domains.

#### **Phases of Survivorship**

Mullan (1985), himself a cancer survivor, defined survival as a useful concept because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. He identified survival beginning at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments.

Mullan noted that the cancer survivorship experience varies depending on circumstances and outcomes for each person; however he also identified that most patients go through some predictable and useful stages of survival. He does not suggest that there are formal stages of survival in a clinical sense, but rather that there is a progression of events for most patients that is definable in a general outline. This outline he calls the seasons of survival.

#### **Acute Phase**

The first season of acute survival begins with the diagnosis of the illness. Hassey Dow (1990) describes this period as surviving the diagnosis and treatment. . Mullan identifies this period as the medical stage which is dominated by diagnostic and

## Quality of Life Domains Model

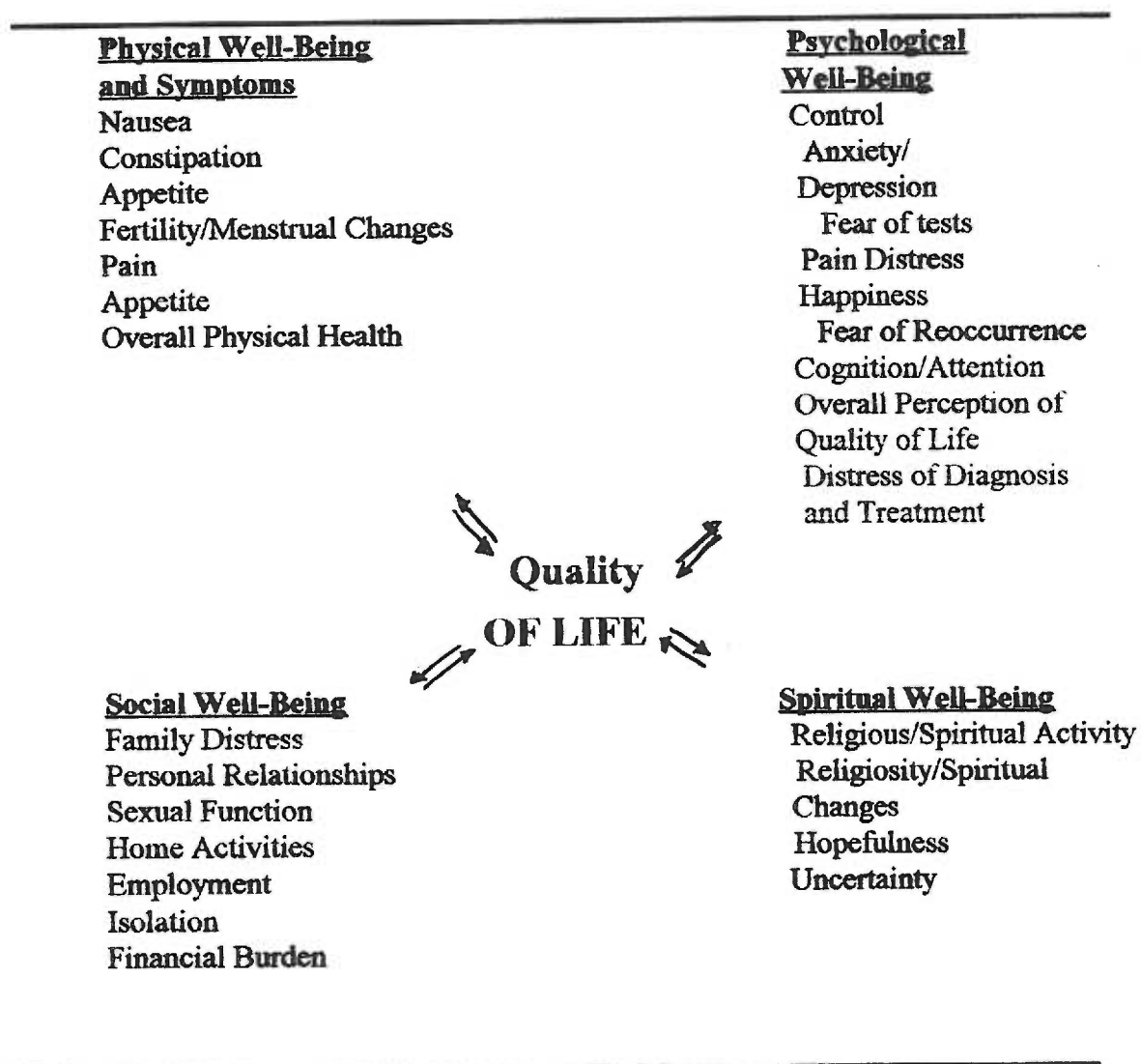


**Figure 1. The Quality of Life Model Applied to Breast Cancer Survivors**

(Ferrell, et al., 1995)

therapeutic efforts to stem the tide of illness. Fear and anxiety are important elements of this phase. The etiology of anxiety for the patient experiencing cancer is often multifocal and persistent in origin (Welch-McCaffrey, 1985). This is a time, too, when patients are called on to deal with their own mortality. People generally feel that they will live a long time into the future. The diagnosis of cancer immediately changes that familiar notion.

The acute survival phase is characterized by the buffer of family and community support. Northouse (1981) studied the relationship between significant others and fear of disease recurrence with 30 mastectomy patients. Results indicated a strong negative relationship between significant others and fear of recurrence. Those subjects reporting fewer significant others had higher fear of recurrence scores. Northouse emphasized the importance of mobilizing support systems as means of lessening the threat of disease recurrence and maximizing subjects' potential for quality of life.

LaTour (1993) refers to the time of diagnosis as a time when the diagnosis of cancer catapults the patient into the senseless world of shock and denial. Listening and concentration are impaired, and at a time when the individual needs information in order to make critical decisions. Almost every woman whom she talked to described herself as in some form of shock or denial during the time surrounding the diagnosis.

#### Extended Phase

The extended survival phase begins when the patient goes into remission or has completed the basic course of treatment and enters the phase of watchful waiting, with periodic examinations and intermittent therapy. Mullan identifies this period as the time that is dominated by fear of recurrence. This period is hallmarked by the impact of treatment, such as fatigue, reduced strength, inability to exercise, and hair loss. Now however, all these same treatment related issues are experienced in the community and the work place rather than in the health care center. Maher (1982) found that cancer survivors had difficulty in resuming life-oriented modes of thought, and expressed

uncertainty over the future. These feelings were most often linked to the ambivalence survivors felt when acute treatment ended, since they had come to depend on the intense social and emotional support that is characteristic of the acute treatment phase.

Welch-McCaffrey, Hoffman, and Leigh (1989) identified uncertainty about the future, fear of recurrence, and fear of reentry into work situations as major psychosocial concerns confronting cancer survivors. Approximately 25% of individuals with a cancer history experience some form of employment discrimination based on their disease (Hoffman, 1989). Even though the majority of cancer survivors do not suffer from limiting physical handicaps, many continue to face discrimination because they are perceived to be handicapped. Hoffman has described three "myths" associated with the employment discrimination faced by cancer survivors: that cancer is a death sentence, that cancer is contagious, and cancer survivors are an unproductive drain on the economy (Hoffman, 1987).

In a case-controlled review of over 100 individuals with recurrence, 30 per cent found the recurrence experience less traumatic than their original diagnosis (Weisman & Worden, 1988). The investigators found that the impact of recurrence was modified through consistent follow-up care, and continued emotional and family support in the after-treatment phase. Northouse (1981) found that women with breast cancer had heightened fears about cancer recurrence at the end of treatment, even though there was no medical evidence of disease.

For cancer survivors, uncertainty about the future is a common concern that usually emerges most strongly once the acute phase of treatment is completed. In a study of 60 male survivors of Hodgkin's disease and 20 age-matched controls, Cella and Tross (1986) found greater death anxiety within 2 years after therapy when compared with more protracted survival. Other research by Cella (1988) and Maher (1982) have reported that fear of death is common during the treatment period and may persist years after

therapy is completed. Maher indicated that the reactions related to fear of recurrence ranged from worry and anger in the middle of the night, to panic and thoughts of suicide. In comparing 10 cancer survivors 3 years after therapy with a matched sample of healthy controls, Schmale et al (1983) described a greater incidence of general health worries associated with recurrence and a sense of lower self-control in the survivor sample. Mullan (1985) linked the fear of recurrence with unpredictable behavior by former patients. The fear of recurrence can either lead to hypochondria or physician avoidance.

Many patients anticipating the completion of treatment do so with ambivalence (Maher, 1982). Happiness that the treatment is over is coupled with the anxiety of losing contact with the health care team that provides surveillance. A report by Viswanathan and Kachur (1986) described agoraphobic attacks stemming from fear of abandonment at the end of therapy. This phenomenon correlated with diminished contact with health caregivers, in triggering separation anxiety and fear of loss of control. Gorzynski and Holland (1979), in their commentary on the psychosocial impact of testicular cancer in young men, noted behavioral changes upon the completion of therapy. The men talked more of fears concerning the cessation of therapy, made an increase in the number of phone calls to caregivers, and had more outpatient visits for minor complaints which were perceived to be symptoms of reoccurrence.

Anger toward perceived inadequacies during diagnosis and treatment phase may also predominate in survivors (Maher, 1982). Shanfield (1980) discusses survivor bitterness over missed diagnoses, the ignoring of important complaints by physicians, and inadequate support during acute therapy. This is an important point for health care providers to keep in mind as patients transition from sick to well role during the extended period of survival.

Since this extended phase is not characterized by medical and nursing intervention, doctors and nurses have a diminished role in providing support and

counseling. This results in the patient and family fending for themselves in a "healthy" world. At this phase programs such as the "I Can Cope Program" of the American Cancer Society are helpful. The most common form of referral to these resources is by word of mouth from other patients.

#### Permanent Phase

Mullan's term, "permanent survival", is not found in other literature on survival. It often times is termed "cure". The patient in this phase is indeed a survivor. Physically and emotionally, however, the cancer experience leaves an impression. Health professionals may view the time of remission as a "new lease on life," yet the positive aspects of such may be colored by chronic anxiety that parallels remission.

LaTour was asked by a friend if she referred to herself as having had breast cancer or as having breast cancer. She considered this to be a hard question as it goes beyond whether she has disease in her body. She says "I am clear of cancer, and if someone asks, I say I 'had' breast cancer. Yet in a sense breast cancer still has me and always will". She speaks further as to what women do with their breast cancer experience, how patients assimilate it into their lives from this point forward, and what kind of survivor they will be. For her, she assimilated it in to her life by writing a book. Another woman who underwent the first bone marrow transplant for breast cancer in Texas in 1989 was asked to speak for multiple groups. After a year she decided to leave Texas and moved to an area that did not know her health history. She had decided that she didn't want people to feel sorry for her anymore.

What women do with their breast cancer experience varies. Some seek out opportunities to talk about it, for them to talk is to cure and help. Others turn to more active involvement in their churches and synagogues, while they take an active role in educating women. Others move into fund-raising activities or Reach to Recovery Program. These women turn their breast cancer and their anger at the disease into a job

or a mission. There are some breast cancer survivors that find a meaning in life through their cancer.

Carter (1993) describes six phases of a survival process that are conceptually distinct yet have overlapping properties. Survivors go through the phases in a nonlinear manner, sometimes simultaneously. Her study sampled breast cancer patients with a survival of greater than five years. The phases are interpreting the diagnosis, confronting mortality, reprioritizing, coming to terms, moving on, and flashing back.

An example of this was a twenty year survivor that said she had come to terms with cancer many years ago. She eluded to "forgetting" about cancer through the years, but added that cancer is not something that someone totally forgets. She discussed cancer in the past tense and was living a productive life and currently without the fear of recurrence. She perceived participating in interview as an aspect of integrating the cancer experience into her life. This example of ongoing integration took place 20 years after her diagnosis and treatment. This woman, as many other women like her, hoped that she would help others by telling her story.

Carter further describes other informants that had difficulty in integrating cancer into their life context. Fixation on the belief that there may be "lingering cells in her body" caused one woman to continually worry that the cells would reemerge as another cancer. She believed that fate was the cause of her cancer, and that her cancer was a form of "incomplete punishment".

Mullan (1985) also refers to the long-term, secondary effects of cancer treatment on health as representing another area in which permanent survivors are at risk. Secondary tumors as a result of various cancer treatments, have been reported in successfully treated cancer patients. There are also concerns about reproductivity and frustrations of sterility for those of child bearing years.

### Quality of Life Domains

This component of the literature review will summarize the four quality of life domains that are described by Hassey Dow and Ferrell et al(1995): physical psychological, social and spiritual.

#### Physical Well-Being

In spite of advances with symptom management for breast cancer patients, some women may experience residual effects of treatment. These physical effects include: fatigue, weight gain, menopausal symptoms, fertility concerns and pain.

During the acute phase of treatment, side effects such as nausea, vomiting, alopecia, skin changes and lymphedema are common (Hassey Dow, Ferrell et al, 1995). Wandel (1991) describes chronic physiological sequel related to treatment. Although her work looks at survivorship of cancer patients in general, this information applies to breast cancer patient issues particularly during the acute phase of survivorship. Effects of surgery can include symptoms of lymphedema, arm stiffness, and body image changes. Interestingly, body image changes, and the adaptation issues that patients face spurred some of the earliest efforts at cancer rehabilitation i.e. the Reach for Recovery Program. Radiation-induced complications are primarily seen when endothelial or connective tissues are damaged, and include tissue necrosis or fibrosis. These late effects can occur even if acute side effects are absent (Bloomer, 1975). Effects of radiation therapy are a function of radiation dose, total treatment time and the area of which the body is radiated.

Effects of chemotherapy result from antitumor drugs that are effective because they kill or injure cells that are actively dividing. This includes cells in the bone marrow, the lining of the gastrointestinal tract, the nails, the gonads and hair. (Loescher, Welch-McCaffrey, & Leigh, 1989). The class of chemotherapeutic agents most often associated with these symptoms are the alkylating agents.

Fatigue is a major problem with women with breast cancer (Blesch et al, 1991). Blesch et al measured fatigue with a variety of tools , and evaluated its occurrence among a sample of breast and lung cancer patients. Ninety nine percent of their subjects experienced varying levels of fatigue that were significantly correlated with pain.

Pain is of particular concern in those patients with bone metastasis. Metastasis can cause severe pain involving the ribs with intercostal neuralgia or to the vertebral column. Other syndromes such as brachial plexopathy, can also result in severe pain. Patients without metastatic disease have pain prevalence rates of 33-52%. This prevalence increases to rates of 56-68% in metastatic disease (McGuire et al,1992). Bone metastasis is also associated with complications including fractures, spinal cord compression and hypercalcemia.

Weight gain may occur in 50-90% of breast cancer patients receiving adjuvant therapy (Demark-Wahnefried et al, 1993). A weight gain of up to 20 pounds is common among premenopausal women. Decreased physical activity, hormonal changes and increased dietary intake and depression may be factors contributing to weight gain.

As Mullan (1985) identified, fertility issues are a major concern of young cancer patients who have postponed childbearing until later in life. Hassey Dow et al.,(1990) found that among young survivors of breast cancer, fertility concerns were one of the major issues affecting overall quality of life. Sterility for patients undergoing radiation therapy is dependent on age . Ovarian function during child bearing years is affected by 500-1000 rads (Hassey Dow, 1991). Estrogen deficiency related to natural aging menopause or chemotherapy-related premature menopause can have a negative effect on sexuality and overall well-being. Menopausal symptoms include sleep disorders, sweats, headache, vaginal dryness and hot flashes.

### Psychological Well-Being

Ferrans (1994) reported positive changes resulting from the cancer experience. The patients reported that they had become better people and understood life better. Respondents in this study reported decreased concern for trivial matters and an increased appreciation for family and friends. Ward and colleagues (1992) found that 30 % of women experienced psychological distress at the end of breast cancer treatment. Other psychological changes affecting quality of life include: body image changes, fear about recurrent cancer, uncertainty over the future, and depression.

Woods and Earp (1978) noted a relationship between the number of physical symptoms following mastectomy and the incidence and severity of depression. According to Brandt (1995), depression occurs in 25%-45% of women with breast cancer and increases with advancing disease. Early studies (Maguire et al., 1978) reported respondents who had significant depression. Patients reported feelings that nobody cared, but even worse, was that the patients themselves didn't seem to care about anything. Type of surgery also may have an influence on the severity of impact (Kemeny, Wellisch, & Shain, 1988; Mock, 1993). Of the 12 respondents who reported significant devastation and depression, only 3 stated that there their depression had resolved. Two of these three had local excision of the tumor, the other had a radical mastectomy. All of the respondents who continued to feel devastated and depressed had mastectomies.

Some have argued that the sense of disfigurement resulting from a mastectomy is a short-term concern that resolves over time (Holleb, 1974). However more recent studies have shown that distress can continue far longer, ranging from 2-13 years for the majority, and for some respondents distress continued without resolution (Northouse, 1990). Younger women and those who have mastectomies seem to be at greater risk for

body image disturbances, however women who are older are still at significant risk for psychological changes secondary to body image adjustment.

A study on breast cancer and self blame by Houldin, Jacobsen and Lowerys (1996) confirmed earlier research that some women respond to the diagnosis of breast cancer by blaming themselves. The number of women in this study who blamed themselves (39%) is similar to the 41% that Taylor et al. (1984) reported. Thus, although research and media reports about possible ways to prevent breast cancer (e.g., reducing dietary fats) have increased in recent years, these two studies suggest that the extent to which women blame themselves has remained relatively constant.

#### Social Well-Being

Multiple studies have reported changes in the family network and work-related issues. (Berry, 1993; Carter, 1994; Hoffman, 1989) As discussed earlier, often times job discrimination occurs related to the history of breast cancer. Another problem that occurs with breast cancer survivors is associated with the issue of obtaining health insurance. Most adults obtain health insurance through their employment, so many problems occur when employment is terminated or individual coverage is canceled. Preexisting health conditions, such as cancer can be a barrier for those survivors wishing to change their health insurance. Follow-up care is often times expensive and not affordable, thus avoided by some breast cancer survivors. Another problem is the expense of medications, including pain medications. Cherny and Portenoy (1994) pointed out that the excessive cost of medications is one of the major barriers to effective pain management.

Within the family unit, some members may react to the survivor in their sick role and be unable to put the illness behind them (Smith, Lesko, 1988). Intimate relationships are also affected by the cancer experience. Fobair and colleagues (1986) identified a significant divorce rate in their sample of Hodgkin's disease patients. They postulated

that marital stress may accumulate during cancer therapy and it is put aside during active treatment. LaTour (1993) describes one of the greatest misconceptions about couples and breast cancer is that men immediately abandon women, either literally or emotionally, when their wife or lover has breast cancer. The author met only a few women who felt that their cancer had contributed to the end of their relationships. And in all those cases the women said there were marital problems prior to the cancer.

Loss of friends was identified by Watt et al., (1993) as another social issue. Friends have been reported to avoid people diagnosed with cancer for a variety of reasons, such as fear of mortality and fear that cancer is contagious.

#### Spiritual Well-Being

Spiritual support was found to be important in patients diagnosed with cancer (Padilla et al., 1990). Survivors of breast cancer had spiritual experiences that strengthened them during their most vulnerable times of diagnosis and early treatment (Wyatt et al., 1993).

Spiritual distress, characterized by loneliness and grief, have been identified in studies of patients with advanced cancer (O'Conner et al., 1990). On the other hand, Ferrell (1995) reported that hopefulness, having a purpose in life, and positive and and spiritual changes were noted in her sample of cancer survivors.

#### Summary of Literature Review

The review of literature demonstrates that there are particular QOL characteristics that breast cancer patients experience in three different phases of survivorship. The first phase (acute phase) is characterized by experiences that relate to the initial diagnosis and treatment. Issues of mortality, shock and denial are very poignant during this time. However, this phase is also buffered by family and community support. The second phase (extended phase) begins when the patient goes into remission or has completed

treatment. Fear of recurrence, uncertainty about the future, and reentry into work situations are very characteristic during this time. Ambivalence is also felt by survivors when treatment has ended, since they had come to depend on the intense social and emotional support that is characteristic of the acute treatment phase. The third phase (permanent phase), is often termed "cure". What women do with their breast cancer experience at this phase varies and may include joining support groups or educating other women. Still others wish to move, they do not want people to feel sorry for them any more. They make every attempt to return to their pre breast cancer experience state.

The quality of life domains, physical, psychological, social and spiritual well-being all have their own individual characteristics. The physical well-being quality of life domains include characteristics such as nausea, vomiting, alopecia, skin changes and lymphedema. Fatigue, pain, fertility concerns, menopausal symptoms and weight gain are also symptoms that the breast cancer survivor experiences. The psychological well-being domain has changes affecting quality of life: body image changes, fear about recurrent cancer, uncertainty about the future, depression and self-blame. Social well-being characteristics include changes in the family network and work related issues. Loss of friends is identified as another social issue. The spiritual well-being domain is characterized by spiritual experiences that strengthened them during their breast cancer experience. Spiritual distress, characterized by loneliness and grief, has been identified as well.

### **Conceptual Framework**

The literature has demonstrated that there are many quality of life changes in the breast cancer survivor. Throughout the phases of survivorship patients experience a variety of concerns with varying degrees of intensity. Much of the literature has discussed the issues of QOL with the acute survivor phase. More recent literature has

explored some of the issues with the extended and permanent phase. A consensus shows that intermediate and late physical effects, changes in social well-being and spiritual aspects of having survived breast cancer and its' treatment are strong influences on perceptions of quality of life long-term.

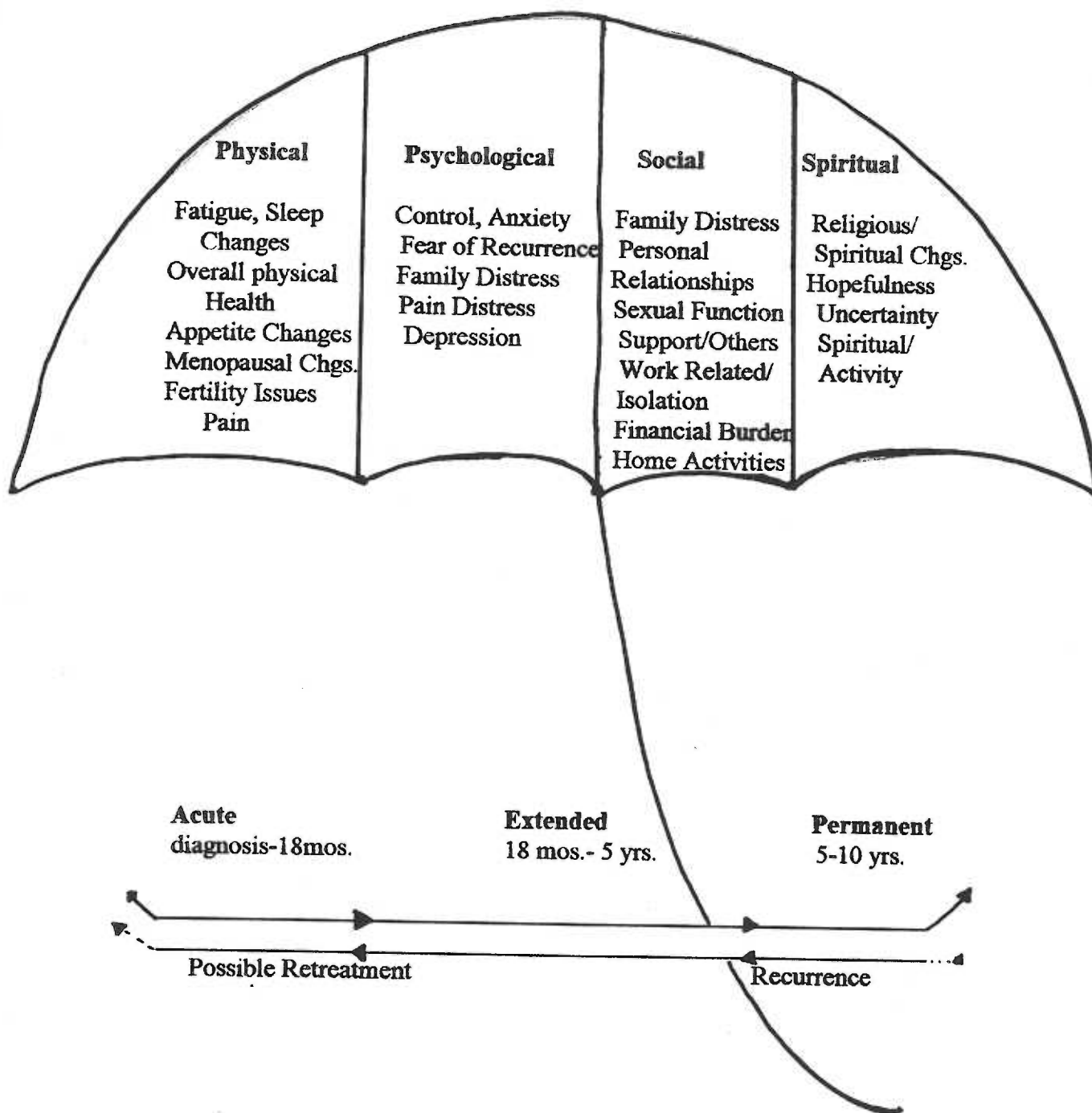
The conceptual framework for this study has two components. The first component is Mullan's (1985)"seasons in survival" framework. As previously described, he describes three seasons: diagnosis of disease where the season is defined and dominated by cancer treatment; extended survival where patients enter a phase of watchful waiting that is eclipsed by fear of disease reoccurrence; and permanent survival where the likelihood of reoccurrence is so small that the disease is considered permanently arrested.

The other component of the conceptual framework for this study is the Quality of Life model adapted for cancer survivors (Ferrell, 1992a, 1992b; Ferrell, Grant et al., 1992; Padilla, Ferrell, Grant, & Rhiner, 1990, Hassey Dow et al., 1995, Ferrell et al 1995). The model of Quality of Life for cancer patients includes four domains physical, social, psychological and spiritual well-being.

This study incorporates these two frameworks together by describing the quality of life domains for breast cancer patients in each phase of Mullan's survivorship model, and how QOL domains may change or remain constant over time. (See Figure 2)

Figure 2. shows the conceptual framework used for this study. This framework is based on the work of the Ferrell et al (1995) with adaptations made to coincide with later work by these researchers. Subsequent work done by Ferrell et al., suggested that nausea, vomiting , constipation were not significant issues of quality of life for breast cancer survivors. Weight gain, sleep changes, menopausal changes and fatigue were significant issues in the physical domain and were added to the conceptual framework model for this study. These are reflected in Figure 2.

**Figure 2. Conceptual Framework Model**



### **Research Questions**

Review of the literature and subsequent development of the conceptual framework for this investigation, have led to three research questions on which the investigator focused.

1. What is the quality of life of breast cancer survivors within the physical, psychological, social, and spiritual domains?
2. How does the quality of life of breast cancer survivors differ in the three phases of survivorship?
3. For breast cancer survivors in the acute phase of survivorship; what do nurses do that most impacts the survivors' quality of life?

### Chapter 3

#### Methods

The purpose of this research was to study the quality of life of breast cancer survivors within the physical, psychological, social and spiritual domains and to describe the quality of life of breast cancer survivors in each of the three phases of survivorship. Also breast cancer survivors in the acute phases of survivorship were asked to identify what nurses do that most impacts the survivors' quality of life?

#### Setting

This descriptive study was composed of a sample derived from the Tumor Registry at Oregon Health Sciences University, a large teaching hospital, in Portland Oregon. The Tumor Registry at Oregon Health Sciences University follows all cancer patients from the time of diagnosis to death and has information regarding the patients' status, location and date of last follow-up.

The Oregon Health Sciences University Cancer Committee requested that a report of the research findings be presented to the committee after the study completion. There is no requirement to seek permission of the Cancer Committee or other body to use the Tumor Registry other than the approval of the Institutional Review Board.

#### Sampling

The sample size was limited to breast cancer survivors who continued to be followed by physicians at Oregon Health Sciences University per Institutional Review Board request. This reduced the original projected sample from the Tumor Board's Registry from 320 to 136. Thirty-six of these survivors were in the permanent phase, 76 in the extended phase and 24 in the acute phase. Four of these potential subjects were not included per physician request and two of these had died during the study. Sample size was limited in number in the acute phase due to the back log of at least six months

that the Tumor Board Registry has for entry of newly diagnosed patients. Therefore, the actual time period for the acute phase of this study was adjusted to include the survivors who were seven months to 18 months since diagnosis.

### Instruments

Instruments for measuring the variables included the following:

1.) A Demographic Data Tool, to describe the sample and to determine disease characteristics and treatment that might influence quality of life, including ethnicity, age, socioeconomic status, marital status, educational background, religious affiliation, and support group involvement. (See appendix A)

2.) The Quality of Life -Cancer Survivors (QOL-CS) Tool created by Betty Ferrell and Karen Hassey Dow (1995). This instrument was adapted from previous QOL instruments developed by researchers at the City of Hope National Medical Center. Items were added to the original QOL instrument by Ferrell and Hassey Dow to address issues of breast cancer patients, such as fertility, menopause, body image and positive changes such as hope for the future.

The adopted version of this QOL-CS tool is a 41-item rating scale. Each item is rated on a scale of 0-10 with 0 being the worst possible and 10 representing the best possible. The QOL-CS contains 4 subscales representing the four QOL domains: physical, psychological, social and spiritual.

Psychometric analysis based on administration of the QOL-CS to 695 cancer survivors, was reported by Hassey Dow et al., (1995). Test-retest reliability demonstrated  $r = .89$  for the overall QOL-CS tool. Internal consistency using Cronbach's

alpha co-efficient for the entire QOL-CS was  $r = .93$ . Validity measures included establishment of content validity factor analysis, and multiple regression for predictive validity, and concurrent validity of the QOL-CS tool with the FACT tool ( $r = .78$ ) (Ferrell et al., 1995). (See Appendix B)

3.) QOL -Breast Cancer- Qualitative Tool. This was composed of two qualitative questions which ask all survivors in the acute phase to address the third research question of the study which relates to how nurses impact the quality of life of breast cancer patients.

"Throughout your breast cancer diagnosis and treatment, was there something that nurses did that particularly impacted your quality of life? (This impact may have been either positive or negative.) Please describe these."

"Throughout your breast cancer diagnosis and treatment, were there things that you would have liked for nurses to do that might have affected your quality of life? Please describe these." (See Appendix C).

### Procedure

As indicated previously, after approval was obtained from the Institutional Review Board, a mailed survey was used to obtain a sample of breast cancer survivors in each phase of survivorship. Introductory letters from the physician and from the investigator were sent out to all eligible survivors followed by another mailing two days later that further explained the study. The questionnaires accompanied the second letter. A stamped self addressed envelope was included for the participant's convenience. Each questionnaire was coded by survivorship and identification number. (See Appendix D, E) The QOL - Breast cancer Qualitative tool was included for the acute phase survivors. Subjects were informed that results of the research would be shared with them if they desired was also included (Dillman, 1978). A designated question at the end of the questionnaire asked that they indicate yes if they wished to receive a report of the results.

In the second mailing, the questionnaire was accompanied by a letter from the investigator further explaining the research study and reinforcing the issue of the protection of confidentiality. (See Appendix F). Phone numbers of the investigator, the Medical Services Director, and the Oregon Health Sciences University Institutional Review Board were provided. First class mail was used and a stamped self addressed return envelope was provided.

Twenty questionnaires were returned by the Post Office as undeliverable. A follow-up postcard was sent two weeks later to all survivors whose first questionnaires had not been returned (See appendix G). The post card thanked all those survivors who had completed the survey and reminded those who had not to please complete the survey and return it to the investigator as soon as possible. (Dillman, 1978)

A total of four weeks were allowed for data collection. A summary of costs associated with the study is attached. (See appendix H)

The results of the study were shared with the survivors upon request. All but one respondent requested results.

#### Protection of Human Subjects

This study was approved by the Institutional Review Board for expedited review and informed consent was waived. A contingency for approval was placed on the study. The IRB asked that a letter from the primary physician of the breast cancer survivor accompany the investigator's letter of introduction. It provided assurance that information would be kept confidential, and that the information would not be shared with the physician or any other health care provider directly or indirectly involved with their care. This letter was drafted by the investigator and signed by the primary physician. (See appendix D)

### Data Analysis

All data from the demographic questionnaire and the QOL-CS were coded, verified, and entered using CRUNCH statistical software. Missing data were limited to only one questionnaire (missing page) from a survivor in the extended phase. In this case, the data were entered as no response. Data were recoded on two questions (13a,13b) for those responses that indicated 0 (not at all distressing) related to chemotherapy and radiation. The answer was recoded to no response if these subjects had indicated on the demographic questionnaire that they had not received chemotherapy or radiation. This correction was made on 13 responses.

To describe the sample, analysis of the demographic data included descriptive statistics; means, frequencies and ranges. This was done for the entire sample and for the sample in each phase.

To answer the first research question regarding the quality of life of breast cancer survivors in the physical, psychological, social and spiritual domains, descriptive statistics (frequencies, means, standard deviations) were used to describe responses to the QOL-CS questionnaire. The purpose was to observe, describe, and document responses as they occurred. Analysis of variance (ANOVA) was also done on all data from the QOL-CS questionnaire. All items were transposed for analysis such that the "0" anchor consistently equaled the "worst outcome" and the 10 anchor consistently equaled "best outcome". The entire sample was analyzed for mean scores with each item categorized under one of the four subscales.

For the second research question regarding how quality of life varies in the three phases of survivorship, inferential statistics were utilized to test the hypothesis that quality of life differed in the three phases of breast cancer survivorship. ANOVA and an examination of the means and standard deviations of all three groups were done to see if there were differences between the groups.

The third question was an open ended question about what the nurse did to impact quality of life for the breast cancer survivor during the acute phase of survivorship. The theory for this question rises out of the conceptual framework of this study. The responses from this question were reported by number of responses. The results were described by using a narrative form including quotes in an attempt to capture the words shared by the survivors. For reporting purposes the responses were examined for themes.

There was also information that breast cancer survivors shared by writing unsolicited notes on the questionnaires. So that this information would not be forgotten, responses were included and characterized by themes. (See Appendix I)

## Chapter 4

### Results

#### Response Rate

Of the 132 questionnaires that had been mailed to breast cancer survivors, 20 were returned by the postal service as undeliverable. Fifty-six completed questionnaires were returned, with an overall response rate of 50%. There were 12 responses from the acute phase survivor group, for 21% of the total sample; 32 responses from the extended phase representing 57% of the total; and 12 responses from survivors of the permanent phase, or 21% of the total.

The demographic data for the 56 breast cancer survivors who comprised the sample are included in Table 1. All of the survivors were female. The mean age of the total sample of 56 survivors fell within in the age group of 56-60 years (range 31-85). The highest educational level was at least a high school diploma. The Protestant faith was the predominate religion. The sample was predominately Caucasian (93%). The majority of survivors were employed full-time or part-time or were retired. A small percentage were unemployed related to disability, however 67% of those disabled were disabled unrelated to their breast cancer. The majority of respondents had a household income of \$30,000 or more. Nearly half of the survivors indicated that their spouse was their strongest support system. The majority of the sample had no support group involvement.

Almost half (45%) of the survivors did not know what type of breast cancer they had. Of those that did know, a third reported their cancer was Intraductal. The majority of survivors had mastectomies with or without reconstruction. One fifth of the sample had radiation therapy; one third had chemotherapy and one third had hormone therapy. No survivors had bone marrow transplants. Three respondents indicated that they had some other type of treatment. This was additional surgery for revisions of

Table 1: QOL Demo.- Characteristics of Survivors in the 3 Phases. (N=56)

| Phase of Survivorship       | Frequency | Percent | Frequency | Frequency | Frequency |
|-----------------------------|-----------|---------|-----------|-----------|-----------|
| Acute                       | 12        | 21.4    |           |           |           |
| Extended                    | 32        | 57.1    |           |           |           |
| Permanent                   | 12        | 21.4    |           |           |           |
|                             |           |         | Acute     | Extended  | Permanent |
| <b>Age</b>                  |           |         |           |           |           |
| 31-35                       | 1         | 1.8     | 0         | 1         | 0         |
| 36-40                       | 4         | 7.1     | 1         | 3         | 0         |
| 41-45                       | 7         | 12.5    | 4         | 3         | 0         |
| 46-50                       | 6         | 10.7    | 3         | 3         | 0         |
| 51-55                       | 8         | 14.3    | 1         | 7         | 0         |
| 56-60                       | 9         | 16.1    | 1         | 4         | 4         |
| 61-65                       | 6         | 10.7    | 1         | 3         | 2         |
| 66-70                       | 7         | 12.5    | 1         | 5         | 1         |
| 71-75                       | 4         | 7.1     | 0         | 4         | 0         |
| 76-80                       | 3         | 5.4     | 1         | 1         | 1         |
| 81-85                       | 1         | 1.8     | 0         | 1         | 0         |
| <b>Educ./highest degree</b> |           |         |           |           |           |
| none                        | 4         | 7.3     | 0         | 2         | 2         |
| high school                 | 33        | 60.0    | 9         | 18        | 6         |
| associate                   | 7         | 12.7    | 0         | 6         | 1         |
| bachelor                    | 4         | 7.3     | 0         | 3         | 1         |
| masters                     | 4         | 7.3     | 1         | 1         | 2         |
| doctorate                   | 3         | 5.5     | 1         | 1         | 1         |
| no response                 | 1         | 0.0     | 0         | 0         | 0         |
| <b>Religion</b>             |           |         |           |           |           |
| Protestant                  | 23        | 41.1    | 4         | 16        | 3         |
| Catholic                    | 11        | 19.6    | 2         | 5         | 4         |
| Jewish                      | 3         | 5.4     | 0         | 1         | 2         |
| None                        | 8         | 14.3    | 4         | 3         | 1         |
| Other                       | 11        | 19.6    | 2         | 7         | 2         |
| <b>Ethnic Group</b>         |           |         |           |           |           |
| African American            | 2         | 3.6     | 1         | 1         | 0         |
| Asian                       | 1         | 1.8     | 1         | 0         | 0         |
| Hispanic                    | 1         | 1.8     | 1         | 0         | 0         |
| White (Non-Hispanic)        | 52        | 92.9    | 9         | 31        | 12        |
| <b>Employment</b>           |           |         |           |           |           |
| Full-time                   | 17        | 30.4    | 4         | 9         | 4         |
| Part-Time                   | 5         | 8.9     | 2         | 2         | 1         |
| Unemployed r/t disabili     | 12        | 21.4    | 5         | 6         | 1         |
| Unemployed look work        | 1         | 1.8     | 0         | 1         | 0         |
| Retired                     | 13        | 23.2    | 2         | 9         | 2         |
| Homemaker                   | 7         | 12.5    | 0         | 4         | 3         |
| Student                     | 1         | 1.8     | 0         | 0         | 1         |

Table 1: (cont'd)

| Disability r/t Br. Ca      | Frequency | Percent | Frequency | Frequency | Frequency |
|----------------------------|-----------|---------|-----------|-----------|-----------|
|                            |           |         | Acute     | Extended  | Permanent |
| yes                        | 4         | 33.3    | 1         | 2         | 1         |
| no                         | 8         | 66.7    | 4         | 4         | 0         |
| <b>Income</b>              |           |         |           |           |           |
| <10,000                    | 9         | 17.3    | 1         | 7         | 1         |
| 10,000-19,999              | 7         | 13.5    | 2         | 3         | 2         |
| 20,000-29,999              | 2         | 3.9     | 0         | 1         | 1         |
| 30,000-39,999              | 8         | 15.4    | 3         | 5         | 0         |
| 40,000-49,999              | 11        | 21.2    | 0         | 8         | 3         |
| >50,000                    | 15        | 28.9    | 4         | 6         | 5         |
| No response                | 1         | 0.0     | 0         | 0         | 0         |
| <b>Most support source</b> |           |         |           |           |           |
| Spouse                     | 26        | 47.3    | 5         | 16        | 5         |
| Partner                    | 3         | 5.5     | 1         | 2         | 0         |
| Friend                     | 12        | 21.8    | 4         | 5         | 3         |
| Family not spouse          | 12        | 21.8    | 2         | 7         | 3         |
| Other                      | 2         | 3.6     | 0         | 1         | 1         |
| <b>Support Group</b>       |           |         |           |           |           |
| Yes                        | 10        | 18.2    | 3         | 6         | 1         |
| No                         | 45        | 81.8    | 19        | 15        | 11        |
| <b>Type Breast Cancer</b>  |           |         |           |           |           |
| Intraductal                | 18        | 32.7    | 5         | 7         | 6         |
| Paget Disease              | 1         | 1.8     | 1         | 0         | 0         |
| Lobular Carcinoma          | 4         | 7.3     | 0         | 4         | 0         |
| Other                      | 7         | 12.7    | 1         | 5         | 1         |
| Do not know                | 26        | 45.5    | 5         | 15        | 6         |
| <b>Type of treatment</b>   |           |         |           |           |           |
| Surgery                    | 24        | 42.9    | 5         | 13        | 6         |
| Lumpectomy                 | 17        | 30.4    | 5         | 9         | 3         |
| Mastectomy w/o recon       | 17        | 67.9    | 2         | 13        | 2         |
| Mastectomy w/ recon        | 24        | 42.9    | 4         | 14        | 6         |
| Radiation                  | 19        | 33.9    | 5         | 10        | 4         |
| Chemotherapy               | 18        | 32.1    | 3         | 10        | 5         |
| Hormone Therapy            | 17        | 30.4    | 3         | 11        | 3         |
| Bone Marrow Transpl.       | 0         | 0.0     | 0         | 0         | 0         |
| Other                      | 3         | 5.4     | 0         | 2         | 1         |

Note: Some patients had more than one type of treatment

|                             |    |      |   |    |   |
|-----------------------------|----|------|---|----|---|
| Recurrence                  | 6  | 10.7 | 0 | 5  | 1 |
| <b>Last Follow-up Visit</b> |    |      |   |    |   |
| < 30 days                   | 19 | 33.9 | 5 | 11 | 3 |
| 30-60 days                  | 15 | 26.8 | 3 | 9  | 3 |
| 60-180 days                 | 17 | 30.4 | 4 | 9  | 4 |
| 180-365 days                | 5  | 8.9  | 0 | 3  | 2 |

reconstruction's. Ten percent (10%) of the survivors had experienced recurrence. The majority of the survivors had been seen for medical follow-up in the last six months.

### QOL-CS Analysis

In order to answer the first research question and to describe the quality of life of breast cancer survivors within the physical, psychological, social and spiritual domains, table 2 presents the mean scores and standard deviations with each item categorized under one of the four subscales. The subscale score is the total sum divided by the number of items. The mean total QOL-CS for all items was 6.38. The total subscale scores ranged from the lowest in Psychological Well-being ( $x = 5.89$ ), followed by Spiritual Well-being ( $x = 6.33$ ), Social Well-being ( $x = 6.99$ ), to the highest scores on Physical Well-being ( $x = 7.19$ ).

The potential range of scores for each of the items on the Physical Well-being subscale was 0-10. Overall, subjects reported moderate symptoms with fatigue, aches or pains, sleep changes and weight gain. Appetite changes, vaginal dryness/ menopausal symptoms and menstrual or fertility changes were also moderate symptoms in this population. The mean value for over all physical health scores was 6.78.

The overall score for the Psychological Well-Being subscale represented the worst outcomes for all of the subscales. The potential range of scores for each of the items was 0-10. The actual scores indicated that the subjects' perceptions of the worst aspects affecting psychological well-being were recall of distress from the initial diagnosis, and distress from cancer treatment. In addition, fears of future diagnostic tests, spread of disease (metastasis), and fear of second cancer had the worst outcomes affecting psychological well-being. Concerns over how treatment had affected their appearance and self-concept, what degree there was control over things in life, ability to concentrate, feelings of usefulness, depression, to what degree life had returned to

normal, distress of illness on family, and amount of support from others were moderate outcomes.

Despite the worst outcomes in psychological well-being affecting quality of life, subjects also identified that they had acceptable satisfaction with life, felt happiness and ability to cope as a result of their disease and treatment. A single quality of life item that asked subjects to rate overall quality of life was reported had the highest mean score. Overall subjects identified that they had high happiness and that quality of life was good.

The potential range of scores for Social Well-Being subscale was 0-10. The actual scores ranged from 3.3 to 8.5. Concern for daughter or other female relatives regarding breast cancer had the lowest scores. Financial burden as a result of illness, impact of illness with activities at home and impact on sexuality were in the moderate range on the scale. Yet, the items reflecting health care interfering with personal relationships, isolation related to illness, and isolation related to treatment were the highest rated aspects of social well being affecting quality of life.

The potential range of scores for individual items of the Spiritual Well-Being subscale was 0-10. The actual score range was 4.5 to 7.5. Uncertainty over the future and degree that illness has made positive changes had the worst outcomes. The importance of participation in religious activities, other spiritual activities and spiritual life change related to illness were in the moderate range. Items having the best outcomes on the subscale included hopefulness and having a life purpose.

The second research question focused on determining how quality of life of breast cancer survivors differs within the four domains (physical, psychological, social and spiritual) across three phases of survivorship (acute, extended and permanent). In order to answer this question, the means and standard deviations were computed. Analysis of Variance (ANOVA) with the Sums of squares based on unique variance, mean sums of squares, F and P values were calculated to determine if there were differences

Table 2: Quality of Life Mean Scores and Standard Deviations  
of the Physical, Psychological, Social and Spiritual Domains

| QOL Domains                 | N = 56 |     |
|-----------------------------|--------|-----|
| Physical                    | Mean   | SD  |
| Fatigue                     | 6.4    | 3.2 |
| Appetite                    | 8.2    | 2.8 |
| Aches/Pain                  | 6.1    | 2.9 |
| Sleep Chgs                  | 6.8    | 3.2 |
| Weight Gain                 | 6.9    | 3.3 |
| Menop Chg                   | 7.1    | 3.4 |
| Fertility /Menses Chs.      | 9.2    | 2.3 |
| Physical Health             | 6.8    | 2.4 |
| Total                       | 7.2    | 2.1 |
| Psych                       | Mean   | SD  |
| Cope/disea                  | 7.4    | 2.7 |
| Cope/tx.                    | 7.1    | 3.1 |
| QOL                         | 7.5    | 2.2 |
| Happiness                   | 7.2    | 2.4 |
| Control                     | 6.9    | 2.5 |
| Satisfaction                | 7.4    | 2.3 |
| Concentrate                 | 6.5    | 2.5 |
| Useful                      | 6.9    | 2.6 |
| Appear.Chg                  | 4.9    | 3.6 |
| Self-Concept                | 6.0    | 3.5 |
| Initial Diagnosis Distress  | 2.1    | 3.2 |
| Chemotherapy Distress       | 2.4    | 2.3 |
| Radiation Distress          | 3.8    | 2.9 |
| Completion of Tx.           | 5.6    | 3.2 |
| Surgery Distress            | 3.1    | 2.9 |
| Depression                  | 6.1    | 2.8 |
| Fear Diagn. Test            | 5.3    | 3.3 |
| Fear of Mets                | 5.9    | 4.1 |
| Fear of Recurrence          | 5.3    | 3.6 |
| Fear of Second Cancer       | 4.7    | 3.5 |
| Degree life back normal     | 6.7    | 3.0 |
| Family Distress r/t illness | 6.3    | 2.7 |
| Amt support                 | 6.9    | 2.9 |
| Anxiety                     | 5.2    | 2.9 |
| Total                       | 5.9    | 1.7 |

Table 2 Quality of Life Scores (cont'd)

|                                    | Mean | SD  |
|------------------------------------|------|-----|
|                                    |      |     |
| <b>Social</b>                      |      |     |
| Relationship Interference          | 8.5  | 2.6 |
| Sexuality Impact                   | 6.9  | 3.7 |
| Employment Interference            | 7.4  | 3.7 |
| Home Activities Interference       | 7.0  | 3.3 |
| Concern for daughter               | 3.3  | 3.4 |
| Financial Burden                   | 6.4  | 3.5 |
| Isolation r/t illness              | 8.1  | 2.9 |
| Isolation r/t tx.                  | 8.5  | 2.9 |
| Total                              | 7.0  | 2.1 |
| <b>Spiritual</b>                   |      |     |
|                                    | Mean | SD  |
| Importance of Rel. Activities      | 6.0  | 4.2 |
| Importance of Spiritual Activities | 6.7  | 3.8 |
| Spiritual Life Change              | 6.4  | 3.4 |
| Uncertainty re future              | 4.5  | 3.3 |
| Positive Cgs.                      | 4.8  | 3.7 |
| Purpose/Mission                    | 6.8  | 3.3 |
| How Hopeful                        | 7.9  | 2.6 |
| Total                              | 6.3  | 3.0 |

Table 3: QOL-CS- Quality of Life of Cancer Survivors  
N=56

| Phase         | Frequency | Mean | SD  |
|---------------|-----------|------|-----|
| QOL-overall   |           |      |     |
| Acute         | 12.0      | 6.2  | 1.3 |
| Extended      | 32.0      | 6.5  | 1.6 |
| Permanent     | 12.3      | 7.3  | 1.3 |
| Physical      |           |      |     |
| Acute         | 12.0      | 7.0  | 1.8 |
| Extended      | 32.0      | 6.9  | 2.2 |
| Permanent     | 12.0      | 8.1  | 2.0 |
| Psychological |           |      |     |
| Acute         | 12.0      | 5.5  | 1.0 |
| Extended      | 32.0      | 6.0  | 1.9 |
| Permanent     | 12.0      | 6.2  | 1.6 |
| Social        |           |      |     |
| Acute         | 12.0      | 7.0  | 2.2 |
| Extended      | 32.0      | 6.9  | 2.2 |
| Permanent     | 12.0      | 7.3  | 1.8 |
| Spiritual     |           |      |     |
| Acute         | 12.0      | 5.4  | 2.2 |
| Extended      | 32.0      | 6.2  | 2.4 |
| Permanent     | 12.0      | 7.5  | 1.9 |

| ANOVA         | QOL  |        |      |      |      |
|---------------|------|--------|------|------|------|
| Source        | df   | SS (U) | MSS  | f    | p    |
| Between Subj. | 55.0 | 126.6  |      |      |      |
| P (Phase)     | 2.0  | 7.2    | 3.6  | 1.6  | 0.21 |
| Error 1       | 53.0 | 119.4  | 2.3  |      |      |
| Physical      |      |        |      |      |      |
| Source        | 55.0 | 246.9  |      |      |      |
| P (Phase)     | 2.0  | 12.9   | 6.5  | 1.46 | 0.24 |
| Error 1       | 53.0 | 234.0  | 4.4  |      |      |
| Psychological |      |        |      |      |      |
| Source        | 55.0 | 149.3  |      |      |      |
| P (Phase)     | 2.0  | 3.2    | 1.6  | 0.58 | 0.56 |
| Error 1       | 53.0 | 146.1  | 2.8  |      |      |
| Social        |      |        |      |      |      |
| Source        | 55.0 | 240.2  |      |      |      |
| P (Phase)     | 2.0  | 2.1    | 1.0  | 0.22 | 0.79 |
| Error 1       | 53.0 | 238.2  | 4.5  |      |      |
| Spiritual     |      |        |      |      |      |
| Source        | 55.0 | 290.5  |      |      |      |
| P (Phase)     | 2.0  | 25.0   | 12.5 | 2.49 | 0.09 |
| Error 1       | 53.0 | 265.5  | 5.0  |      |      |

in the quality of life over the three phases of survivorship. The results are presented in Table 3.

In the physical domain, those in the acute phase had a mean quality of life score of 7.03, the extended phase 6.91, and the permanent phase 8.11. According to the ANOVA there were no statistical differences in this domain across the three phases of survivorship ( $p = 0.24$ ).

In the psychological domain, those in the acute phase had a mean QOL score of 5.46, the extended phase 5.96 and the permanent phase 6.15. The ANOVA verified that there were no significant differences in this domain across the three phases of survivorship ( $p = 0.56$ ).

Within the social domain, those in the acute phase had a mean QOL score of 7.02, the extended phase 6.85, and the permanent phase 7.33. The ANOVA verified that there was no significant differences in this domain across the three phases of survivorship ( $p = 0.79$ ).

Within the spiritual domain, those in the acute phase had a mean QOL rating of 5.43, in the extended phase 6.24, in the permanent phase 7.45. Although this domain had the greatest degree of variance across the three phases of survivorship, the ANOVA verified that there were not significant differences ( $p = 0.09$ ).

The overall QOL scores for all four domains indicated a mean 6.23 for the acute phase, 6.49 for the extended phase and 7.26 for the permanent phase. There was no evidence of significant differences across the three phases ( $p=0.21$ ).

Internal consistency was tested using Cronbach's alpha co-efficient for the total QOL -CS tool ( $r = .95$ ). Alphas for each domain were: physical ( $r = .86$ ); psychological ( $r = .94$ ); social ( $r = .80$ ) and spiritual ( $r = .79$ ). (See Table 4).

**Table 4. Internal Consistency - Quality of life of Breast Cancer Survivors N=56**

| <b>Domain</b> | <b>Chronbach's Alpha</b> |
|---------------|--------------------------|
| Physical      | $r = .86$                |
| Psychological | $r = .94$                |
| Social        | $r = .80$                |
| Spiritual     | $r = .79$                |
| Total QOL     | $r = .95$                |

### Results of Open Questions from Survivors in the Acute Phase

Of the 12 responses from breast cancer survivors in the acute phase, seven answered the two open ended questions regarding how nurses impacted their quality of life. Table 5 summarizes the themes in responses obtained from the QOL - Breast Cancer - Qualitative Questionnaire, (see Appendix C). Actual responses from questionnaires are used as examples of survivors responses to these questions.

**Question One:** Throughout your breast cancer diagnosis and treatment, was there something that nurses did that particularly impacted your quality of life? (This impact may have been either positive or negative.) Please describe these.

Themes for responses to this question included; teaching, positive attitude, instilling hope, support and caring.

#### Teaching

Breast cancer survivors in the acute phase of their survivorship valued the teaching that nurses do. The two survivors who cited teaching as important at this time in their experience indicated that they needed a lot of information to help them through the experience.

" I had excellent care from Dr. \_\_\_'s Oncology RN. I was given explicit information as to what to expect along the way."

"The nurses were superb, but I needed more information. I had to seek more information from a connection I had in Seattle for support groups and Reach for Recovery."

#### Positive Attitude

To one survivor it was important that the nurses project a positive attitude. It was important that this survivor that she have a positive environment as she was going through her diagnosis and treatment.

"Yes. There was a nurse whose name was S. She gave me my chemo. She was a very positive person and she helped me in every way. When I wasn't feeling well she was always there."

### Instilling Hope

One survivor in the acute phase valued hope. Latour (1993) refers to the emotional phases of breast cancer as Phase I with initial diagnosis where women immediately have a vision of their own death. Phase II, which surrounds surgery and treatment is the "I will live stage\_\_". This is when breast cancer patients experience hope as they actively undergo treatment to get better. The survivor that valued hope stated this:

"Nurses who share stories of relatives, friends, other patients or themselves who had experienced breast cancer and had treatment and were doing fine. Survivors, this gave me hope when I was afraid of dying".

### Support

The theme of support was cited by the largest numbers of survivors who responded to this question ( 3 of 7). This was demonstrated not only in the statements made by these survivors but also as they looked back and saw that they felt they had not received enough information about support groups. They had to seek out information about this as it was not offered to them during the acute phase of their illness. One survivor named certain nurses that were supportive. Another survivor mentioned her doctor and the radiation nurses and doctors.

"Both R. And K. were very caring, which meant the world to me. I was very comfortable contacting them when needed. I was scared and bewildered and in need of TLC and they both understood." "I feel between Dr.\_\_ and the radiation nurses and doctors they helped me cope with a lot of things. I had a major surgery (kidney removed) at the same time as the treatment was going on, so it seemed like a long process."

**Table 5 Quality of Life-Breast Cancer - Qualitative Responses (N =7)**


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Throughout your breast cancer diagnosis and treatment were there things that nurses did that particularly impacted your quality of life? (This impact may be either positive or negative.)

**Question 1 Responses:**

|         |          |                   |              |         |        |
|---------|----------|-------------------|--------------|---------|--------|
| Themes: | Teaching | Positive Attitude | Instill Hope | Support | Caring |
|         | 2        | 1                 | 1            | 3       | 2      |

Throughout your breast cancer diagnosis and treatment were there things that you would have liked for your nurses to do that might have affected your quality of life? Please describe these.

**Question 2 Responses:**

|         |                    |                  |                       |
|---------|--------------------|------------------|-----------------------|
| Themes: | Operational Issues | Comfort Measures | Supply of information |
|         | 2                  | 2                | 3                     |

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One survivor referred to the negative experience she had in the hospital with a Reach for Recovery volunteer from the American Cancer Society. According to her the timing for the visit was off and the volunteer did not appear sensitive to this.

"Right after my surgery this person from the American Cancer Society for Reach for Recovery came to see me. I was in pain and not in the mood for her visit. She was very persistent and not very sensitive to my desire for her to not bother me at this time."

### Caring

A recurrent theme in the responses revolved around the caring that nurses demonstrated. What the survivors needed at this time in their experience was caregivers that appeared to care about what they were going through.

"Nurses seemed particularly caring and compassionate. They were concerned for my comfort but also efficient at what they did. One negative incident, however, occurred during a chemotherapy session when two nurses were engaged in a heated argument. I found having to listen to their problems stressful and uncomfortable. I felt like they considered the patients, who couldn't help but overhear their strife, as so much as furniture".

"The nurses in OHSU that administered the chemo treatments were all very gentle and caring. I was treated with respect and attention. It was unnecessary for me to use my buzzer as my needs were anticipated in advance."

**Question Two:** Throughout your breast cancer diagnosis and treatment, were there things that you would have liked for nurses to do that might have affected your quality of life? Please describe these. Themes inherent in the survivors responses included operational issues, comfort measures, and supplying of information.

### Operational Issues

One patient, who was also a nurse was critical of the operations of the clinic. She compared it to her own experience as a former employee of a surgery clinic. "I couldn't

believe how much the nurses in the clinic stood around. The rooms were never ready. I used to be a clinic nurse. None of my doctors had to look for anything in rooms that I set up."

"The only gripe I have with OHSU is the hospital food. It truly was the worst possible. The staff has no control over this aspect of care. I have been in other hospitals as a patient and the food was something to look forward to, there it was dreaded."

#### Comfort Measures

One patient referred to comfort interventions that would have improved her quality of life during her treatment. She refers to massages. Massage intervention has been found to have medicinal purposes for not only the relief of physical and emotional tension but also the 'laying on of hands' and the physical attendance of the caregiver provides an intervention is interpreted as supportive and caring by the recipient.

"While in the hospital it would help to have massages, or body rubs for greater relaxation."

#### Supplying of Information

Some of the survivors felt it was important as they indicated in their responses to the first question, that they be given information. Three of the seven responses cited this as important.

"More information on support groups. I was not given any local contacts during treatment and diagnosis"

One extended survivor's survey was returned with her description of her quality of life with two cancer occurrences. Her optimistic and positive attitude is demonstrated with both experiences. Her story is included as Appendix H.

### Summary of Qualitative Themes

Overall, survivors in the acute phase of survivorship, reported that the things that nurses did that particularly impacted their quality of life included positive attitude, instilling hope, support and caring. Of these, support was mentioned most frequently in their responses. The survivors reported themes of operational issues, comfort measures and the supplying of information as things that they would have liked nurses to do that might have affected their quality of life.

## **Chapter 5**

### **Discussion and Implications for Practice**

This study contributes to our knowledge of four domains (physical, psychological, social and spiritual) of quality of life in breast cancer survivors and supports findings from other research related to survivors' quality of life. A new dimension has been added to the body of knowledge that exists regarding the quality of life for breast cancer survivors, in that this study has investigated how the quality of life varied in the acute, extended and permanent phases of survivorship. Information was also obtained from this study regarding what nurses did and what breast cancer survivors would have liked for nurses to do that might have affected their quality of life in the acute phase of their survivorship.

The demographic data yielded interesting results. The mean age group of 51-60 reflected the age that breast cancer is most likely to occur. Sixty percent of the respondents had at least a high school education, this compared to similar studies of higher educational levels of bachelor degree or greater. (Ferrell et al., 1995). The education level of the survivors should not be interpreted to mean that women with higher education get breast cancer; but more likely it is an artifact of who gets studied. Family or friend support was high with a total of 81%, and only 18% used support groups during their breast cancer experience.

Almost half of the survivors did not know what type of breast cancer they had, a surprising statistic with increased awareness regarding breast cancer. However, a large group of the survivors recall experiencing great distress at the time of diagnosis. They may have been informed at the time of diagnosis of the type of cancer

but did not remember related to distress. This reinforces the importance of ongoing teaching. This was also demonstrated with survivor's responses as to what nurses could do differently to affect quality of life.

Physical changes such as aches and pains and fatigue need more attention among long-term survivors of breast cancer. Sleep changes and weight gain were also moderate outcomes of survivors. Fatigue was of particular distress for those survivors that received chemotherapy and radiation. The literature supports fatigue as a common effect of these treatments. Questions concerning fatigue, aches and pains, weight gain and sleep disturbances could be routinely included in follow-up visits. Offering suggestions such as the importance of pacing activities, allowing rest periods, strengthening exercises, and nutrition programs have the potential to improve physical endurance. Effective pain management, particularly during the acute phase of survivorship, is important for successful recovery and is extensively documented in the literature.

Psychologically, breast cancer survivors' demonstrated the worse outcomes of the four domains. Recall of distress associated with initial diagnosis and distress from treatment had the worst QOL outcomes. Distress of illness on family had a moderate outcome. This is not uncommon for survivors of life-threatening events. Survivors in all three phases of survivorship rated high distress with this item. Support groups and or extensive support from caregivers, spouses, family and friends may help alter recall and change the perceptions of the experience and improve quality of life.

Fears of future tests, spread of disease and fear of a second cancer continue to impact breast cancer survivors and affect quality of life. This demonstrates the importance of developing teaching and support programs from the time of diagnosis to dispel myths, enhance knowledge and reduce fears.

Outcomes over how treatment affected appearance and self-concept were also moderate outcomes for all phases of survivorship. This stresses the importance again of the support needed for survivors, such as making resources available for prosthesis fitting, wigs, and beauty consultant services. As well, information should be available at the time of diagnosis regarding reconstruction if appropriate.

Difficulty concentrating, loss of control over things in life, feelings of use and depression had moderate outcomes. Again, this stresses the importance of supportive programs for survivors at all phases of their experience.

In spite of these psychological outcomes, survivors reported that they felt happiness in their life and overall rated their quality of life as good.

The most distressing outcome for breast cancer survivors socially was the concern for their daughter or relatives regarding breast cancer. This concern is probably a reflection of heightened public awareness regarding the risk factors of breast cancer. Family research and support interventions will need more attention in the future to meet these concerns. Financial burden was another area in need of attention. Educational programs in the work place are of particular importance. The focus of these programs should be on dispelling myths and misconceptions regarding breast cancer.

Sexuality was a moderate outcome for those breast cancer survivors that were in all phases of survivorship. Some of these outcomes were related to treatment, others to issues of body image and self-concept. Assessment and early intervention regarding sexuality concerns is of utmost importance from the time of diagnosis and throughout treatment and recovery.

Uncertainty over the future and degree that illness had made positive changes were worse outcomes for breast cancer survivors. Again another reason to provide

breast cancer patients with resources for support. Breast cancer survivors reported changes in spiritual life changes as they journeyed through their breast cancer experience. Breast cancer survivors themselves have found ways to create a balance in their life and find ways to derive a sense of purpose after cancer.

Quality of life scores for this study compare favorably with those found in Hassey Dows' (1995) study, (see Table 6) indicating high reliability with the QOL-CS tool. Her study had a sample size of 294. Although this study was smaller  $N = 56$ , similar trends were found.

This comparison, however, must be qualified given minor differences in the QOL questionnaires used for the two studies. Modifications were made in the tool by Hassey Dow et al. after they reported the results of their original study. Based on further analysis of their data these items were found to be non-discriminating: nausea, vomiting, and constipation. These items were deleted from the questionnaire that was made available for use in this study, and this omission was noted prior to data collection.

The analysis of how quality of life varies in the three phases (acute, extended, permanent) demonstrated that there is no significant variation across the three phases. The domain that came closest to having statistical significance in variation was the spiritual domain. As time since diagnosis extended, items related to the spiritual domain improved. It appears that over time, breast cancer survivors have more opportunity to reflect on the impact of their spiritual life and its relationship to the breast cancer experience. And as time goes on and survivorship extends into the permanent phase, survivors become more hopeful and optimistic about their future.

Acute phase survivors responded to questions regarding how nurses impacted their quality of life, and what nurses could have done differently to improve their quality of life. The major themes for how nurses impacted QOL for survivors included; the importance of teaching, maintaining a positive attitude, instilling hope and by being

**Table 6. Quality of Life Score Comparison of the Physical, Psychological, Social and Spiritual Domains of Hassey-Dow and Andreas**

| Domain        | Hassey-Dow<br>(N=294) |      | Andreas<br>(N=56) |      |
|---------------|-----------------------|------|-------------------|------|
|               | Mean                  | SD   | Mean              | SD   |
| Physical      | 7.75                  | 1.72 | 7.12              | 2.12 |
| Psychological | 5.77                  | 1.59 | 5.89              | 1.65 |
| Social        | 6.93                  | 1.91 | 6.99              | 2.09 |
| Spiritual     | 6.56                  | 1.84 | 6.33              | 2.29 |
| Total         | 6.51                  | 1.35 | 6.38              | 1.52 |

supportive and caring. The words they shared enriched the research and made it a more real experience. They demonstrated how even the smallest intervention, a caring attitude, and a supportive environment impacts the breast cancer survivors' quality of life.

Survivors suggested nursing interventions that could improve their quality of life during the acute phase of survivorship. These suggestions included nurses needing to offer more information regarding breast cancer and treatment as well as support groups and resources. This need is demonstrated in the QOL-CS also. Comfort measures including back and body rubs and massages were suggested as an intervention that would improve quality of life.

### **Limitations**

Although this study had similar results to other quality of life studies, a major limitation of this study was the small sample size. It would have been desirable to have a more equal and representative representation from each survivor phase. This small sample size was limited because of the Institutional Review Board requirement to access only those patients in the Registry that were currently being followed at Oregon Health Sciences University. Also contributing to the limited sample size, the study was not able to access the acute phase survivors from diagnosis to six months post diagnosis. This was related to the Tumor Registries' backlog with data entry of newly diagnosed breast cancer patients. In future studies it will be important to capture these survivors' experiences. In addition, the sample also was not representative of minorities. Ninety-three percent of the sample was Caucasian. However this is representative of the minority distribution in Portland.

### **Conclusion**

Attention to the quality of life of breast cancer survivors over time is long overdue. This descriptive study evaluated the quality of life in four domains (physical, psychological, social and spiritual), and how quality of life changed over time in the

three phases of survivorship (acute, extended permanent) for 56 breast cancer survivors. The study also evaluated the responses of seven acute phase survivors to two open ended questions about the impact nurses had on their quality of life.

Breast cancer survivors have identified aspects of physical, psychological, social, and spiritual well-being affecting their quality of life. Physical changes such as fatigue and aches and pains need more attention. Psychologically, breast cancer survivors demonstrated the worse outcomes of the four domains. Items related to distress with initial diagnosis and treatment had high negative quality of life outcomes. Socially, breast cancer survivors reported the most distressing concern was the concern for their daughters or relatives regarding breast cancer. Research involving survivor and family support interventions needs more attention to meet these concerns. Spiritually, uncertainty over the future and the degree that illness had made positive changes were worse outcomes. However breast cancer survivors themselves have found ways to create balance in their lives and find ways to derive a sense of purpose after cancer.

The analysis of 56 breast cancer survivors in three phases (acute = 12, extended = 32, permanent = 12) demonstrated that there is no significant variation in quality of life over time. The spiritual domain was closest to having significance. As time from diagnosis passed, breast cancer survivors became more hopeful and optimistic.

Acute phase survivors responded to how nurses impacted their quality of life with themes of positive attitude, instilling hope, teaching, support and a caring attitude. Responses to what the nurses could have done to improve their quality of life brought forward themes of the need for more information about support groups and treatment, and increased comfort interventions.

Continued breast cancer research to include a larger focus on the issues of long term survivors is vital. In spite of the times with current cost cutting and capitated

healthcare, this study demonstrates a need to incorporate education and support over time for breast cancer survivors.

Overall, these research findings can assist oncology nurses to understand what components of quality of life are important to breast cancer survivors. The breast cancer patient's care does not cease at discharge. Nurses must work with survivors to improve quality of life over the long term.

### **Future Directions**

There are many questions that remain unanswered with the breast cancer survivorship experience. One very important indication for further research is with minority populations. Culture and ethnicity play an important part in how the survivor experiences breast cancer.

Another approach to studying quality of life of breast cancer survivors over time would be to conduct a longitudinal study with the same sample of survivors. In this way, their experiences can be monitored and quality of life outcomes could be evaluated as time from diagnosis extends.

There is also an indication from this study that more research needs to be conducted regarding the impact of support groups on quality of life. A study looking at this would extend the information we currently have available regarding the efficacy of support groups, and have the potential to improve quality of life for breast cancer survivors over the long-term.

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APPENDIX A**Quality of Life of Breast Cancer Survivors- Demographic Data Tool**

*Please answer the following questions as completely as possible.*

**1. What is your current age?** \_\_\_\_\_

**2. Current Education Status:**

**Highest Degree Completed: (check only one)**

None \_\_\_ GED \_\_\_ High School Diploma \_\_\_ Associate \_\_\_

Bachelor \_\_\_ Masters \_\_\_ Doctorate \_\_\_

**3. Religious Affiliation:**

Protestant \_\_\_ Catholic \_\_\_ Jewish \_\_\_ None \_\_\_

Other (Please specify) \_\_\_\_\_

**4. Ethnic Group:**

African American \_\_\_ Asian \_\_\_ Hispanic \_\_\_ Native American \_\_\_

Pacific Islander \_\_\_ White (Non-Hispanic) \_\_\_

Other (please specify) \_\_\_\_\_

**5. Current Employment Status: (check all that apply)**

Full-time \_\_\_ Part-time \_\_\_ Unemployed by choice \_\_\_ Unemployed  
through disability \_\_\_ (if yes, is this related to your breast cancer?)

yes \_\_\_ no \_\_\_

Unemployed and looking for work \_\_\_ Retired \_\_\_ Homemaker \_\_\_

Student \_\_\_

**6. Household Salary Range per year:**

50,000 or more \_\_\_\_\_

40,000 to 49,999 \_\_\_\_\_

30,000 to 39,999 \_\_\_\_\_

20,000 to 29,999 \_\_\_\_\_

10,000 to 19,999 \_\_\_\_\_

Less than 10,000 \_\_\_\_\_

**7. Support system: ( From whom since your diagnosis, treatment and survivorship have you receive the most emotional support?)**

Spouse \_\_\_\_\_ Partner \_\_\_\_\_ Friend \_\_\_\_\_ Family (other than spouse) \_\_\_\_\_ Other (please specify) \_\_\_\_\_

**8. Support Group Involvement:(Have you been involved with a support group(s) since your breast cancer has been diagnosed?)**

yes \_\_\_\_\_ (specify name/type of support groups) \_\_\_\_\_

no \_\_\_\_\_

**9. Type of Breast Cancer:**

Intraductal carcinoma \_\_\_\_\_ Adenocarcinoma \_\_\_\_\_ Paget's Disease \_\_\_\_\_ Lobular

Carcinoma \_\_\_\_\_ Other (please specify) \_\_\_\_\_ Don't know \_\_\_\_\_

**10. Type of Treatment:(check all that apply)**

Surgery \_\_\_\_\_ Lumpectomy \_\_\_\_\_ Mastectomy without reconstruction \_\_\_\_\_

Mastectomy with reconstruction \_\_\_\_\_ Radiation \_\_\_\_\_ Chemotherapy \_\_\_\_\_

Hormone Therapy \_\_\_\_\_ Bone Marrow Transplant \_\_\_\_\_

Other (please specify) \_\_\_\_\_

**11. Have you experienced recurrence of your breast cancer?**

yes \_\_\_\_\_ (If yes please specify when this occurred after diagnosis and treatment)

\_\_\_\_\_

no \_\_\_\_\_

**12. Indicate the last time you were seen by a health care provider regarding your breast cancer for treatment or a check-up.**

less than 30 days \_\_\_\_\_

2 years \_\_\_\_\_

6 years \_\_\_\_\_

30-60 days \_\_\_\_\_

3 years \_\_\_\_\_

7 years \_\_\_\_\_

60-180 days \_\_\_\_\_

4 years \_\_\_\_\_

8 years \_\_\_\_\_

180-365 days \_\_\_\_\_

5 years \_\_\_\_\_

9 years \_\_\_\_\_

10 years \_\_\_\_\_

**APPENDIX B**  
**Quality of Life -Cancer Survivors Tool (QOL-CS)**

**Directions:** The purpose of this questionnaire is to learn how your experience with breast cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time.

Please circle the number 0-10 that best describes how you feel right now.

**1. To what extent are the following a problem for you:**

**a. Fatigue**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**b. Appetite changes**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**c. Aches or pain**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**d. Sleep changes**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**e. Weight gain**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**f. Vaginal dryness/ menopausal symptoms**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**g. Menstrual or fertility changes**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

**2. Rate your overall physical health**

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

**3. How difficult is it for you to cope as a result of your disease?**

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 very difficult

4. How difficult is it for you to cope today as a result of your treatment?

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 very difficult

**Quality of Life/ Breast Cancer**

5. How good is your quality of life?

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

6. How much happiness do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

7. To what degree do you feel like you are in control of things in your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

8. How satisfying is your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

9. How is your present ability to concentrate or to remember things?

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

10. How useful do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

11. Has your illness or treatment caused changes in your appearance?

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

12. Has your illness or treatment caused changes in your self concept

(the way you see yourself)?

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

13. How distressing were the following aspects of your illness and treatment?

a) Initial diagnosis

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very

distressing

b) Cancer chemotherapy

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

**Quality of Life Scale / Breast Cancer****c) Cancer radiation**

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very  
distressing

**d) Cancer surgery**

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very  
distressing

**e) Completion of treatment**

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very  
distressing

**14. How much anxiety do you have?**

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

**15. How much depression do you have?**

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

**16. To what degree are you fearful of:****a) Future diagnostic tests**

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

**b) Spreading (metastasis) of your breast cancer**

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

**c) Recurrence of breast cancer**

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

**d) A second cancer**

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

**17. To what degree do you feel your life is back to normal?**

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

18. How distressing has your illness been for your family?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

**Quality of Life Scale/ Breast Cancer**

19. Is the amount of support you receive from others sufficient to meet your needs?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

20. Is your continuing health care interfering with your personal relationships?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

21. Is your sexuality impacted by your illness?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

22. To what degree has your illness and treatment interfered with your employment?

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

23. To what degree has your illness and treatment interfered with your activities at home?

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

24. How much isolation do you feel is caused by your illness?

none 0 1 2 3 4 5 6 7 8 9 10 a great deal

25. How much isolation do you feel is caused by your treatment?

none 0 1 2 3 4 5 6 7 8 9 10 a great deal

26. How much concern do you have for your daughter(s) or other female relatives regarding breast cancer?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

27. How much financial burden have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 a great deal

28. How important to you is your participation in religious activities such as praying, going to church or temple?

not all important 0 1 2 3 4 5 6 7 8 9 10 very important

**Quality of Life Scale/ Breast Cancer**

29. How important to you are other spiritual activities such as meditation or praying?

not at all important 0 1 2 3 4 5 6 7 8 9 10 very important

30. How much has your spiritual life changed as a result of your cancer diagnosis?

less important 0 1 2 3 4 5 6 7 8 9 10 more important

31. How much uncertainty do you feel about your future?

not at all uncertain 0 1 2 3 4 5 6 7 8 9 10 very uncertain

32. To what degree has your illness made positive changes in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

33. Do you sense a purpose/ mission for your life or a reason for being alive?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

34. How hopeful do you feel?

not at all hopeful 0 1 2 3 4 5 6 7 8 9 10 very hopeful

**Do you wish to receive a summary report of the findings of this study?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**APPENDIX C****Quality of Life/Breast Cancer- Qualitative Tool**

***Directions: These questions were designed for breast cancer survivors that are in the acute phase of their survivorship. Please respond to the questions as to how you feel right now. Please feel free to use the back of the paper to complete your response.***

**Throughout your breast cancer diagnosis and treatment were there things that nurses *did* that particularly impacted your quality of life? (This impact may be either positive or negative.)**

**Throughout your breast cancer diagnosis and treatment, were there things that you would have liked for nurses to do that might have affected your quality of life?  
Please describe these.**

APPENDIX D

Letter Sent by Attending Physician  
April 11, 1996

name ~

Dear Ms. last name ~,

As a physician involved in your care for breast cancer, I would like to encourage you to participate in a research study being conducted by Lori Andreas regarding the quality of life of breast cancer survivors. Lori Andreas, RN, is a graduate nursing student at Oregon Health Sciences University that has been involved in the care of breast cancer patients for many years. I have included with this letter a letter from her that introduces this study.

The information provided by you will be helpful to meet patient needs throughout the various phases of survivorship. All information you provide will be kept confidential and your responses will not be identified in any way with your name. Your responses will be returned directly to the investigator (Lori Andreas) and will not be shared using your name with myself or any other health care provider that is directly or indirectly involved in your care.

Your willingness to participate in the study will be indicated by the completion of the questionnaire that will follow in the mail within a couple of days.

Thank you for your consideration.

Sincerely,

APPENDIX EInitial Letter to Subjects Requesting  
Participation

April 11, 1996

name ~

Dear Ms. last name ~,

As a nurse caring for breast cancer patients for the last 17 years, I have developed an interest in the quality of life that my patients experience during the diagnosis, treatment, and survivorship of their illness. I sensed that changes in the quality of life of cancer patients did occur. However, nurses like me who work in acute care settings have limited exposure to breast cancer survivors after they complete their initial treatment and may not fully understand what patients experience over time. Now, as I complete my graduate studies as a Clinical Nurse Specialist at the Oregon Health sciences University School of Nursing, I am interested in conducting a study that is aimed at helping nurses and other health care professionals to understand the quality of life issues experienced by breast cancer survivors in the acute, extended and permanent phases of survivorship. Breast cancer survivors who are in contact with Oregon Health Sciences University are invited to participate in this study.

I am writing to you, a breast cancer patient/survivor who has had contact with Oregon Health Sciences University, to ask if you would be willing to participate in this study by answering a questionnaire about your present quality of life. Completion of this questionnaire would take 30-45 minutes of your time.

Your participation in this study is entirely voluntary. Refusal to participate will not affect your care at OHSU. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences University. All results are confidential and will be used for research purposes only. The information that you will provide will not be placed in your medical record nor released to your physician. All information for this study will be reported anonymously and you will not be identified.

Within the next few days, I will be sending you a questionnaire about your quality of life and a stamped self-addressed envelope. I hope that you will consider assisting me with this study by returning the completed questionnaire. Your contribution will be extremely valuable. Information provided by you and other breast cancer survivors will be helpful to nurses and other health care professionals who are interested in enhancing patients' quality of life through the various stages of survivorship. When the study is completed I will share my findings with you in a summary report if you desire.

The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887.

Thank you for considering my request for your participation in this important study. If you have questions regarding the study, please feel free to contact me at (503) 494-5884.

Sincerely,

Lori Andreas, RN, BSN  
Clinical Nurse Specialist Graduate Student  
Oregon Health Sciences University School of Nursing

APPENDIX F

Letter Sent with Questionnaire to Subjects

April 15, 1996

name ~

Dear Ms. last name ~,

A short time ago I contacted you explaining my interest in the quality of life of breast cancer patients during the acute, extended and permanent phases of survivorship. As you know from my earlier letter, I am conducting a study that is aimed at helping nurses and other health care professionals to understand the quality of life issues experienced by breast cancer patients. Hopefully, with information provided by you and other breast cancer survivors we will be better able to meet patient needs throughout the various phases of survivorship.

Enclosed you will find a questionnaire that has two parts. The first questions are for background information about you. The second part asks questions about your experience with breast cancer. If you are willing to participate in this study, please answer the questions as completely as possible and return the questionnaire in the stamped self-addressed envelope that I have provided. The return of the questionnaires within the next two weeks would be appreciated.

I want to assure you again that the information that you provide in this questionnaire will be held in confidence and will be used only for research purposes, it will not be placed in your medical record or released to your physician. You are not required to participate in this study. All information for the study will be reported anonymously. The completed returned surveys will indicate your willingness to participate.

I would be happy to share the results of my study with you if you are interested. If you would like to receive the results, please indicate this in the space provided on the last page of the questionnaire.

Thank you for your participation in this valuable study. If you have questions about the study, please feel free to contact me at (503) 494-5884.

Sincerely,

Lori Andreas, RN, BSN  
Clinical Nurse Specialist Graduate Student  
Oregon Health Sciences University School of Nursing

APPENDIX GFollow-up Postcard

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Thank-you if you have completed  
the Quality of Life Survey! If you haven' had  
a chance to complete it, please do so and return  
it as soon as possible. The information you  
have to share is valuable!

Thank-you

Lori Andreas RN

503-494-5884

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APPENDIX H

## Itemized Expenses for QOL Breast Cancer Survivors Study

Duplication Costs = \$60.00  
1st Mailing Costs = \$32.28  
2nd Mailing Costs = \$105.98  
3rd Mailing Costs = \$22.40  
4th Mailing Costs = \$15.88  
Stationary Costs = \$ 10.00  
Clerical Support = \$104.00

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Total = \$350.54

First Mailing = Introductory letters to 134 Survivors

Second Mailing = Letter with Questionnaires and Return Stamped Self Addressed

Envelope to 134 survivors

Third Mailing = Reminder/ Thank-you Postcard to 112 survivors

Fourth Mailing = Report of Results to 56 Survivors

## APPENDIX I

### One Survivor's Experience with two Breast Cancer Diagnoses

One extended phase survivor's survey was returned with her responses indicated in two different colors of ink. This survivor responded to the items on the questionnaire for her two breast cancer experiences. Her first diagnosis was intraductal cancer for which she had a mastectomy without reconstruction, radiation and chemotherapy. The second was lobular carcinoma for which she had a mastectomy without reconstruction. Her survey was not included in the study because her responses were in two different phases. However this survivor had many comments throughout her questionnaire, and these are included here to capture the essence of what she had to say about her experience. Since she was in the extended phase she had not been given the two open-ended questions.

Her responses to the items were remarkably similar for both experiences in the four domains, except she experienced a much worse outcome with fatigue with her first experience. This was probably related to the extensive treatment she received at the times particularly, radiation. She rated her psychological responses with good outcomes for both experiences. She stated "My quality of life relative to breast cancer is not my problem now, or in the past- In 1991 my husband had a major stroke- that has put limits on my quality of life. The caregiver routine can be tough, and limits freedom. So I'm trying to make 'lemonade' out of the lemon." With her first experience in 1979 she rated her distress on her family as moderate. With her second diagnosis, her husband had suffered a stroke and her surgery had little impact on him. "My husband suffered brain damage by his stroke- his judgment is poor and my surgery in 1994 was a mere "Blip" to him. Our adult son, who is out of state, has shown concern."

She completed the survey by stating, "Some of these questions were difficult to answer. In 1979 I decided not to worry about cancer- I could get killed crossing the street - so, I put worry aside, kept in touch with my doctors and followed 'orders', and I was concerned enough that I should go for check-ups, scans etc. Worry did nothing for me. I had a 12 year old child and I had to get on with my life. In 1994, I went into the surgery with few qualms- I knew the surgery wasn't all that bad- get in, get it over with and get on with things. Again I go for check-ups as scheduled and have too much else to do to worry. On a day to day basis, arthritis and osteoporosis is more of a concern than cancer potential."

This woman exemplified what it was like to experience breast cancer not once but twice in her life. She rated her quality of life overall with good outcomes with both experiences. She shared the impact of her husbands' illness and what effect that had on her quality of life. She described how she had become a caregiver and what that was like for her when she experienced cancer for the second time.

## APPENDIX J

### Other Themes From Questionnaire

Some of the survivors wrote notes to the investigator on their questionnaire where they wanted to explain something further or give an insight about their experience and how it affected their quality of life. There were two acute survivors that communicated in this fashion, six extended survivors and one permanent.

The themes were relationship disruption, body image changes, lymphedema, hormonal issues, depression and anger.

#### Relationship Disruption

Two survivors wrote how their breast cancer experience had affected their relationships with their significant others and family.

"Cancer changed my life. I got a divorce, I lost my home."

"My partner thinks this is my death sentence. It is very bad on him. My parents call all too often worried about everything wanting to see my doctor weekly."

#### Body Image Changes

One survivor referred to her changes in her body with humor. She stated "I used to have a nice body...now I have nice hair! But I still have a great sense of humor and a big agenda in life."

#### Lymphedema

The QOL questionnaire did not address the issues surrounding lymphedema. Two survivors referred to this as a distressing issue for them.

"Swelling of my arm has caused me more problems than the cancer. You should address this problem. It is terrible."

"The removal of lymph nodes has left some discomfort."

#### Hormonal Issues

Two survivors wrote of the changes that they experienced with Tamoxifen.

"The Tamoxifen gave me severe hot flashes which no one wanted to do anything about. I had the hot flashes for the first three years after surgery. I met a lady who told me the name of a prescription her doctor gave her after her surgery. I then had to get this filled from my doctor in town. It worked"

"I'm 81 and I'm taking Tamoxifen. Imagine hot flashes at my age!"

### Depression

One survivor who had rated depression with a worse outcome stated" One thing I will mention is probably depression-. I am so depressed I can't open my mail or pay the bills. I just can't accept any responsibility

But life doesn't stop! My daughter is helping me. That is why I'm late sending this, I never received (or opened) your first letter."

Another survivor described how difficult it was to cope as a result of her treatment.

I am moved to tears while filling out this questionnaire. It is obvious to me there is a very deep emotional impact from treatments!"

### Anger

Two survivors used the survey as a means to communicate anger. It was difficult to differentiate if they were angry at their breast cancer or at the physicians. They also communicated about their rights as women dealing with breast cancer.

"I personally feel doctors in general are way to callous to our feelings concerning women's breasts. If we would cut off their penis they would understand our connection to our breasts-. My generation will not continue to put up with no research on women's' disease. Thank-you for doing this study!"

"I had researched my cancer and read Susan Love's Breast Book. I demanded a lumpectomy with my 2.2 tumor- against my doctors' wishes- I'm very glad with my decision even though my doctor said it could recur in a couple of years. I also refused to

sign the consent form until it only listed lumpectomy! Women need to stand up for their rights!"