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## Quality Of Life In Older Breast Cancer Survivors

Victoria Loerzel  
*University of Central Florida*



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QUALITY OF LIFE IN OLDER BREAST CANCER SURVIVORS

by

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A dissertation submitted in partial fulfillment of the requirements  
for the degree of Doctor of Philosophy  
in the College of Nursing  
at the University of Central Florida  
Orlando, Florida

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Major Professor: Karen Dow Meneses

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## ABSTRACT

Quality of life (QoL) in cancer survivors is an important area of research. While data are available about QoL and breast cancer, there is a paucity of research regarding older breast cancer survivors. The purpose of this research was to examine QoL in older women with early stage breast cancer, within the first year of post-treatment survivorship. The specific aims of this study were to: 1) Describe the changes in overall QoL and the four QoL domains of Physical, Psychological, Social, and Spiritual well-being; 2) Examine the effects of a psychoeducational support intervention on QoL outcomes in older women; and 3) Describe nurses' perceptions of their interactions with older breast cancer survivors.

A descriptive, longitudinal design was used to answer the research questions. Data for this study were drawn from the Breast Cancer Education Intervention (BCEI), a longitudinal psychoeducational support intervention for women with early stage breast cancer. Fifty women from the BCEI who were 65 years of age and older were included in this sample, of whom 24 were assigned to the Experimental (EX) Group and 26 were assigned to the Wait Control (WC) Group. Data were collected at three time points: baseline, three months, and six months after study entry. Measurement tools included the BCEI Demographics Form, the Quality of Life-Breast Cancer Survey (QoL-BC), and field notes of the BCEI Research Nurses. The QoL-BC survey is a 50-item scale that measures QoL in women with breast cancer. Descriptive statistics, Generalized Estimating Equation (GEE) methods and t-tests were used to answer research questions #1 and #2. Content analysis was used to answer research question #3.

Subjects reported good overall QoL at baseline, but QoL declined over six months. Physical and Psychological well-being declined from baseline to six months later. Social well-

being initially improved from baseline to three months but declined at six months. Spiritual well-being initially declined at three months and improved at six months. There was insufficient power to detect a difference in the effects of the BCEI Intervention between the two groups. However, the decline in overall QoL was less in the EX Group. *Field notes* focusing on nurses' perception of their interactions with older women revealed four themes. These themes include: continuing breast-related health, personal health issues, family health issues, and potential stressors.

Results from this study suggest that: 1) changes in overall QoL and within the four QoL domains occur over time; 2) decline in overall QoL was lessened by the BCEI Intervention; and 3) concerns after treatment are both breast cancer and non-breast cancer related. Study findings can direct future research in the following areas: 1) identification of specific concerns within each QoL domain that could lead to an increase or decrease in well-being in older breast cancer survivors; 2) interventions tailored to the needs of older breast cancer survivors to maintain, improve, or lessen decline in QoL after treatment; and 3) reconceptualizing QoL in older breast cancer survivors to include non-cancer related factors.

The dissertation is dedicated to my family. To Jerry and Joyce Wochna, thank you for a lifetime of love, support, faith and encouragement. Without your solid foundation, my successes would not have been possible. To my husband Steven, thank you for your love, support, patience, perspective and humor. Words can not express how grateful I am to you. To Marnie and Allyson, you have both been my “rocks” of support. Thank you for all your understanding. To Cheryl Brohard-Holbert, Gage Gwyn and Laurie Stark, thank you for your support, I look forward to returning it very soon.

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## **CHAPTER 1: INTRODUCTION**

Breast cancer is the most common cancer diagnosed in women in the United States. The mean age of women diagnosed with breast cancer is 61 with women age 75 to 79 having the highest incidence. Today, there are more than 2.3 million women surviving with breast cancer. As the Baby Boomer generation ages and their life expectancy increases, the number of older women diagnosed and surviving with breast cancer is also expected to increase. Throughout this dissertation, “older” represents women age 65 and older.

Evidence suggests that women with breast cancer experience adverse effects related to their cancer that can affect quality of life (QoL) after treatment. Data also suggest that QoL after treatment may be influenced by non-cancer related stressors that occur before a diagnosis of breast cancer. The majority of research regarding QoL in women with breast cancer focused on women with an average age of 50 years. Despite the increased risk for breast cancer in aging women, less research attention has been paid to women age 65 and older. The overall purpose of this research was to examine QoL in women with early stage breast cancer who are age 65 and older and are within the first year of post-treatment survivorship.

The goal of this research was to add to the body of knowledge concerning QoL in older women after treatment for early stage breast cancer. The research proposal in Appendix C includes extensive details of the study’s overall purpose, specific aims, research design, methods and analysis. This dissertation used a secondary analysis based on data drawn from the Breast Cancer Education Intervention (BCEI), a longitudinal psychoeducational support intervention trial. A descriptive, longitudinal design using mixed methods was used to examine QoL in older women with breast cancer and to answer the research questions.

This dissertation followed the University of Central Florida alternate model and is comprised of three manuscripts that focus on older, early stage breast cancer survivors after treatment. Consistent with the background and literature review, the first manuscript, entitled *Quality of life in women age 65 and older surviving early stage breast cancer: A review of the literature*, focuses on the state of the science related to women, age 65 and older, with early stage breast cancer after treatment. The second manuscript, entitled *A longitudinal study of quality of life in older women with early stage breast cancer in the first year of post-treatment survivorship*, describes the Overall QoL and QoL within the domains of Physical, Psychological, Social, and Spiritual well-being in women age 65 and older with early stage breast cancer who are within the first year post-treatment. This manuscript also describes the effect of the BCEI psychoeducational support intervention in these women. The third manuscript, entitled *Nurses perceptions of their interactions with older women with early stage breast cancer within the first year of post-treatment survivorship*, explores nurses' perceptions of their interactions with women, age 65 and older, with early stage breast cancer.

## **CHAPTER 2: QUALITY OF LIFE IN WOMEN AGE 65 AND OLDER SURVIVING EARLY STAGE BREAST CANCER: A REVIEW OF THE LITERATURE**

### Introduction

Quality of life (QoL) is recognized as a multidimensional concept with perception based on the subjective experiences of the individual assessing it.<sup>1-5</sup> For the purposes of this literature review, QoL is defined as a personal sense of well-being that encompasses physical, psychological, social and spiritual dimensions.<sup>6-8</sup> Other dimensions have also been identified and include health and functioning, socioeconomic,<sup>9</sup> functional ability, family well-being, emotional well-being, treatment satisfaction,<sup>2</sup> and physical functioning.<sup>1</sup> For persons surviving cancer, the period after treatment can be a complex time in which survivors experience physical and psychosocial effects,<sup>10-14</sup> which in turn, may affect QoL.

Quality of life is recognized as an important outcome of cancer treatment. Improving quality of care and QoL in those affected by cancer are goals set forth by the National Cancer Institute's (NCI) *Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer*.<sup>15</sup> The National Institutes of Health (NIH) encourages using QoL endpoints in NIH-funded clinical trials. In addition, the National Institute of Aging's (NIA) *Action Plan for Aging Research: Strategic Plan for Fiscal Years 2001-2005*<sup>16</sup> recognizes the need to address knowledge deficits regarding the elderly, disease and aging. One of the primary goals of its strategic plan is to improve health and QoL in older people. Older people with cancer have been identified as an unexplored population.<sup>17-19</sup> In this paper, "older" is defined as age 65 or older. Combined, these organizations outline a need for more research regarding QoL after cancer treatment.



The aging of Baby Boomer generation makes QoL research in older populations with cancer particularly salient. Because of the growth expected in the 65 and older age group and because the incidence of cancer increases with age, the number of all cancers diagnosed annually is expected to double from the current rate of 1.3 million to 2.6 million by 2050.<sup>17</sup> Currently, 57% of all new cancer diagnoses and 71% of cancer-related deaths occur in people age 65 and older.<sup>19</sup> In women, breast cancer is the most common cancer.<sup>20</sup> The mean age of all women diagnosed with breast cancer is 61, while women ages 75 to 79 have the highest incidence rate.<sup>21</sup> In brief, there are many older women living with breast cancer, and in the future, there will be many more. These figures make older women with early stage breast cancer a particularly important population to study.

Today, there are more than 2.3 million women surviving with breast cancer.<sup>21</sup> Since more than 90% of all breast cancers are diagnosed in early stages, prior to metastasis,<sup>22</sup> more older women will become cancer survivors in the near future. After treatment, women are at risk for physical and psychosocial consequences that can affect QoL. Physical effects include fatigue,<sup>23</sup> pain, cognitive changes,<sup>23</sup> lymphedema, sexual effects, pulmonary, neurologic, gastrointestinal,<sup>12</sup> and cardiac effects.<sup>12, 24, 25</sup> Psychosocial effects include fear of recurrence, depression, uncertainty in illness, and finding meaning in illness.<sup>10</sup> The majority of research on QoL in breast cancer survivors has been conducted in samples of women with an average age near 50 years.<sup>6, 26-34</sup> Less research attention has been given to women over the age of 65 years.

Since the number of older women who will receive a diagnosis of breast cancer is large and will increase, it is important to better understand the needs of this population. Thus, the goal of this paper is to: 1) review the literature review concerning quality of life in women, age 65

and older, surviving with early stage breast cancer after treatment; 2) describe implications for future research; and 3) describe implications for nursing practice.

### Methods

A review of literature was conducted using Medline, CINAHL, PsychInfo and Ageline databases. The literature search was conducted in several phases. First, the search began by using the keywords: quality of life, breast cancer and older women. No date limitations were used. This search yielded fifty-four articles in CINAHL/PsychInfo, 127 articles in Medline and nine articles in Ageline, totaling 190 articles. Several articles were duplicated between the databases. The title and abstract of each article were reviewed to determine if the articles met inclusion criteria. Articles were included if they: 1) were published in a peer-reviewed journal; 2) included an age group of 65 and older as either the only population or a specific comparative group; 3) focused on the post-treatment phase of breast cancer; 4) focused on women with early stage disease and; 5) were published in the English language. Dissertations, editorials, and articles that focused on breast cancer in men were excluded. Six articles met the inclusion criteria.

Second, the search was expanded since so few articles were found. The key words of breast cancer and older women were retained, and new keywords were added that related to aspects of QoL that had been previously reported in breast cancer survivors.<sup>6, 30</sup> These additional keywords included: physical well-being, psychological well-being, social well-being, spiritual well-being, survivorship, coping, adaptation, fatigue, pain, lymphedema, sleep disturbances, insomnia, weight gain, menopause/menopausal symptoms, sexual functioning, cognitive functioning, social support, fear of recurrence, depression, relationships, employment, body

image, meaning in illness, religion, spirituality, hope, and uncertainty. Each of these keywords was added to the previously used keywords, breast cancer and older women. This search yielded an additional 408 articles in CINAHL/PsychInfo and 682 articles in Medline. Duplicate articles were noted throughout the searches. The new articles from this expanded search were reviewed according to the same inclusion criteria used in the first phase of the search. Five new articles were identified bringing the total number of articles retrieved to eleven.

Third, the reference lists of the eleven included articles were hand searched and evaluated for relevance. Two more articles were identified bringing the total number of articles to thirteen. Fourth, this author also reviewed articles in her possession from previous work and identified one additional article that met the inclusion criteria for this review bringing the total number of articles to fourteen. This literature review will present the available knowledge concerning QoL of older women, age 65 and older, with early stage breast cancer after treatment.

### Findings

Fourteen studies met inclusion criteria and are included in this discussion. Seven studies focused exclusively on women with breast cancer age 65 and older. Four studies compared women with breast cancer age 65 and older to age-based controls. Three studies were conducted that compared women, age 65 or older, to younger women with breast cancer.

#### Women age 65 and older

Seven studies examined QoL specifically in women with early stage breast cancer age 65 and older. These studies have focused on QoL outcomes in older women after surgery and the ability of older women to find meaning in illness. See Table 1 for a summary.

### *Effect of surgery on QoL outcomes*

Four studies looked at the effects of treatment on outcomes of QoL. De Haes and colleagues<sup>35</sup> compared QoL in women with breast cancer age 70 and older ( $N=136$ ) who had received lumpectomy plus tamoxifen or mastectomy as primary treatment. This was a randomized clinical trial. QoL was measured using an unspecified QoL questionnaire that evaluated 9 domains. Women completed this survey between two and twelve months after surgery. Data were analyzed using Wilcoxon signed ranks test. Results showed that regardless of treatment, women experienced similar levels of fatigue, physical and emotional functioning, fear of recurrence, social support, and leisure-time activities. Women with mastectomy reported significantly more arm problems ( $p=.004$ ), and women who received breast-conserving treatment had better body images ( $p=.006$ ). This study concluded that older women who had conservative treatment had better QoL than women who had more extensive surgeries.

Using longitudinal design, Mandelblatt and colleagues<sup>36</sup> examined the impact of axillary dissection (AD) in women, age 67 and older, who had early stage breast cancer ( $N=571$ ). Post-treatment QoL was a primary outcome of the study. The Medical Outcomes Study-Short Form (SF-12) measured physical and mental functioning, while fear of recurrence was measured using two items from the Cancer Rehabilitation Evaluation Survey-Short Form (CARES-SF). The study included an additional question involving the impact of breast cancer on life. Subjects completed surveys at one and two years after surgery. Data were analyzed using analysis of variance (ANOVA) and chi square distribution statistics. Longitudinal data were measured using Generalized Estimating Equation (GEE) methods. Results indicate that 60% of the sample reported arm problems (i.e. swelling, loss of arm movement, and limitations of use) at some time during the study, and 83% of women who received AD reported arm problems. In addition,

women with arthritis were more likely to report arm problems 2 years after surgery. Women who received AD and reported arm problems reported lower physical ( $p=0.0001$ ) and mental functioning ( $p=0.04$ ) at both points of the study. Finally, women who experienced arm problems indicated that the breast cancer had a more severe impact on their lives than women who did not have arm problems ( $p= 0.0006$ ). This study concluded that AD increased the risk of developing arm problems within two years and had negative effects on QoL.

In another study, Mandelblatt and colleagues<sup>37</sup> used a randomized cross-sectional design to describe the long-term impact of primary therapy on QoL and satisfaction in early stage breast cancer survivors age 67 and older ( $N=1,812$ ). Women who were three to five years post-treatment and received either breast conservation treatment (BCT) or mastectomy were included in this sample. Physical functioning was examined using the SF-12. Social and role function, vitality, and general health were examined using scales from the Medical Outcomes Survey Short Form-36 (SF-36). Data were analyzed using chi square distribution, t tests, and logistic regression. Results indicate that regardless of the treatment group, women did not differ significantly in any of the scales. Having a co-morbid illness prior to treatment affected physical outcomes ( $p=<.001$ ). Women with axillary dissection reported more arm problems, which negatively impacted all other outcomes ( $p=<.001$ ). In addition, older women who felt they were not given a choice about treatment reported more pain, poorer mental health, and less satisfaction ( $p=.0001$ ). The study concluded that processes of care, not treatment, were important predictors of long-term QoL in these older women.

In a longitudinal clinical trial, Figueiredo and colleagues<sup>38</sup> examined the effect of surgery preference and surgery received on body image and mental health in women age 67 and older ( $N=563$ ). Data were collected using the SF-36, CARES-SF, and two investigator-

developed questions. Data were analyzed using chi square distribution, t tests, ANOVA, Pearson and Spearman rank correlation, path analysis and GEE methods. Results indicated that physical appearance was important for 31% of the sample when making treatment decisions. In addition, younger women and those with fewer co-morbid illnesses were more likely to be concerned about appearance. At one and two year follow-ups, women who received mastectomy had more concerns about body image ( $p<.0001$ ) and worse mental health ( $p<.05$ ) than women who received BCT. Generally, if subjects did not receive the type of treatment preferred, they reported greater concern for body image and poorer outcomes related to mental health. This study concluded that body image is important to older women, and receiving treatments according to preference about appearance was an important factor for positive mental health outcomes.

In summary, four studies focused on QoL outcomes after primary treatment and suggested that conservative treatment leads to better QoL. Women who receive more aggressive treatments such as mastectomy experience more arm problems, concerns with body image, and poor mental health. Women who received axillary node dissection also report more arm problems, and this had a negative impact on QoL. In addition, if older women felt involved in treatment decisions, they reported better mental health and satisfaction.

### *Meaning in Illness*

Three qualitative studies explored meaning in illness after breast cancer. In the first, Feher and Maly<sup>39</sup> used structured interviews and open-ended questions to examine religious and spiritual coping strategies in women age 65 and older ( $N=33$ ) who were recently diagnosed with breast cancer. Content analysis was used to analyze data. All of the subjects in this study

indicated that their faith had been maintained or strengthened during illness. Three themes emerged during analysis. First, women felt that their religious and spiritual faith helped give them the emotional support needed in order to cope with breast cancer and make meaning in their lives during illness. Faith gave women a sense of companionship and being taken care of. Faith also provided emotional support and helped women control their fears, take comfort, and have a sense of well-being. Second, older women used their associations with the church to maintain social connections with others. Being associated with a church or religious community allowed women to keep in touch with others through volunteer work and their relationship with the leader of their church. In addition, women liked being prayed for by others. Women felt protected, loved, and unafraid due to the presence of God in their lives. Third, women were able to make meaning in their lives through their faith. They felt that faith acted as a moral compass and gave them identity. In addition, some women felt that their illness was in God's hands and out of their control. They believed their illness was for a greater purpose. Overall, women used religion and faith to cope with their illness.

Utley<sup>40</sup> sought to discover the meaning of cancer in older, long-term breast cancer survivors using qualitative analysis. Twenty women, age 65 and older who were five to twenty-nine years past diagnosis, participated in three life history interviews. Results showed that women experience three distinct and progressive phases of finding meaning in their illness. The first phase viewed cancer as sickness and then death. Women talked about expecting to feel sick if they had cancer and how their expectation did not correlate with how they really felt. The second phase viewed cancer as an obstacle and something to overcome. Women realized cancer was something they could live with. In the third phase, cancer was viewed as transforming. Women realized that their lives changed and could see how cancer benefited them and their

lives. The meaning of cancer evolved over time, and most women experienced a positive effect from having cancer.

Through methods informed by grounded theory, Crooks<sup>41</sup> developed the theoretical model of *Living Day by Day* in which older women went through several phases before coming to terms with and finding meaning in their disease. Twenty women, age 66 to 94 with early stage breast cancer, participated in this study. Initially, women “faced the music” by finding out about their diagnosis and taking action against it through treatment. “Getting back to normal” after treatment was a considerable task for older women. In this phase, women acknowledged the physical changes that they experienced, such as pain or the loss of a breast, and strategized to assimilate these changes into their lives. In addition, older women were able to realize that having cancer changed how other people viewed them as individuals. As a result, older women protected family members by downplaying their own fears and concerns and sharing information about themselves with others in similar situations or with those who cared about their situation. “Getting perspective” is the third phase in which older women sought perspective on their disease and life expectancy. Women made decisions for themselves based on their comparison of themselves to other women in similar situations and those with different illnesses to determine if their problems were more or less significant. Older women used this strategy to affirm previous decisions and to determine how much effort should be given to concerns about the diagnosis and fears of recurrence. Finally, “being different than before” was the last phase identified by older women. Women became aware of the isolation caused by the diagnosis and the need for time to make sense of the changes. Older women examined their belief systems and focused on the important things in their life. Ultimately, this process of finding meaning in illness allowed women to live each day to the fullest.



In summary, three qualitative research studies discussed meaning in illness in older early stage breast cancer survivors. The next section of the review will focus on studies that compare women, age 65 and older, surviving with early stage breast cancer to age-based controls without cancer.

#### Women age 65 and older and age-based controls

Women age 65 years and older with early stage breast cancer were compared to women with and without cancer. Two studies compared older women with breast cancer with age-based controls without cancer, and two studies compared older women to both age-based controls without cancer and younger women with and without cancer. These studies focused on symptom distress, physical functioning, and psychological well-being, which will be discussed in the next section. See Table 2 for a summary.

#### *Symptom distress*

Using descriptive, correlational design, Heidrich and colleagues<sup>42</sup> examined symptoms, symptom belief, and QoL in older women (age 65 or older) with chronic illnesses with ( $n=18$ ) and without ( $n=24$ ) breast cancer. Symptom distress was measured by the Heidrich Symptom Bother Scale-Revised (SB-R); symptom belief was evaluated by asking women the origin of their symptoms; QoL was measured using the SF-36; and the Purpose in Life Scale was used to measure existential QoL. The Center for Epidemiologic Studies Depression Scale (CES-D), State-Trait Anxiety Inventory, and Older Americans Resources Service Schedule of Illnesses (OARS) were also used. Data were analyzed using Wilcoxon-Mann-Whitney U test and chi-square distribution tests.

Results showed that both groups of women reported multiple symptoms and low levels of symptom distress. Symptoms reported included pain, fatigue, aching, joint pain, dry mouth, weight gain, lack of concentration, weakness, constipation, and hot flashes. Aching was the only symptom reported more often by women with breast cancer ( $p < 0.05$ ). Women in both groups attributed their symptoms to aging, chronic conditions, or unknown causes. Women in the breast cancer group rarely associated their symptoms with breast cancer. When older women were able to attribute symptoms to a cause, they found them less distressing than women who were not able to identify a cause for their symptoms. In summary, symptom experience and symptom attribution were similar in both groups. Although women with breast cancer reported experiencing symptoms, they reported low levels of distress. In addition, they rarely associated their symptoms with breast cancer, instead attributing symptoms to aging and other chronic conditions.

### *Physical functioning*

Satariano and colleagues<sup>43</sup> conducted a longitudinal study to examine instrumental functioning in women with breast cancer ( $n=422$ ) compared to non-cancer peers ( $n=478$ ). Women were divided into three age groups: age 55 to 64, 65 to 74 and 75 to 84 and were compared to non-cancer peers within their age group. Instrumental daily living was measured using the Instrumental Activities of Daily Living (IADL) survey at three and twelve months after diagnosis. Data were analyzed using Redit analysis. Results showed that at three months post-diagnosis, women with cancer, ages 55 to 64 and 65 to 74 reported more instrumental functioning problems (e.g. housekeeping, preparing meals, shopping) compared to controls within their age group. Women ages 75 and older reported the fewest instrumental functional

problems compared to similar-aged controls: these women named transportation as the most problematic issue. At twelve months, women ages 55 to 64 were more similar to their control group, but women ages 65 to 74 continued to report less independence than their control group. Women with cancer, ages 75 to 84 were again not significantly different from their control group in respect to instrumental functioning or independence at the twelve month time point.

Kroenke and colleagues<sup>44</sup> (2004) examined physical and psychosocial changes due to breast cancer using non-cancer comparison groups of women of different ages. The total sample was obtained from the Nurses' Health Study and the Nurses' Health Study II and consisted of 122,969 women, of which 1,082 had breast cancer. Comparative groups for this prospective, longitudinal study included younger (ages 40 and younger), middle-aged (41 to 64 years), and older women (ages 65 and older). Measurement tools included the SF-36 and the CARES-SF. Data were analyzed using linear regression methods. Results indicated that the youngest women with breast cancer experienced the most significant declines in physical roles, social functioning, bodily pain and mental health compared to their non-cancer peers ( $p < 0.05$ ). Both groups of older women experienced statistically significant declines in physical functioning, role limitations due to both physical and emotional problems, and bodily pain ( $p < 0.05$ ). However, older women without breast cancer showed about half the decline as their peers with breast cancer. Physical declines in the oldest groups were similar regardless of disease state. These researchers suggest that the declines were related to age instead of treatment or the disease itself. This study concluded that older women fare better than younger women in physical and psychosocial domains after diagnosis.

### *Psychological well-being*

Using a 2x2 cross-sectional design, Heidrich<sup>45</sup> examined the influence of age and type of illness on health and functioning, self-interpretive mechanisms, and psychological well-being. Women with breast cancer ( $n=86$ ) and osteoarthritis ( $n=102$ ) were divided into two age groups for comparison: young-old (ages 60 to 74) and old-old (ages 75 and older). Multiple instruments were used in this study and included the OARS ADL measure for functional health status; Heidrich's Symptom Bother Scale; a social comparison scale; a social network index to assess social integration; single-item questionnaires to assess illness perceptions; the CES-D; Rosenberg's Self-Esteem Scale; and Ryff's scales of psychological well-being. Data were analyzed using analysis of co-variance (ANCOVA) and multivariate analysis of covariance (MANCOVA).

Results indicated that age did not influence outcomes such as health, functioning and psychological well-being. However, type of illness did influence these outcomes. Compared to women with breast cancer, women with arthritis reported more symptom bother and problems with activities of living ( $p=0.0001$ ). Women with arthritis also reported their illness as less controllable and more severe and chronic ( $p<0.001$ ) than women with breast cancer. Women in both groups compared themselves with other women they knew, making upward and downward comparisons to help discern their own appraisal of psychological well-being. These appraisals influenced psychological outcomes. Women who made upward comparisons had better psychological well-being. This study indicates that older women with arthritis reported more symptom bother than women with breast cancer. In addition, positive appraisal or comparisons influenced psychological outcomes.

In summary, studies that compared older women with breast cancer to non-cancer age-based controls suggest the following: 1) older women believe that the symptoms they experience after breast cancer are related to age or chronic illness, not breast cancer; 2) older women experience changes in functioning, but so do their non-cancer peers, suggesting that declines in physical functioning may be attributable to age, not treatment; 3) older women with arthritis report more symptom bother than women with breast cancer. The next section of the review will focus on differences between older and younger women with breast cancer.

#### Older women compared to younger age groups

Three studies compared older and younger women with breast cancer. These studies examined functional status, cognitive functioning, and overall QoL. Please see Table 3 for a summary.

##### *Functional status*

Fehlaur, Tribius, Mehnert, and Rades (2005) compared functional status based on age at diagnosis in long-term breast cancer survivors. The effects of adjuvant treatment on health-related QoL (HR-QoL) were also examined. The sample consisted of 370 women treated with lumpectomy, axillary node dissection, and radiation. Women were grouped according to time of follow-up (either seven or twelve years), age at time of therapy (<50 years, 50-65 years, and >65 years), and type of treatment. Measurements included the European Organisation for Research and Treatment of Cancer's (EORTC) Quality of Life Questionnaire (QLQ-C30) and the EORTC Breast Cancer Module (QLQ-BR23). Data were analyzed using two-way multivariate analysis of variance (MANOVA) and post-hoc Scheffe tests.

Results indicated that at seven and twelve years from treatment, the oldest women at the time of treatment reported worse physical functioning ( $p<0.001$ ) and more body pain ( $p<0.01$ ) compared to younger women. Older women had significantly more arm symptoms ( $p=0.005$ ) at twelve years, and their illness had less financial impact ( $p=0.006$ ) compared to younger women. Global HR-QoL scores improved significantly for older women at the twelve year follow-up ( $p=0.006$ ) despite these concerns. The type of treatment did not have an impact on HR-QoL in this study. This study concluded that age at time of therapy is related to differential disturbances in HR-QoL.

### *Cognitive functioning*

Cognitive functioning in older women after treatment for early stage breast cancer has been examined in the literature. Cimprich<sup>46</sup> examined the effect of age and type of surgery on attentional fatigue in women ( $N=74$ ) with early stage breast cancer. This study had three groups: younger (ages 25 to 45), middle-aged (ages 46 to 64) and older (ages 65 to 74) women. The capacity to directed attention (CDA) was measured before and after surgery (lumpectomy or mastectomy). Four measures of CDA were used, which tested the subjects ability to block a competing stimulus when they focused on a task. Data were analyzed using ANOVA, t tests, and multiple regression.

Results indicate that older women had significantly lower total attention scores than younger women at baseline ( $p< 0.05$ ). Older women also experienced significant losses in overall attention performance ( $p= 0.04$ ) and total attention scores ( $p<.05$ ) over time compared to younger women. Within the older group, women who received mastectomy also showed significantly greater loss in total attention scores compared to women of the same age who

received breast conservation treatments ( $p= 0.05$ ). More extensive surgeries led to more attention deficits. This study concluded that age and type of surgery affected the capacity to direct attention in older women with early stage breast cancer.

### *Overall quality of life*

Using a cross-sectional design, Cimprich and colleagues<sup>47</sup> examined the relationship between age at diagnosis and QoL in long-term breast cancer survivors ( $N=105$ ). Women were divided into groups that represented life stages: younger women (ages 45 and younger), middle age (ages 46 to 65) and older (ages 66 and older). Quality of life outcomes were measured by using the Quality of Life-Cancer Survivors (QoL-CS) instrument, which focuses on physical, psychological, social, and spiritual well-being. Data were analyzed using ANOVA and multiple regression.

Results indicate that that older women have significantly worse physical well-being scores ( $p= 0.008$ ) than middle-aged women but significantly better social well-being scores ( $p= 0.025$ ) than the youngest women. Within the physical domain, older women reported significantly ( $p< 0.05$ ) more problems with fatigue, pain, constipation, and sleep changes compared to younger women. Within the psychological domain, older women reported significantly less ( $p< 0.05$ ) distress at diagnosis and treatment but better outcomes related to changes in appearance than younger women. Within the social domain, older women reported significantly lower impact ( $p< 0.05$ ) on sexuality, employment, and family distress than younger women. In the spiritual domain, older women also reported significantly fewer ( $p<.05$ ) positive changes as a result of breast cancer than younger women and more uncertainty for the future

compared to middle-aged women. This study concluded that life stage at the time of diagnosis had a significant impact on long-term QoL in breast cancer survivors.

In summary, studies that examined age-related differences in women with breast cancer showed the following. Compared to younger women, older women reported: 1) worse physical well-being and functioning; 2) less distress from diagnosis; 3) better outcomes for appearance; 4) less distress related to sexuality; 5) less distress related to employment; 6) less family distress; 7) more decline in cognitive functioning; and 8) fewer positive changes from breast cancer.

### Discussion

It is surprising that the literature review yielded so few articles that specifically focused on women, age 65 and older with early stage breast cancer. However, these fourteen articles provide a beginning foundation for knowledge concerning this population in five areas. First, studies have shown the benefits of conservative surgical treatment for breast cancer and keeping older women involved in their treatment choices. Overall, older women who receive breast conservation treatments report fewer QoL concerns than women who received mastectomy and axillary dissection. Older women who were treated conservatively report fewer arm problems<sup>35</sup> and better physical functioning<sup>37</sup> than older women who received mastectomy. The experience of having arm problems negatively affected other QoL outcomes.<sup>36,37</sup> In addition, older women consider their physical appearance when making treatment decisions,<sup>38</sup> leading to better outcomes. Women who felt that they had treatment options reported better mental health and satisfaction compared to women who felt that they were not involved in decisions related to their treatment.<sup>37</sup>



Second, studies have examined physical symptoms, physical functioning, and physical well-being in older women after treatment for early stage breast cancer. While older women reported more physical symptoms compared to younger women,<sup>47</sup> they report a similar number of symptoms compared to women of the same age with other chronic illnesses.<sup>42</sup> In addition, older women with breast cancer report less symptom bother than older women with arthritis.<sup>45</sup> Older women with breast cancer rarely attribute their symptoms to breast cancer but instead attribute symptoms to aging and other chronic illnesses.<sup>42</sup> Older women also report worse physical well-being<sup>47</sup> and worse physical functioning<sup>48</sup> compared to younger women. However, in studies that used age-based controls without cancer, these declines were also noted in older women of the same age without cancer.<sup>43,44</sup> These findings suggest that older women naturally experience declines in physical functioning. Breast cancer is not necessarily the cause of these declines.

Third, it has been reported that older women with early stage breast cancer report fewer psychological effects compared to younger women. Older women report being less distressed at diagnosis and through treatment and report fewer concerns with changes in their appearance compared to younger women.<sup>47</sup>

Fourth, several social differences have been noted between older and younger women with early stage breast cancer. Compared to younger women, older women report that breast cancer has less of an impact on sexuality, employment, family distress,<sup>47</sup> and finances.<sup>48</sup> In addition, older women experience greater cognitive losses and a reduced attention span compared to younger women with breast cancer.<sup>49</sup>

Finally, spirituality in older women with early stage breast cancer has been explored. Older women report that faith assists with coping and emotional support and allows them to

maintain a social connection with others.<sup>39</sup> Through faith, older women are able to find meaning in having breast cancer,<sup>39-41</sup> which allows older women to live each day to the fullest.<sup>41</sup>

Conflicting information is presented related to the ability of older women with breast cancer to note the positive effects having cancer has had on their lives. While, qualitative studies have reported that older women experienced positive effects from having breast cancer,<sup>40</sup> quantitative studies report that older women experience fewer positive changes compared to younger women with breast cancer.<sup>47</sup>

### Implications for Research

Despite current findings, several areas were identified for future research. Given the limited research concerning older women, it is possible that there are factors within this older population that have not yet been identified that may have an impact of QoL. More research will help eliminate knowledge gaps and identify these factors in older women.

First, while we do know that older women experience side effects and symptoms, the extent of the symptom experience is unknown. How specific symptoms affect aspects of everyday life or how older women manage side effects is also unknown. Problems such as fatigue, pain, lymphedema, functional limitations, and fear of recurrence need to be further explored so that healthcare providers can assist older women in managing their concerns to improve or maintain QoL.

Second, the impact of co-morbid illnesses in older women after treatment for breast cancer is unknown. Research demonstrates that the presence of co-morbidity affects screening<sup>50</sup> and treatment<sup>51, 52</sup> of breast cancer, but it is not known how co-morbidities influence QoL in older women after treatment for breast cancer. Only three studies in this review addressed co-

morbid illnesses. Women with arthritis were more likely to report arm problems after surgery;<sup>36</sup> having a co-morbid illness prior to treatment negatively affected physical outcomes;<sup>37</sup> and women with fewer co-morbid illnesses were more likely to be concerned about their appearance after surgical treatment for breast cancer. It is likely that older women will have at least one co-morbid illness by the time they are diagnosed with breast cancer,<sup>19</sup> and knowing how to manage the effects of treatment within the context of other illnesses will be crucial to improving QoL in these women.

Third, appropriate interventions for older women with breast cancer have not been explored. This information is important because older women may have different educational needs and learning styles than younger women. Crooks<sup>41</sup> stated that the older women in her study rejected the written materials offered by health care providers. Older women felt that providers were not interested in them as people when they were given written material without a verbal explanation. The current method of giving patients copious amounts of reading material about managing their symptoms may be ineffective in older populations.

Finally, the use of various standardized measurement tools, each of which examine and measure different dimensions of QoL in older women, makes comparison of these studies difficult. Opportunity exists to duplicate or confirm the results of these studies using measurement tools that have been previously used in this population. This may help support results of prior studies.

### Implications for Nursing Practice

Through this research, several implications for nursing practice can be offered. First, older women who receive more conservative surgical treatments, such as lumpectomy

experience fewer side effects and better outcomes than women who receive mastectomy. Since women over the age of 55 are more likely to receive mastectomy,<sup>53</sup> nurses may use this information to identify older women at risk for side effects caused by the treatment. Once identified, educational programs or guidelines can be developed to assist these women in reducing or managing their symptoms and improving QoL.

Second, older women want to be involved in treatment decisions, especially those that impact their appearance. In nursing and the health professions, there may be a misperception that older women are not concerned about their appearance or body image, which may lead to a lack of patient involvement in treatment decisions. Nurses should consider that many older women are interested in preserving their appearance and may want to know all of the treatment options available to them. In addition, education may need to be provided on the use of prosthetics and reconstructive surgery in order to help older women preserve their appearance.

Third, while it has been reported that older women experience more physical symptoms compared to younger women with breast cancer, it has also been reported that older women experience similar symptoms to older women without breast cancer but with other chronic illnesses. In addition, older women may not demonstrate the level of distress regarding their symptoms that nurses expect. During follow-up visits after treatment, nurses may need to explore the symptoms of older women in order to help them manage their concerns. Education regarding symptom management should be specifically tailored to help older women maintain or improve their physical functioning and QoL. However, tailoring interventions to older women may also be challenging when basing the intervention on research that has dealt with younger populations, which highlights the need for research based on older women.

Fourth, psychosocial findings related to older women with breast cancer suggest that older women experience fewer effects compared to younger women. Despite these findings, nurses should still consider the individuality of the experience of having breast cancer and explore the psychosocial impact of diagnosis and treatment in all women with breast cancer in order to provide appropriate counseling and interventions.

Fifth, faith is important to many older women with breast cancer. It should be recognized that some older women draw upon their faith for support and coping. Nurses may want to incorporate faith into their assessment of patient coping methods. In addition, nurses may consider discussing the positive changes that breast cancer may have brought to the patients' lives.

### Conclusions

This review of the literature has summarized what is currently known about QoL in older women, ages 65 and older, with early stage breast cancer. Currently, the literature suggests that older women: 1) have better QoL outcomes when they receive conservative surgical treatments such as lumpectomy; 2) want to be involved in decisions concerning their treatment; 3) experience more physical symptoms and declines in functioning compared to younger women, but experience similar symptoms and functioning compared to women of the same age with other chronic illnesses; 4) have fewer psychosocial concerns compared to younger women; and 5) use faith to cope and find meaning in their illness.

Despite current research, areas for future research exist related to older women with early stage breast cancer after treatment. More research is needed to determine the extent of

symptoms in this population, the effect of co-morbid illnesses after treatment for breast cancer, and appropriate interventions to help older women improve their QoL.

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## **CHAPTER 3: A LONGITUDINAL STUDY OF QUALITY OF LIFE IN OLDER WOMEN WITH EARLY STAGE BREAST CANCER IN THE FIRST YEAR OF POST-TREATMENT SURVIVORSHIP**

### Introduction

Breast cancer is the most common cancer among women in the United States.<sup>1</sup> Today, there are more than 2.3 million women alive who have survived breast cancer.<sup>2</sup> The mean age of all women diagnosed with breast cancer is 61, and women between the ages of 75 to 79 have the highest incidence of the disease.<sup>2</sup> As the Baby Boomer generation advances toward older age with increased life expectancy, the number of older women diagnosed with breast cancer is also expected to increase.<sup>3</sup>

This paper defines “older” as age 65 and older. Older women with breast cancer receive standard treatments such as mastectomy, lumpectomy, radiation, chemotherapy, and/or hormonal therapy.<sup>4-7</sup> Older breast cancer survivors are at risk for adverse effects after treatment that may have an impact on quality of life (QoL).<sup>8-14</sup> At diagnosis, older women may also experience other chronic illnesses in addition to breast cancer which may have further impact on QoL.<sup>15</sup>

Research demonstrates that women of different ages diagnosed with breast cancer have different concerns and needs.<sup>16, 17</sup> However, current research has recently begun to explore these needs in women with breast cancer who are age 65 and older and in the first year of survivorship. The purpose of this paper is to report the results of a study of QoL in older, early stage breast cancer survivors in the first year of post-treatment survivorship. The specific aims were to: 1) Describe changes that occur over time in overall QoL and the QoL domains of Physical, Psychological, Social and Spiritual well-being for women with breast cancer aged 65 and older in the first year of post-treatment survivorship; 2) Examine the effects of the BCEI

psychoeducational support interventions on QoL outcomes among older women with breast cancer.

### Literature Review

Data show that cancer and its treatment affect QoL in breast cancer survivors; however, the effect on QoL in older women is unclear. Many studies that examine QoL report the average age of the participants as 50 years.<sup>18-27</sup> Such data can not be generalized to an older sample. Exclusion or lack of participation of older women in clinical trials has led to a knowledge deficit in many areas regarding older women with breast cancer. This literature review is limited to research that specifically included women age 65 and older in their samples.

Several studies have focused on QoL outcomes in older women after surgical treatment for early stage breast cancer. These studies indicate that older women who receive conservative treatments such as lumpectomy experience fewer arm problems,<sup>28-30</sup> fewer concerns with body image,<sup>28, 31</sup> and better mental health<sup>28</sup> compared to women who receive mastectomy and axillary lymph node dissection. In addition, older women reported better mental health when they felt involved in making their treatment decisions.<sup>30</sup>

Other studies have focused on physical outcomes in older women after treatment for early stage breast cancer. Physical effects, such as fatigue,<sup>28, 32</sup> arm problems related to axillary dissection, such as lymphedema, swelling and numbness,<sup>30</sup> pain,<sup>33</sup> concerns with physical functioning,<sup>34</sup> weight gain, constipation,<sup>32</sup> dry mouth, weakness, and hot flashes,<sup>32</sup> have been reported by older women. Compared to younger women, older women report more physical symptoms.<sup>35</sup> However, compared to women their own age with chronic illnesses other than breast cancer, older women with breast cancer report similar symptoms.<sup>32</sup> In addition, older

women with breast cancer report being less bothered by symptoms than women with other chronic illnesses such as arthritis.<sup>33</sup>

Declines in physical well-being and functioning have also been reported by older women. Compared to younger women, these declines in well-being and functioning are more severe in older women<sup>35, 36</sup> but similar to declines experienced by older women without a history of breast cancer.<sup>34, 37</sup>

Psychological effects reported by older women include concerns with emotional functioning,<sup>34</sup> fear of recurrence, lack of social support,<sup>28</sup> body image concerns,<sup>28, 31</sup> and cognitive changes.<sup>32, 38</sup> All of these effects may have an impact on QoL outcomes in older women with early stage breast cancer. Older women have reported experiencing less distress at diagnosis and during treatment compared to younger women with breast cancer.<sup>35</sup>

Socially, compared to younger women, older women report fewer concerns with sexuality, employment, family distress,<sup>35</sup> and finances.<sup>36</sup> In contrast, cognitive changes and deficits in concentration are more prominent in older women compared to younger women.<sup>39</sup>

Spiritually, while the importance of faith and religion has been noted in many women with breast cancer, benefits related to religion and spirituality have been reported in older women with breast cancer. Religion and faith give older women support, comfort, and a feeling of connectedness.<sup>40</sup> Faith also helps older women cope and make meaning in their illness.<sup>40</sup> Conflicting information exists concerning the ability of older women to note positive changes in their lives after breast cancer. Utley<sup>41</sup> reports that older women are able to see the benefits from cancer; however, Cimprich<sup>38</sup> reports that older women note fewer positive changes from their breast cancer diagnoses than younger women.

In summary, this literature review showed that older women experience multiple side effects and concerns after treatment for breast cancer. Compared to younger women, older women report declines in their physical functioning; however, their non-cancer peers also experience physical decline. Psychologically, older women report less distress at diagnosis compared to younger women. Socially, older women face fewer financial concerns compared to younger women. Older women also report more cognitive changes compared to younger women. Spiritually, faith and religion are also important to older women and helps them to cope and make meaning of their illness.

### Theoretical Framework

The Conceptual Model of Quality of Life in Aging Breast Cancer Survivors (QoL-ABCS) was used to frame the present study. The Model is shown in Figure 1. The QoL-ABCS uses the domains of Physical, Psychological, Social, and Spiritual well-being from the Quality of Life for Breast Cancer Survivors conceptual framework.<sup>22, 42, 43</sup> The model uses the WHO (World Health Organization) definition of QoL as “an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns.”<sup>44</sup>

The QoL-ABCS acknowledges that QoL is influenced by more than health-related factors. Aging may also influence QoL in older women. The QoL-ABCS accounts for both of these factors by demonstrating the influence of well-being and age on QoL. This model maintains: 1) QoL is multi-dimensional, subjective and dynamic; 2) the domains of QoL are interactive with each other and one concept within a domain often influences another domain; 3) aging influences perception of QoL in survivorship; 4) perception of Physical, Psychological,



Social, and Spiritual well-being influences QoL in survivorship; 5) perception of QoL influences well-being in survivorship.

## Methods

### Research Design

This study used a longitudinal repeated measures approach to examine QoL in older women with early stage breast cancer in the first year of post-treatment survivorship. Data were drawn from a larger study, the Breast Cancer Education Intervention Study (BCEI). The BCEI was a longitudinal intervention trial that examined the effect of a psychoeducational support intervention for early stage breast cancer survivors. Details of this study are described elsewhere.<sup>45-47</sup>

### Sample

Subjects for this study included 50 women, age 65 and older from the BCEI. Inclusion criteria included: 1) female; 2) histologically confirmed early stage breast cancer [Stage 0-II]; 3) completion of treatment; 4) within the first year post-treatment; and 5) able to communicate in English. Subjects may have been on hormonal or anti-HER2 therapy at the time of study entry. Women with advanced or metastatic disease at the time of diagnosis were excluded from the study. All subjects were community dwelling. In this convenience sample, there were 24 older women assigned to the Experimental (EX) Group and 26 women assigned to the Wait Control (WC) Group.

## Measurement Tools

Demographics were obtained using the *BCEI Demographic Tool*. This 32-item tool includes items concerning sociodemographic characteristics (e.g., age, ethnicity, primary language, income, occupational status, religious affiliation) and treatment variables.<sup>45</sup>

Quality of life was measured using the *Quality of Life Instrument- Breast Cancer* (QoL-BC). The QoL-BC scale is a 50-item scale that specifically measures QoL in women with breast cancer. The QoL-BC was adapted from the QoL-Cancer Survivors Scale (QoL-CS).<sup>18,23</sup> The QoL-BC uses a 10-point rating scale used to describe QoL problems or concerns within four identified QoL domains-Physical, Psychological, Social and Spiritual well-being.<sup>23</sup> Scoring is based on a scale of 0 = best outcomes to 10 = worst outcomes. Thus, the lower the total score, the better the QoL. Reliability for the QoL-BC was established using the QoL-CS, which indicated a test-retest reliability of 0.89 and a Cronbach's alpha of 0.93.

In the BCEI, alpha coefficients for the total QoL and subscales were as follows: Overall QoL = 0.91; Physical well-being = 0.99; Psychological well-being = 0.96; Social well-being = 0.84; and Spiritual well-being = 0.85.<sup>45</sup> In the current study, the alpha coefficients for total QoL and each QoL subscale were: Overall QoL = 0.80; Physical well-being = 0.66; Psychological well-being = 0.93, Social well-being = 0.81; and Spiritual well-being = 0.78.

## Procedures

Several steps were followed to obtain, clean, and analyze the data for this secondary analysis. First, the investigator obtained written permission from the principal investigator of the BCEI Research Study (See Appendix D). Second, Institutional Review Board (IRB) approval was obtained from the University of Central Florida's Office of Research and Commercialization

(See Appendix E). Third, this investigator received eight de-identified data files in SPSS-v13<sup>48</sup> for subjects age 65 and older. These files contained data collected at baseline (Time 1), month 3 (Time 2), and month 6 (Time 3). Fourth, Dr. Xiaogang Su, a biostatistician, was asked to provide a statistical consultation for the Generalized Estimating Equation (GEE) portion of the analysis (See Appendix G).

Finally, data files were examined for accuracy, missing data, and outliers prior to analysis using descriptive statistics.<sup>49</sup> Frequencies were run on all variables to evaluate completeness of the data. No unexpected missing data were noted. However, two subjects who were age 65 and older did not complete the study. One subject withdrew from the study prior to data collection at Time 2. Another subject died prior to the final data collection (month 6) due to causes unrelated to breast cancer or participation in the study. This resulted in complete data for forty-nine subjects at month 3 and forty-eight subjects at Time 3.

### Data Analysis

Descriptive statistics including frequencies, means, and standard deviations (*SD*) were used to describe overall QoL and the four QoL domains. Generalized Estimating Equation methods,<sup>50, 51</sup> which are useful in analyzing correlated longitudinal data, were used to evaluate the overall effect of the BCEI intervention. Two-sample and paired t tests were used to further analyze between group differences and within group longitudinal changes. Bonferroni type adjustments were also made. In the t tests, three inferences were made for each variable, bringing the significance level to .017 (.05/3). Descriptive statistics and t tests were run by the investigator using SPSS-v13<sup>48</sup> software. GEE analysis was run using software developed in *R*<sup>52</sup> by Dr. Xiaogang Su, the biostatistician consultant.

Research Question # 1 describes the changes that occurred over time in overall QoL and the QoL domains of Physical, Psychological, Social, and Spiritual well-being for older breast cancer survivors in the first year of post-treatment survivorship. Descriptive statistics, including means and standard deviations, were used to answer this research question. Overall QoL for the entire sample was determined by using the overall mean score of the combined subscales (i.e., Physical, Psychological, Social, and Spiritual well-being) from the QoL-BC scale. Subscale scores were determined by using the combined mean scores for all items within each subscale.

Research Question # 2 used GEE analysis to examine the effects of the BCEI psychoeducational support interventions on QoL outcomes among older breast cancer survivors in the first year of post-treatment survivorship. Without adjusting for covariates, GEE methods were used to examine the effects of the BCEI intervention using the outcome variables of overall QoL and the four QoL subscales. Two-sample and paired t tests were also used to make detailed between and within group comparisons for overall QoL and subscale scores for the EX and WC Groups.

## Results

The results section will first describe the baseline characteristics of the sample. The answers to each specific research question follow.

### Characteristics of the Sample

Demographic characteristic of this sample consisted of 50 older breast cancer survivors in the first year of post-treatment survivorship. The mean age of this sample was 72.1 years (*SD*: 5.12) with a range of 65 to 83 years. The majority of the sample was Caucasian (82%) and reported English (92%) as their primary language. Slightly less than half of the sample reported

an educational level of college or better (44%). The majority of the sample reported being Christian of varying denominations (98%). More than half the sample was married (56%). Most subjects (80%) were not employed; 8% worked full-time and 12% worked on a part-time basis. Approximately half the sample (44%) had an annual family income of \$30,001 or more, and 42% had an annual family income of \$30,000 or less.

Disease- and treatment-related demographics indicated that 70% of the sample was diagnosed with Stage I breast cancer, and 30% was diagnosed with Stage II. Women were treated with lumpectomy (72%), mastectomy (24%), or bilateral mastectomy (2%). Other treatment included chemotherapy (18%), radiation therapy (78%), and hormonal therapy (84%). Table 4 lists a complete summary of demographic statistics.

Baseline demographic and cancer treatment characteristics were compared to determine whether there were any significant differences between the EX and WC groups. No statistically significant demographic differences were noted between the two groups. Table 5 lists a complete summary of the demographic characteristics of each group.

### Quality of Life in Older Breast Cancer Survivors

*Research Question # 1 described the changes that occur over time in overall QoL and the QoL domains of Physical, Psychological, Social, and Spiritual well-being for older breast cancer survivors in the first year of post-treatment survivorship.*

At baseline, mean overall QoL was 2.38 ( $SD = 0.1.02$ ). At Time 2, it was 2.48 ( $SD = 1.20$ ), and at Time 3, 2.58 ( $SD = 1.33$ ). Overall QoL worsened at Time 2 and continued to worsen at Time 3. Table 6 presents the mean QoL scores and standard deviations. Figure 2 plots the mean overall QoL scores over time.

Changes in the QoL subscale scores were noted for the entire sample. Table 6 presents the mean subscale scores and standard deviations. Physical well-being declined from baseline to Time 2 and Time 3. Psychological well-being declined from baseline to Time 2 and Time 3. Social well-being improved at Time 2 but declined at Time 3. Spiritual well-being declined at Time 2, then improved at Time 3. Figure 3 plots the mean QoL subscale scores over time.

*Research Question # 2 examined the effects of the BCEI psychoeducational support intervention on QoL outcomes among women with breast cancer aged 65 and older in the first year of post-treatment survivorship.*

At baseline, there were no significant differences in the mean scores for overall QoL between the EX and WC Group. In addition, there were no significant differences for overall QoL at any time point between the two groups. Table 7 shows the mean overall QoL scores for each group over time and the results of independent sample t-tests for overall QoL. Figure 4 plots the changes in the mean overall QoL scores for each group over time.

At baseline, there were no significant differences in the mean scores for the four QoL subscales (i.e., Physical, Psychological, Social, and Spiritual well-being) between the EX Group and the WC Group. In addition, there were also no significant differences for any of the QoL subscales at any time point between the two groups. Table 7 shows the mean QoL subscale scores for each group. Figure 5 plots the mean changes in the four QoL subscales for both groups at each of the three time points.

GEE analysis indicates that there was no treatment effect or intervention effect over time between these groups of older women for overall QoL or for Physical, Psychological, Social, or Spiritual well-being. Absolute Robust Z Scores ranged from -0.591 to 1.749 indicating no significant difference in intervention effects between the two groups. See Table 8 for a summary.

### *Within Group Differences: Overall QoL and QoL Domains*

Within group differences were noted for both the EX and WC Groups. Within the EX Group, significant changes were noted from baseline to Time 2 for Physical well-being, indicating a worsening of physical well-being,  $t(22) = -2.962, p = .007$ . From Time 2 to Time 3, Physical well-being scores remained stable. In addition, the following changes occurred but were not statistically significant: 1) Overall QoL declined slightly, but steadily from baseline to Time 3; 2) Psychological well-being gradually worsened from baseline to Time 3; 3) Social well-being improved at Time 2, then declined slightly at Time 3; 4) Spiritual well-being declined from baseline to Time 2 and slightly improved to above baseline scores at Time 3.

Within the WC group, overall QoL steadily declined from baseline to Time 3. Physical, Psychological, and Social well-being also declined from baseline to Time 3. Spiritual well-being worsened from baseline to Time 2, then improved from Time 2 to Time 3. None of these changes were statistically significant. Figures 4 and 5 also plot the mean overall QoL and QoL subscale changes, respectively, for each group.

## Discussion

### *Quality of Life in Older Women with Breast Cancer*

When examining the entire sample, mean scores for overall QoL and the four QoL domains reported by older breast cancer survivors within the first year post-treatment indicate that older women reported generally good baseline overall QoL and QoL within the domains of Physical, Psychological, Social, and Spiritual well-being. However, they reported that QoL changes occur over time. Overall QoL slightly declined over a period of six months. In addition, Physical and Psychological well-being declined over time. Social well-being initially

improved and then returned to baseline. Spiritual well-being initially worsened before returning to baseline.

Declines in Physical and Psychological well-being may possibly be related to non-cancer related experiences and events. The initial improvement in Social well-being may be related to participation in the psychoeducational support intervention study where the subjects received individualized attention. Likewise, the subsequent decline in Social well-being may have been related to fewer contacts with subjects at the end of the study. The initial decline in Spiritual well-being which was followed by improvement of Spiritual well-being may be related to the QoL-BC survey.

#### *Effects of the BCEI on Older Women with Breast Cancer*

At baseline, mean scores for overall QoL were comparable for the EX and WC Groups. Over time, both groups reported a decline in overall QoL over time. The sample size in this study was small; therefore, statistically significant differences between groups could not be established. Data from the WC Group suggest that QoL in older women with breast cancer may naturally decline in the first year of post-treatment survivorship. Data from the EX Group also suggest that QoL in older women declines after treatment. However, this decline was noted to be less pronounced in the EX Group compared to the WC Group. It is possible that the potential effect of the intervention in older women with early stage breast cancer was to lessen the decline in overall QoL.<sup>53</sup> The possibility that an intervention may lessen the decline of QoL in older breast cancer survivors after treatment is a new and important finding.

Within the four QoL domains, there were no significant differences between the groups at any time point. However, some differences are worth noting. Within the Physical domain, while



well-being declined for both groups during the six months of the study, QoL initially declined more sharply for the EX Group compared to the WC Group. This decline may possibly be linked to participation in the intervention, which may have alerted subjects to physical problems related to breast cancer that they previously attributed to some other cause. This new way of thinking about their symptoms may have prompted older women to report worsened physical symptoms related to their cancer at Time 2. Within the Psychological domain, well-being also declined for both groups with the decline more notable in the WC Group. Subjects within the EX Group may have been experiencing a psychological benefit directly related to their participation in the intervention. Within the Social domain, well-being appeared to improve for the EX Group at Time 2, perhaps indicating that the EX Group received immediate benefits from the personalized attention they received during the delivery of the intervention. This response differs from the WC Group, which reported a steady decline in Social well-being over time. Within the Spiritual domain, both the EX Group and WC Group reported initial decline in Spiritual well-being; however, this decline was more pronounced in the WC Group.

Overall, this study demonstrated that older women reported positive baseline overall QoL within the first year of post-treatment survivorship, but overall QoL declined slightly over time. Physical and Psychological well-being also declined over time. Social well-being initially improved, but, again, declined over time. Spiritual well-being initially worsened, but improved six months later. When examining the effects of a psychoeducational support intervention, both groups experienced a downward trend in overall QoL during the study period, with QoL in the EX Group showing a smaller decline compared with the WC Group. The intervention appears to have lessened the decline in overall QoL for the EX Group compared to the WC Group. At this

time, the small sample size makes definitive statements concerning QoL in older breast cancer survivors difficult to assert and future research is needed.

### Strengths

Several study strengths are identified. First, findings from this secondary analysis represent an important contribution to the literature and for future research since few studies specifically focus on older women with breast cancer. While study results did not detect a significant intervention effect between the EX and WC Groups, there was an interesting attenuation in the decline of overall QoL reported by the EX Group. The majority of cancer-related QoL studies aim to improve QoL. At baseline, both groups reported good overall QoL. However, over time, QoL declined more notably in the WC group. Thus, an important conceptual contribution exists—researchers must consider the attenuation of decline in QoL rather than striving for significant improvement in QoL. This study sets the stage for future research to use larger samples and observe subjects over longer periods of time in order to examine possible statistically significant differences and intervention effects in older breast cancer survivors.

Second, study results can serve as a pilot for development of future interventions for older breast cancer survivors. Knowledge gained from this study may help guide researchers in future development of age appropriate and tailored interventions that may help women maintain, improve or lessen decline in QoL. In addition, this study provided data that can be used to determine power in future intervention studies with older breast cancer survivors.

### Limitations

Several weaknesses are also noted. Limitations exist within the QoL-BC measurement tool. While the QoL-BC has been applied to other groups of women with breast cancer of varying ages, the components of each domain may not adequately represent concerns of older breast cancer survivors during post-treatment survivorship. While the QoL-BC tool had acceptable alpha levels in this sample, they were comparatively lower than in the parent BCEI study. The alpha co-efficient for the Physical subscale was considerably lower than those reported in other studies. Domains, such as physical functioning reported in other studies,<sup>34, 36, 37</sup> are not represented in the QoL-BC tool and could not be directly measured for this sample. Finally, concerns for fertility and menstrual changes reported in younger women<sup>18</sup> did not apply.

Another limitation found with QoL-BC tool is that some items were non-directional. For example, questions such as “How much has your spiritual life changed as a result of your diagnosis?” and “Has your illness or treatment caused changes in your self concept (the way you see yourself)?” are non-directional and were problematic for interpretation.<sup>54</sup> Rewording these items in future studies of older breast cancer survivors may make responses easier to interpret. While the QoL-BC survey has provided valuable information concerning older women with breast cancer, it requires further use in older samples to determine reliability. In addition, the potential to develop instruments specific to older breast cancer survivors is needed.

### Implications for Research and Practice

There are few studies that specifically focus on older breast cancer survivors. Several areas of research are warranted for the future. First, future studies could focus on determining the extent of symptoms and their degree of distress in older breast cancer survivors. Second, future

research studies could focus on specific concerns within each QoL domain that may further have an impact on QoL among older breast cancer survivors. Third, future research may be developed to better understand the experiences that may contribute to decline in QoL for older women during their first year of post-treatment survivorship. Fourth, larger sample sizes and observing subjects over longer periods of time may provide a more accurate account of the natural history of QoL after treatment in older breast cancer survivors. Fifth, outcomes of such studies may lead to the development of interventions specifically tailored to the needs of the older women surviving with breast cancer. Finally, future research may strive to maintain QoL at higher levels than would naturally occur in older breast cancer survivors in the first year after treatment.

In practice, nurses can use findings to further examine whether gradual declines occur over time among their own patients. Nurses may also consider the education and support they provide for their patients. Older breast cancer survivors may have differential educational and support needs after treatment. Nurses may consider tailoring their teaching to the needs and styles of older breast cancer survivors rather than providing generic information to all patients.

### Conclusions

The findings of this study add to the body of knowledge concerning older breast cancer survivors in the first year of post-treatment survivorship. It is one of the first reported studies of post-treatment interventions that included older breast cancer survivors. A vital finding showed that the BCEI Intervention attenuated the decline of QoL in the EX Group compared with the WC Group. The findings of this study can serve as the basis for future intervention studies targeting the needs of older women.

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## **CHAPTER 4: NURSES PERCEPTIONS OF THEIR INTERACTIONS WITH OLDER WOMEN WITH EARLY STAGE BREAST CANCER WITHIN THE FIRST YEAR OF POST-TREATMENT SURVIVORSHIP**

### Introduction

*She again expressed concern about her problem not being from breast cancer, but from other situations in her life.* - Excerpt from field note

This statement and statements like it were recorded in field notes written by research nurses involved in a large randomized clinical trial which examined the effectiveness of a psychoeducational support intervention on quality of life (QoL) in women with early stage breast cancer. Such statements are the written accounts of the nurse's, or participant observer's, thoughts and perceptions at the moment of the interaction with the subject. The aim of this study was to describe the perceptions of research nurses during interactions with women, age 65 and older with early stage breast cancer. This study relies on the use of qualitative methods including participant observation in and content analysis of the field notes recorded during the psychoeducational support intervention. The purpose of this paper is to: 1) describe nurses' perception of their interactions with older breast cancer survivors in the first year post-treatment and 2) discuss research and nursing implications based on the knowledge gained from analysis.

### Background

Older women are at increased risk of developing breast cancer.<sup>1</sup> For the purposes of this study and discussion, older women will be defined as age 65 and older. Fifty percent of women diagnosed with breast cancer are 61 years old or older<sup>2</sup>. The majority of these diagnoses will

occur prior to metastasis, ensuring survival rates near 88%.<sup>2</sup> The overall number of women with breast cancer is expected to increase as the Baby Boomer generation ages, making older women a particularly important population of study.

Frequently, research focuses on post-treatment adverse effects, which impact QoL.<sup>3-5</sup> Little attention is given to stressors or experiences that are unrelated to breast cancer, but may impact QoL in older women with breast cancer.<sup>6-8</sup>

## Methods

### Design

The present study is a qualitative, secondary analysis using data from the Breast Cancer Education Intervention (BCEI) trial. The BCEI was a longitudinal clinical trial that examined the effect of the BCEI psychoeducational support intervention for women with early stage breast cancer ( $N= 256$ ), the details of which are described elsewhere.<sup>9-11</sup> All participants had early stage breast cancer, completed treatment at least one month prior to enrolling into the BCEI, and were within the first year of post-treatment survivorship.

In the BCEI, the Experimental group ( $n=129$ ) received the intervention, which included three face-to-face educational and support sessions and three follow-up telephone education and support sessions during a six-month period. Sessions took place in the participant's home, workplace, doctor's office, or another site selected by the participant.<sup>9-11</sup>

Throughout the BCEI trial and specifically during the intervention, research nurses recorded field notes. These notes provided a record of the research nurses' encounters, as participant observers, in the intervention. Research nurses also recorded details of the participant's diagnosis, prior treatment, current treatment and side effects at the time of the initial

interview. For subjects in the Experimental Group, nurses recorded participant-identified problems discussed during the education and support sessions. Notations were also made if the participant brought up other topics during these encounters. These field notes became the object of interest for this research study and had not been previously analyzed.

The goal of the field note analysis was to describe the research nurse's perception of their observations of older women with breast cancer within the context of their participation in the BCEI. Field notes have been widely used in qualitative research.<sup>12-14</sup> However, many studies have used field notes to supplement data obtained in structured or semi-structured interviews.<sup>12, 14</sup> Only one study analyzed the notes as primary source of data.<sup>13</sup> For the purpose of this study, content analysis was used to analyze the field notes.

### Sample

The sample for this study consists of the 24 women, age 65 and older who were in the Experimental Group of the BCEI. Field notes related to interactions with participants in the Wait Control ( $n=26$ ) Group were excluded because the interaction and discussion between the nurses and participants was purposefully limited and brief in order to avoid contamination between the two groups.

### Procedure

This secondary analysis consisted of several steps. First, this investigator obtained written permission from the principal investigator of the BCEI Research Study (See Appendix D). Second, Institutional Review Board approval was obtained from the University of Central Florida's Office of Research and Commercialization for the current study (See Appendix E). Third, this investigator received 50 de-identified Microsoft Word™ files for participants age 65

and older. Each Microsoft Word™ file ranged from one to three pages in length. Each file contained data collected during the BCEI at each point of contact between the research nurse and the participant. These points of contact began with baseline data collection and ended approximately six months later when participants were no longer involved in the BCEI. Fourth, these documents were loaded into Ethnograph (Ethnograph v5.08, Qualis Research), a software package that assists with the coding and sorting of data.

### Analysis

Content analysis of the field notes was based on a systematic process<sup>15</sup>. First, all data were read thoroughly prior to coding to gain an overview of the quality and content of the field notes. Second, data were re-read; codes were generated using language closely reflecting the language used by the nurses in the field notes. For example, if the research nurse observed that the patient experienced a particular side effect or was concerned with an ill family member, codes specifically reflected this. Third, these codes were defined and grouped according to similarities. For example, several participants were worried about the health of family members; hence, the overall code was called “Family illnesses.” Fourth, like codes were examined and similar codes were combined, resulting in the final coding scheme.

The following process supported evidence for confirmability. First, the investigator asked a colleague to review five randomly selected field notes. The colleague has been a professional nurse for more than twenty years. She is also a doctoral student with experience in qualitative methods. Her research focuses on women with chronic illness and she has no oncology experience. Second, the investigator explained that the aim of the study was to describe the nurses’ perception of their interaction with older breast cancer survivors in the first

year post-treatment. Third, the doctoral student reviewed the field notes. She identified themes from the interactions and highlighted the themes. Fourth, the investigator and doctoral student compared their individual themes from the interactions. Fifth, they discussed and agreed the codes were appropriate. For example, one participant had a daughter with breast cancer. The investigator coded the theme as “daughter with breast cancer” and the doctoral student coded the theme as “daughter illness.” These codes were thought to be consistent. Finally, the investigator presented the final codes to her doctoral committee chair.

## Results

### Characteristics of the Sample

Research nurses recorded field notes on events that occurred in a sample of 24 women. The average age of participants was 72 (range from 65 to 80). Most subjects were Caucasian (79.2%), spoke English (87.5%), and had at least a high school/trade school education (66.7%). Over half of the participants were married (54%), and 50% lived with at least one other person in the household. Most women (75%) were not employed. Half of the participants ( $n=12$ ) reported an income of \$30,000 or below. Disease-specific variables indicated that 70.8% had Stage I breast cancer. Most received a lumpectomy (70.8%) and radiation therapy (83.3%) and did not receive chemotherapy (79.2%). The majority (79.2%) were on hormonal therapy at the start of the study. Table 9 provides a complete summary.

### Body of the Findings

Data were summarized according to four main themes. These themes were: 1) continuing breast health; 2) personal health issues; 3) family illnesses; and 4) potential stressors. In the

following section, quotes from the field notes that denote the nurse's perception will be *italicized*, and "double quotation marks" will be used. Instances where the field notes indicated that the participant stated a particular word or phrase will also be *italicized*, and 'singular quotation marks' will be used.

### *Continuing breast-related health*

The field notes featured concerns with continuing breast-related health, which described the participants' experiences with new or ongoing concern related to their breast(s). The field notes conveyed the participants' apprehension regarding mammography, breast symptoms, breast biopsy or surgery, future tests, waiting for test results, refusing more treatment, and breast reconstruction. During the study period, seven women underwent mammography. In most cases, the mammography showed no further evidence of disease. Nine participants experienced new breast symptoms such as a lump, hematoma, rash, open area or sore, and/or itching. Symptoms resolved spontaneously in all but two participants, who dealt with ongoing issues related to their breast. Participants' reactions to continuing breast-related health varied. For example, one woman's oncologist discovered a breast lump. When speaking about her oncologist's recommendation to remove the lump, the woman described her reaction as '*snags along the way are to be expected.*' The field note revealed the nurse's perception that "*She has a very positive attitude and states she deals with life as it comes to her.*" Another woman required a biopsy when a shadow was detected by mammogram. The research nurse observed that the participant acknowledged experiencing a week of "*emotional ups and downs and felt better when the results were negative.*"



Still another entry describes the anxiety that one woman experienced as she waited for her first follow-up mammogram and her extreme concern about going through treatment again. After her interaction with the patient, the nurse noted that “*the participant seems to think about it [recurrence] all the time.*”

### *Personal health issues*

The field notes also captured concerns with personal health issues, or the participants’ experiences with health issues unrelated to their breast cancer such as co-morbid illnesses, non-cancer related illnesses, and falls. Three women discussed managing co-morbid illnesses such as diabetes mellitus, irritable bowel syndrome, diabetic neuropathy, pain, and osteoporosis. The field notes convey that participants were able to manage these illnesses in their lives. For example, one woman had chronic hip, back and knee pain and used a walker to get around. Despite these chronic conditions and other cancer-related conditions, such as lymphedema, which developed during the study period, the research nurse repeatedly recorded her perception that the participant was able to remain “*optimistic*” and “*have a positive attitude.*” Despite both the chronic and new conditions that the participant encountered, she described herself as ‘*in good spirits*’ and ‘*holding her own*’. The field note further reveals the research nurse’s perception that this participant “*feels her QoL is excellent and nothing stops her.*”

The field notes also describe nine participants with transient illnesses such as the common cold, high blood sugar, bronchitis, urinary tract infections, and headaches during the study period. However, two women experienced potentially serious illnesses. The research nurses observed that some women lived with serious health symptoms for several weeks before addressing the symptoms. For example, one participant ignored chest pain for more than a

month because she was caring for her ill daughter. The field note revealed the research nurse's perception that "*she has few concerns about herself, only for her daughter.*" In a later entry, the nurse added her perception that the participant knows "*she has been so focused on her daughter that she has not been centered on herself.*"

### *Family health issues*

The research nurses' field notes also captured family health issues, which described the participants' experiences with ill family members or recently deceased spouses. During the study period, eight women had either an ill spouse or adult child and three women reported being a caregiver for ill family members. The field notes convey participants' concern over the health of their family members and how it related to their own QoL. Participants also expressed concern that their anxiety over the health of their loved ones was reflected in the QoL surveys that they were asked to complete during the study. For example, one participant whose daughter was diagnosed with breast cancer expressed anxiety over her daughter's diagnosis. The research nurse observed that the patient believed her "*anxiety related to daughter's diagnosis may be reflected in answers [on quantitative surveys].*" Another participant had a daughter who was diagnosed with advanced lung cancer. Throughout the study, the research nurse observed that this participant continually put aside her own health to care for her daughter. In a field note entry, the research nurse observed that "*Her daughter continues to do poorly, which is the main cause of this patient's anxiety and low QoL scores.*"

Two participants discussed how the death or illness of their spouse affected their current QoL. One entry describes a woman's concern for her ill husband of 35 years. During one of their interactions, the research nurse observed that the husband has debilitating chronic illnesses

and “*most of patient concerns deal with these issues.*” In a note for a participant whose husband recently died, the research nurse stated “*she [the participant] does not feel she has problems that can be only attributed to her breast cancer.*”

Finally, another entry in the field notes describes how a spouse’s illness left one woman unaffected by her diagnosis of breast cancer. During their interaction, the nurse observed that “*When she was diagnosed with breast cancer- it did not have a great impact because she had experience with [her husbands] illness.*”

#### *Potential stressors*

The last theme captured in the field notes was potential stressors. The field notes conveyed the participants experience and frustration with family issues, housing issues, stressful living situations, a change in physician, car issues, car crashes, holidays, “*little things*” and hurricanes. During the study period, potential stressors were mostly observed by the research nurses to be short-lived: however, two women dealt with ongoing stressors. For example, one participant had continuing issues with a tenant who lived in her home. The nurse observed that the participant did “*Not think [the side effects were] cancer related as much as related to the stress of having the border. She thinks it will resolve now that he is gone.*”

Another field note describes the ongoing family issues of a participant living with two grandchildren and four great-grandchildren in a small house without air conditioning in Florida. The research nurse observed that this participant repeatedly discussed how bothersome the great-grandchildren were and how her grandchildren ‘*irritated*’ her. One entry in the field note describes the research nurse’s perception of how the participant felt “*hopeless in her life,*” but also noted that the participant states that she was ‘*like that even before her diagnosis.*’ The field

notes describe the research nurse's perception of how this participant was being pressured by her family to move closer to them, which would ultimately take the participant father away from her husband who was in a nursing home. Throughout interactions with this participant, the research nurse observed that this woman seemed "*worn down*" and "*overwhelmed*" by life at times.

In addition to the previously mentioned experiences, uncontrollable circumstances were also observed by the research nurses. During the summer and fall of 2004 when these field notes were recorded, Florida experienced four major hurricanes. The field notes describe the research nurse's perception of the frustration of three participants who experienced power outages, phone outages, and damage to their homes. In one field note, the research nurse observed how one participant "*found the experience overwhelming*" and was "*saddened by the experience.*" In another field note, the research nurse observed that a participant who was without power for a week found the experience '*unsettling.*'

### Discussion

Content analysis of these field notes captured research nurses perceptions' of the experiences of women, age 65 and older, with early stage breast cancer within the first year post-treatment. These perceptions would not have been captured using standardized measures. Although the field notes were not originally intended for analysis, the thoughtful perceptions of the participants' comments and behaviors discovered in the data were rich. In summary, these data were categorized according to four major themes: continuing breast-related health, personal health issues, family health issues and potential stressors.

Research nurses noted that continuing breast-related health was a stressful experience for women with breast cancer. They documented a variety of participant responses to continuing

breast-related health, ranging from little concern over new breast symptoms to a great deal of fear. Concern over breast symptoms and recurrence have been reported in the literature in women of all ages with breast cancer.<sup>16</sup>

Research nurses also documented that personal health issues not related to breast cancer, such as co-morbid or chronic conditions, were experienced by this sample. Eighty percent of Americans over the age of 65 have at least one chronic illness,<sup>17</sup> so it is surprising that co-morbid conditions were noted in only three participants. Everyday illnesses and serious health symptoms also occurred in the sample. These findings indicate that older women may have other health concerns besides cancer.

Research nurses observed that family health issues were also a concern for this sample. Understandably, these women were very concerned when a loved one became ill and discussed the anxiety family illness caused. The field notes also report that several women were caregivers. Caregiving itself is stressful,<sup>18, 19</sup> which may lead to some of the anxiety women felt when caring for a loved one.

In addition to capturing patients' concern for the health of loved ones, field notes also noted participants' concern that the stress or anxiety caused by their loved one's illness would be reflected in the quantitative surveys that measured their QoL. These concerns indicate that some subjects seemed to feel that the study was only measuring cancer-related QoL instead of general QoL. This uncertainty concerning what the QoL instruments were measuring raises questions about the validity of QoL measurements in older cancer survivors.

When considering family health, nurses also observed that some older women felt that their QoL issues were related to experiences other than breast cancer. This finding has not been reported in preceding literature. This observation suggests that breast cancer may not be the

biggest or most devastating event these women experience. Nurses observed that the experience of having breast cancer may be overshadowed by other events such as death or illness of a spouse or family member.

Finally, nurses observed that the women in this study experienced a number of potential stressors in their lives. While some of these stressors might be considered minor, significant consequences could result. For example, several women experienced car troubles, which could potentially lead to isolation, loss of social support or missing important follow-up appointments. Other women faced stressors within their own homes and with people living with them. In these instances, women allowed people to live with them, which caused them stress. This suggests that some older woman may place themselves in situations where some company or companionship is better than isolation.

Some of the experiences found in this study have also been noted in the literature. Life experiences and life stress have been examined in relation to their impact on QoL outcomes and survival. While the mean age of participants in these studies was below 65 years, older women did participate. These studies have noted life stressors in women with breast cancer and include: personal or family illness<sup>8</sup>, death of a loved one<sup>6, 8, 20</sup>, financial stressors<sup>6, 8, 20, 21</sup>, ended relationships<sup>6</sup>, conflicts with family<sup>6</sup>, children leaving home, alcoholic family members, moving<sup>22</sup>, and accidents, robberies, and like events<sup>6</sup>.

Studies that have examined life stress have looked at the effect of stressors prior to treatment and their impact on QoL outcomes. Baider and colleagues<sup>21</sup> compared women with breast cancer in different cultural settings, one to five years after diagnosis. They found that the number of stressful life experiences before diagnosis predicted psychological distress after treatment.<sup>21</sup>

Another study by Low and colleagues<sup>8</sup> examined life stress, coping strategies, and adjustment in the year after treatment for breast cancer. This study was longitudinal and followed 558 women over a twelve-month period. The average age of participants was 58.1 years. On average, women reported 1.34 stressful experiences in the year prior to treatment. Results showed that women with more life stressors experienced more depression, less vitality, and more cancer-related distress at baseline however, life stress did not affect psychological adjustment over time.

Golden-Kreutz and Anderson<sup>6</sup> examined the effect of stress on depressive symptoms after breast cancer. This was a prospective, longitudinal study of women ( $N=210$ ) with stage II and III breast cancer. The average age of the participant was 51 years. The majority of subjects experienced at least one major life event in the twelve months prior to diagnosis. Results showed that depression after treatment is due to perceptions of global distress, cancer-related distress, and stressful life events such as financial problems.

In a secondary analysis of the previously mentioned study, Golden-Kreutz and colleagues<sup>7</sup> examined stress at diagnosis in relation to its impact on QoL. Women ( $N=112$ ) were assessed at baseline, four and twelve months after diagnosis. Most subjects experienced at least one life event in the year prior to diagnosis. Results of this study show that life events, cancer-related stress, and perceived global stress all contribute to declines in physical and psychological QoL. Life stress was a predictor of QoL at 12 months. According to the authors, these findings suggest that a diagnosis of cancer may have overshadowed the experience of stressful life events, delaying their impact on outcomes.

Finally, one study examined the relationship between stressful life events and survival in women with breast cancer. Maunsell and colleagues<sup>22</sup> examined how stressful life events that

occurred in the five years prior to a diagnosis of breast cancer impacted survival. The Cox Proportional Hazards model was used for analysis. Participants reported 3.7 stressful experiences in the five years before diagnosis. The subjects ( $N=665$ ) were followed for a seven-year period. Ultimately, stress from life events did not affect survival in women with local or regional breast cancer.

In summary, breast cancer does not occur in isolation but takes place in women's lives at the same time women experience other events and concerns. In this study, nurses observed that older women with breast cancer had concerns after their illness, including continuing breast-related health issues, personal health issues, family illnesses, and potential stressors. Prior studies examined the impact of life stressors and experiences that occur before the diagnosis of breast cancer and how they affect QoL after treatment. These studies have shown that these stressors may negatively impact QoL after treatment. The findings from this study mirror many of the findings reported in the literature concerning patient experiences and stressors. The use of field notes to explore nurses' perceptions adds to the evidence that older women may experience events or concerns in their lives after breast cancer that may be related to QoL outcomes.

### Limitations

This study has a number of limitations. First, field notes were written by research nurses who were participant observers during a psychoeducational support intervention clinical trial. However, at the time of the writing of the field notes, research nurses did not know that their notes would eventually be used in an analysis. Therefore, research nurses were documenting their perceptions of their interactions with participants, but they were only documenting what they felt was important or notable at the time. This led to differences in the quality of and detail



within the field notes. Despite this limitation, the field notes revealed evidence that older women experience concerns other than breast cancer after treatment.

Second, researcher bias (influence that may produce a distortion of the results<sup>23</sup>) may be a factor in analysis. This investigator was involved in the BCEI as a participant observer who recorded the field notes. During analysis, the researcher recalled encounters with these women. For this reason, the researcher avoided reinterpreting the perceptions of other research nurses' as recorded in the field notes, and, instead, conducted the analysis based on the words written in the notes. This required frequent referral back to the field notes to make sure the results represented the research nurses' impressions at the time of the encounter, not the memories of the researcher. This form of analysis was essential in order to reduce or prevent misinterpretation of the data based on memory.

### Implications for Research and Practice

There are several implications for research and practice. First, researchers may consider delving further into the concerns of older women with breast cancer after treatment to achieve a holistic view of QoL in this population. While this is a study with women with breast cancer, three of the four themes identified in the field notes were non-cancer related. This fact demonstrates the complex nature of the lives of older women after treatment for breast cancer. It is likely that all women who experience cancer continue to experience other events and concerns in life that are independent of having cancer. Investigating age-related differences in women's lives during and after treatment for cancer may foster the development of specific interventions to manage to reduce stress in this population.

Second, the measurement of QoL in older women deserves further investigation. Nurse observations in this study demonstrated that older women were concerned about stress and anxiety unrelated to breast cancer, affecting their answers in QoL surveys. Some women in this study seemed to try to separate their breast cancer from the rest of their lives and were concerned that stresses from life events were influencing their responses about QoL and breast cancer. This raises questions regarding the understanding of older women regarding what standardized measurement tools are trying to capture and how they formulate their answers to the questions asked in surveys. Understanding the cognitive process of how older women formulate answers to standardized surveys may improve the reliability and validity of measures.

Clinically, it is important for all nurses to recognize the complexity of older women's lives when a diagnosis of breast cancer is received. For oncology nurses, it is particularly important to realize that older women often have other age-related concerns, during and after their breast cancer treatment. Clinically, the awareness that older women may experience issues and concerns related to continuing breast-related health, personal health issues, family illness and other potential stressors after treatment may help identify and manage concerns. In addition, response to these concerns may be individualized. A holistic assessment consistent with geriatric and health-related concerns is advisable. Awareness of these types of concerns after treatment for cancer also provides an opportunity for nurses, regardless of their specialty practice to collaborate in the care of older women to manage cancer and non-cancer related concerns after treatment that may affect QoL.

## Conclusions

In summary, this study described the research nurses' perceptions of their interactions with older women with breast cancer in the first year of post-treatment survivorship. Content analysis was used to analyze field notes. Using field notes yielded rich findings concerning the lives of older women with breast cancer after treatment. Data suggest that older women have concerns due to continuing breast-related health, personal health issues, family health issues and other potential stressors, all of which may affect QoL. Research implications indicate differential measurement of QoL in older women. Clinical implications suggest that an assessment of older women's concerns is warranted.

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## CHAPTER 5: CONCLUSION

This dissertation draws several conclusions regarding QoL in women, age 65 and older, who have completed treatment for breast cancer. First, the State of the Science demonstrates that fourteen studies focused on women, age 65 and older, after treatment for early stage breast cancer. Together, these studies provide the basis of knowledge concerning this population. Current literature suggests that older women with early stage breast cancer: 1) report better QoL outcomes when they receive conservative treatments; 2) want to be involved in treatment decisions; 3) experience more symptoms and declines in physical functioning, compared to younger women; however, they experience similar symptoms and physical functioning compared to women of a similar age with other chronic illnesses; 4) have fewer psychosocial concerns compared to younger women; and 5) use faith to cope and find meaning in their illness.

Second, results from the data-based quantitative study, which examined QoL in older women with early stage breast cancer in the first year of post-treatment survivorship, demonstrated that baseline overall QoL and QoL within the four domains is good. However, over time, overall QoL gradually declined. In addition, Physical and Psychological well-being declined. Social well-being initially improved before returning to baseline. Spiritual well-being initially declined before returning to baseline.

In this study, there was insufficient power to detect a difference in the effects of the BCEI Intervention between the two groups. Overall QoL declined in both groups. However, the intervention attenuated the decline in QoL for the EX Group.

Third, results from the data-based qualitative analysis of field notes, which examined nurses' perceptions of their interactions with women who participated in a psychoeducational

intervention for women with early stage breast cancer (BCEI), demonstrated that older breast cancer survivors have concerns both related and unrelated to breast cancer after treatment.

Nurses' perceptions were organized into four themes: continuing breast-related health, personal health issues, family health issues and potential stressors. These concerns may affect overall QoL.

These findings offer several implications for research. First, researchers may expand on the current knowledge base regarding QoL in older women after treatment. Areas in need of further research that have been identified by this dissertation include: the symptoms experienced by older women after treatment; the extent of the symptom experience; the impact of co-morbid illnesses on survivorship; and the impact of non-cancer related experiences of older women after treatment. All of these factors may impact QoL after treatment and merit further study.

Second, while there was insufficient power to detect an intervention effect, the decline in QoL was less in the EX Group. Future research may focus on other factors that could influence QoL in older breast cancer survivors. In addition, there is considerable need for research, which may develop interventions tailored to the specific needs of older breast cancer survivors. This dissertation serves as a pilot study and can provide data needed to determine power analysis for future intervention studies for older breast cancer survivors.

Third, the most appropriate way to measure QoL in older breast cancer survivors has yet to be determined. At this time, it is unclear which measurement tools and what dimensions of QoL are most appropriate for use in this older population. In addition, this dissertation has raised questions concerning what is actually being measured in standardized surveys and how older women formulate their answers to survey questions. The potential to develop instruments specific to older breast cancer survivors is vast.



Finally, this dissertation supports the reconceptualization of QoL in older women with breast cancer. Quality of life in older women after treatment for early stage breast cancer is influenced by many factors. These include Physical, Psychological, Social, and Spiritual well-being as well as factors unrelated to breast cancer such as aging and other experiences after treatment. Future research may consider the conceptualization of QoL after treatment as holistic rather than limited to adverse effects directly related to cancer.

## **APPENDIX A: TABLES**

**Table 1: Summary of studies focusing on women age 65 and older only with early stage breast cancer**

Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
De Haes et al. (2003)	Compare effect of treatment on QoL in older women	<p><b>Population:</b> N=136 Age 70 or older, within 1 year of treatment</p> <p><b>Design:</b> Randomized clinical trial</p>	<p><b>Instruments:</b> Unspecified QoL survey covering 9 domains</p> <p><b>Analysis:</b> Wilcoxon Sign Rank test</p>	<ul style="list-style-type: none"> <li>• Women with mastectomy had more arm problems.</li> <li>• Women who received conservative surgery had better QoL</li> </ul>
Madelblatt et al. (2003)	Evaluate long-term impact of primary treatment on QoL and satisfaction	<p><b>Population:</b> N=1812, Age 67 and older, 3 to 5 years post treatment,</p> <p><b>Design:</b> -Randomized cross-sectional design</p>	<p><b>Instruments:</b> SF 12, SF 36</p> <p><b>Analysis:</b> Chi square distribution, t test, logistic regression</p>	<ul style="list-style-type: none"> <li>• Having co-morbid illness affected physical outcomes</li> <li>• AD led to more arm problems which negatively impacted all other outcomes</li> <li>• Women not given choice regarding treatment had more pain, poor mental health and less satisfaction</li> </ul>

Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
Mandelblatt et al. (2002)	Examine the impact of axillary dissection on QoL	<p><b>Population:</b> N=571, Age 67 and older</p> <p><b>Design:</b> Longitudinal</p>	<p><b>Instruments:</b> SF 12, CARES-SF</p> <p><b>Analysis:</b> ANOVA, chi square distribution, GEE</p>	<ul style="list-style-type: none"> <li>• 83% with AD reported arm problems</li> <li>• Women with AD and arm problems report lower physical and mental functioning</li> <li>• Cancer had more of an impact on life if arm problems were reported</li> </ul>
Figueiredo et al. (2004)	Examine the effects of treatment preferences and treatment received on mental health and body image	<p><b>Population:</b> N=563, Age 67 and older, within 2 years of surgery</p> <p><b>Design:</b> Longitudinal clinical trial</p>	<p><b>Instruments:</b> SF 36, CARES –SF,</p> <p><b>Analysis:</b> Chi square distribution, t test, ANOVA, Pearson and Spearman rank correlation, path analysis, GEE</p>	<ul style="list-style-type: none"> <li>• Physical appearance important to older women when making treatment decisions</li> <li>• Women with mastectomy reported body image concerns and worse mental health compared to women who received conservative treatment</li> </ul>

<b>Author and date</b>	<b>Purpose</b>	<b>Study Population and Design</b>	<b>Instruments and Analysis</b>	<b>Major Findings</b>
Feher and Maly (1999)	Examine spiritual and religious coping mechanisms among older women with breast cancer	<b>Population:</b> N=33, new diagnoses <b>Design:</b> Qualitative,	<b>Instruments:</b> Structured interviews, open ended questions <b>Analysis:</b> Content analysis	<ul style="list-style-type: none"> <li>• Faith assisted with coping</li> <li>• Faith provided emotional support</li> <li>• Faith allowed a social connection</li> <li>• Faith allowed women to make meaning in their lives</li> </ul>
Utley (1999)	Discover the meaning of cancer older, long-term breast cancer survivors	<b>Population:</b> N=8, Age 65 to 77, 5 to 29 years post diagnosis <b>Design:</b> Qualitative	<b>Instruments:</b> Life history interviews <b>Analysis:</b> Qualitative analysis using heuristic approach	<ul style="list-style-type: none"> <li>• Meaning of cancer evolved over time</li> <li>• Women experienced a positive effect from cancer</li> </ul>
Crooks (2001)	Discover new understandings of having breast cancer for older women	<b>Population:</b> N=20 Ages 66-94, <b>Design:</b> Qualitative	<b>Instruments:</b> Interviews <b>Analysis:</b> grounded theory	<ul style="list-style-type: none"> <li>• Process of finding meaning allowed women to live each day to the fullest</li> </ul>

**Table 2: Summary of studies focusing on women with early stage breast cancer and age based controls without breast cancer**

Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
Heidrich et al. (2006)	Examine symptoms, symptom belief, and QoL of older women with and without breast cancer	<p><b>Population:</b> N=42, Age 65 and older, Women with and without breast cancer</p> <p><b>Design:</b> Descriptive, correlational</p>	<p><b>Instruments:</b> Heidrich Symptom Bother Scale, SF-36, CES-D, OARS</p> <p><b>Analysis:</b> Wilcoxon Mann-Whitney U test and chi square distribution</p>	<ul style="list-style-type: none"> <li>• Similar symptoms experienced in both groups of women</li> <li>• Symptoms attributed to aging or other chronic illness, rarely to breast cancer</li> <li>• Not knowing cause of symptom led to poorer outcomes</li> </ul>
Satariano et al. (1989)	Compare instrumental functioning of women with breast cancer with age based controls	<p><b>Population:</b> N=900, 3 age groups: 55-64, 65-74, 75-84</p> <p><b>Design:</b> Case control, longitudinal</p>	<p><b>Instruments:</b> IADL</p> <p><b>Analysis:</b> Ridit analysis</p>	<ul style="list-style-type: none"> <li>• Women age 65 to 74 reported more problems with functioning than their age based controls</li> <li>• Women age 75 and older reported the fewest functional problems compared to their age based controls</li> </ul>

Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
Kroenke et al. (2004)	Explore functioning before and after cancer in women of different ages	<b>Population:</b> N=1,082, 3 age groups: 40 and younger, 41-64, 65+, women with and without breast cancer <b>Design:</b> Prospective, longitudinal	<b>Instruments:</b> SF-36, CARES  <b>Analysis:</b> Linear regression	<ul style="list-style-type: none"> <li>• Older women with breast cancer experienced similar declines in functioning when compared to their non-cancer peers</li> <li>• Functional declines attributed to aging, not breast cancer</li> <li>• Youngest women experienced the most significant functional declines compared to their non-cancer peers</li> </ul>
Heidrich (1996)	Examine influence of age and illness type on health and functioning, interpretive mechanisms and their effect on psychological well-being	<b>Population:</b> N=188, women with breast cancer and osteoarthritis, 2 age groups: 60-74 and 75+ <b>Design:</b> 2x2, cross-sectional	<b>Instruments:</b> OARS, Heidrich Symptom Bother Scale, social comparison scale, social network index, CES-D, Rosenberg's Self Esteem Scale, Ryff's scales  <b>Analysis:</b> MANCOVA, ANCOVA	<ul style="list-style-type: none"> <li>• Older women with arthritis report more symptom bother and problems with ADL's than women with breast cancer</li> <li>• Older women with arthritis report their illness as more severe and chronic than older women with breast cancer</li> </ul>

**Table 3: Summary of studies comparing older and younger women with early stage breast cancer**

Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
Fehlauer et al. (2005)	Examine functional status in women of different ages at diagnosis and effects of adjuvant therapy on HR-QoL,	<b>Population:</b> N=370, 3 age groups: younger, than 50, 50-65, 66+ <b>Design:</b> Retrospective	<b>Instruments:</b> EORTC QLQ-C30, EORTC QLQ-BR23 <b>Analysis:</b> ANOVA, post hoc Scheffe tests	<ul style="list-style-type: none"> <li>• Compared to younger women, older women reported worse physical functioning, more body pain, more arm symptoms, and less financial concern</li> <li>• QoL increased over time for older women despite concerns</li> </ul>
Cimprich et al. (2002)	Examine relationship between age and QoL outcomes in long term breast cancer survivors	<b>Population:</b> N=105, 3 age groups: 45 and younger, 46-65, 66+, long-term survivors <b>Design:</b> Cross-sectional	<b>Instruments:</b> QoL-CS <b>Analysis:</b> ANOVA, multiple regression	<p>Compared to younger women, older women reported:</p> <ul style="list-style-type: none"> <li>• more fatigue, pain, constipation, sleep symptoms</li> <li>• less distress at diagnosis , better outcomes related to appearance</li> <li>• fewer concerns with sexuality, employment, family distress</li> <li>• Fewer positive changes and more uncertainty</li> </ul>



Author and date	Purpose	Study Population and Design	Instruments and Analysis	Major Findings
Cimprich (1998)	Determine the effect of age and extent of surgery on cognitive function	<p><b>Population:</b> N=74, 3 age groups: 25-45, 46-64, 65-74</p> <p><b>Design:</b> Pre and post test</p>	<p><b>Instruments:</b> Measures of capacity to direct attention</p> <p><b>Analysis:</b> ANOVA, t tests, multiple linear regression</p>	<p>Compared to younger women, older women reported:</p> <ul style="list-style-type: none"> <li>• Lower attention scores at baseline</li> <li>• Experienced significant losses in attention performance and total attention scores</li> <li>• Older women who received mastectomy reported greater loss in attention than older women with breast cancer</li> </ul>

**Table 4: Demographic characteristics of the quantitative sample (N=50)**

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<b>Age</b>	Mean: 72.10	Range: 65-83
<b>Time since Diagnosis</b>	6 months or less	18 (36%)
	7 months or more	32 (64%)
<b>Race</b>	African American	3 (6%)
	Caucasian	41 (82%)
	Hispanic	4 (8%)
	Native American	2 (4%)
<b>Educational Level</b>	Grade School	2 (4%)
	High School	20 (40%)
	Trade School	6 (12%)
	College	20 (40%)
	Graduate School	2 (4%)
<b>Religious Preference</b>	Catholic	6 (12%)
	Christian	43 (86%)
	Jewish	1 (2%)
<b>Marital Status</b>	Married	28 (56%)
	Divorced	5 (10%)
	Widowed	17 (34%)
<b>Lives Alone</b>	Yes	17 (34%)
	No	33 (66%)
<b>Employment Status</b>	Full-Time	4 (8%)
	Part-Time	6 (12%)
	Retired/Homemaker	40 (80%)

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<b>Income</b>	\$30,000 or less	21 (42%)
	\$30,001 or more	22 (44%)
	Did not care to respond	7 (14%)
<b>Disease Stage</b>	Stage I	35 (70%)
	Stage II	15 (30%)
<b>Surgery Type</b>	Lumpectomy	36 (72%)
	Mastectomy	12 (24%)
	Bilateral mastectomy	2 (4%)
<b>Chemotherapy</b>	Yes	9 (18%)
	No	41 (82%)
<b>Radiation Therapy</b>	Yes	39 (78%)
	No	11 (22%)
<b>Hormonal Therapy</b>	Yes	42 (84%)
	No	8 (16%)

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**Table 5: Demographic characteristics of the Wait Control and Experimental Groups**

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		<b>Wait Control Group (n=26)</b>	<b>Experimental Group (n=24)</b>
<b>Age</b>		72.19 (Range: 65-83)	72.0 (Range: 65-80)
<b>Time since Diagnosis</b>	6 months or less	11 (42%)	7 (29%)
	7 months or more	15 (58%)	17 (71%)
<b>Race</b>	African American	1 (4%)	2 (8%)
	Caucasian	21 (80%)	20 (83%)
	Hispanic	2 (8%)	2 (8%)
	Native American	2 (8%)	0 (0%)
<b>Educational Level</b>	Grade School	0 (0%)	2 (8%)
	High School	9 (35%)	11 (46%)
	Trade School	3 (12%)	3 (13%)
	College	12 (46%)	8 (33%)
	Graduate School	2 (8%)	0 (0%)
<b>Religious Preference</b>	Catholic	2 (15%)	2 (8%)
	Christian	20 (76%)	22 (92%)
	Jewish	1 (4%)	0 (0%)
<b>Marital Status</b>	Married	15 (57%)	13 (54%)
	Divorced	3 (12%)	2 (8%)
	Widowed	8 (31%)	9 (38%)
<b>Lives Alone</b>	Yes	9 (35%)	8 (33%)
	No	17 (65%)	16 (67%)
<b>Employment Status</b>	Full-Time	2 (8%)	2 (8%)
	Part-Time	1 (4%)	3 (13%)
	Retired/Homemaker	23 (88%)	19 (79%)

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<b>Income</b>	\$30,000 or less	9 (35%)	12 (50%)
	\$30,001 or more	13 (50%)	9 (38%)
	Did not care to respond	4 (15%)	3 (13%)
<b>Disease Stage</b>	Stage I	18 (69%)	17 (71%)
	Stage II	8 (31%)	7 (29%)
<b>Surgery Type</b>	Lumpectomy	19 (73%)	17 (71%)
	Mastectomy	7 (23%)	5 (21%)
	Bilateral mastectomy	0 (0%)	2 (8%)
<b>Chemotherapy</b>	Yes	4 (15%)	5 (21%)
	No	22 (85%)	19 (79%)
<b>Radiation Therapy</b>	Yes	19 (73%)	20 (83%)
	No	7 (27%)	4 (17%)
<b>Hormonal Therapy</b>	Yes	23 (88%)	19 (79%)
	No	3 (12%)	5 (21%)

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**Table 6: Descriptive summary statistics for Overall QoL and QoL domains**

	<b>Baseline (N=50)</b>		<b>Time 2 (N=49)</b>		<b>Time 3 (N=48)</b>	
	<b>Mean</b>	<b>S.D</b>	<b>Mean</b>	<b>S.D</b>	<b>Mean</b>	<b>S.D</b>
<b>Overall QoL</b>	2.38	1.02	2.48	1.20	2.58	1.33
<b>Physical Subscale</b>	1.29	.80	1.52	1.02	1.59	1.06
<b>Psychological Subscale</b>	2.65	1.50	2.74	1.69	2.96	1.83
<b>Social Subscale</b>	2.18	1.29	2.11	1.31	2.19	1.43
<b>Spiritual Subscale</b>	3.62	1.54	3.82	1.67	3.59	1.68

**Table 7: Between group differences in Overall QoL and subscale scores using independent t-tests**

	Baseline			Month 3			Month 6		
	WC	EXP	P value	WC	EXP	P value	WC	EXP	P value
<b>Overall QoL</b>									
Mean	2.42	2.45	.900	2.60	2.50	.765	2.63	2.53	.772
S.D.	1.06	.75		1.28	.90		1.44	.95	
<b>Physical</b>									
Mean	1.41	1.15	.241	1.50	1.55	.870	1.60	1.54	.773
S.D.	.94	.6		1.11	.94		1.17	.95	
<b>Psychological</b>									
Mean	2.64	2.66	.967	2.79	2.70	.856	3.05	2.86	.729
S.D.	1.69	1.31		1.94	1.38		2.08	1.56	
<b>Social</b>									
Mean	2.14	2.24	.788	2.26	1.96	.432	2.32	2.04	.504
S.D.	1.40	1.18		1.49	1.06		1.72	1.07	
<b>Spiritual</b>									
Mean	3.48	3.76	.529	3.84	3.80	.925	3.53	3.66	.778
S.D.	1.45	1.65		1.62	1.75		1.68	1.72	

Note: Significance level based on Bonferroni's adjustment,  $p < 0.017$ .

**Table 8: GEE comparisons between groups: Overall QoL and QoL subscales**

	<b>Robust Z Score</b>
<b>Overall QoL</b>	-0.516
<b>Physical well-being</b>	1.749
<b>Psychological well-being</b>	-0.601
<b>Social well-being</b>	-1.613
<b>Spiritual well-being</b>	-0.591

Note: Effects of treatment are not considered significant if the absolute Robust Z Score is <2.0



**Table 9: Demographic characteristics of the qualitative sample (N=24)**

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<b>Age</b>	Mean :72 years	Range: 65 to 80 years
<b>Time since diagnosis</b>	6 months or less	7 (29.2%)
	7 to 15 months	17 (70.8%)
<b>Race</b>	Caucasian	19 (79.2%)
	Hispanic/Latina	2 (8.3%)
	Other	3(12.5%)
<b>Educational level</b>	High school/Trade school	16 (66.7%)
	College	8 (33.3%)
<b>Primary language</b>	English	21 (87.5%)
	Other	3 (12.5%)
<b>Religious preference</b>	Christian	22 (95.8%)
	Catholic	2(8.3%)
<b>Marital Status</b>	Married	13 (54.2)
	Divorced/Widowed	11(45.8%)
<b>Lives alone</b>	Yes	8 (33.3%)
	No	16 (66.7%)
<b>Employment status</b>	Not working	18(75%)
	Full-time	2 (8.3%)
	Part-time	4 (16.7%)
<b>Income</b>	\$30,000 or less	12 (50.0%)
	\$30,001 or more	9 (37.5%)

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<b>Disease stage</b>	Stage I	17 (70.8%)
	Stage II	7 (29.2%)
<b>Surgery type</b>	Lumpectomy	17 (70.8%)
	Mastectomy	5 (21.8%)
	Bilateral mastectomy	2 (8.3%)
<b>Chemotherapy</b>	Yes	5 (20.8%)
	No	19 (79.2%)
<b>Radiation therapy</b>	Yes	20 (83.3%)
	No	4 (16.7%)
<b>Hormonal therapy</b>	Yes	19 (79.2%)
	No	5 (20.8%)

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## **APPENDIX B: FIGURES**

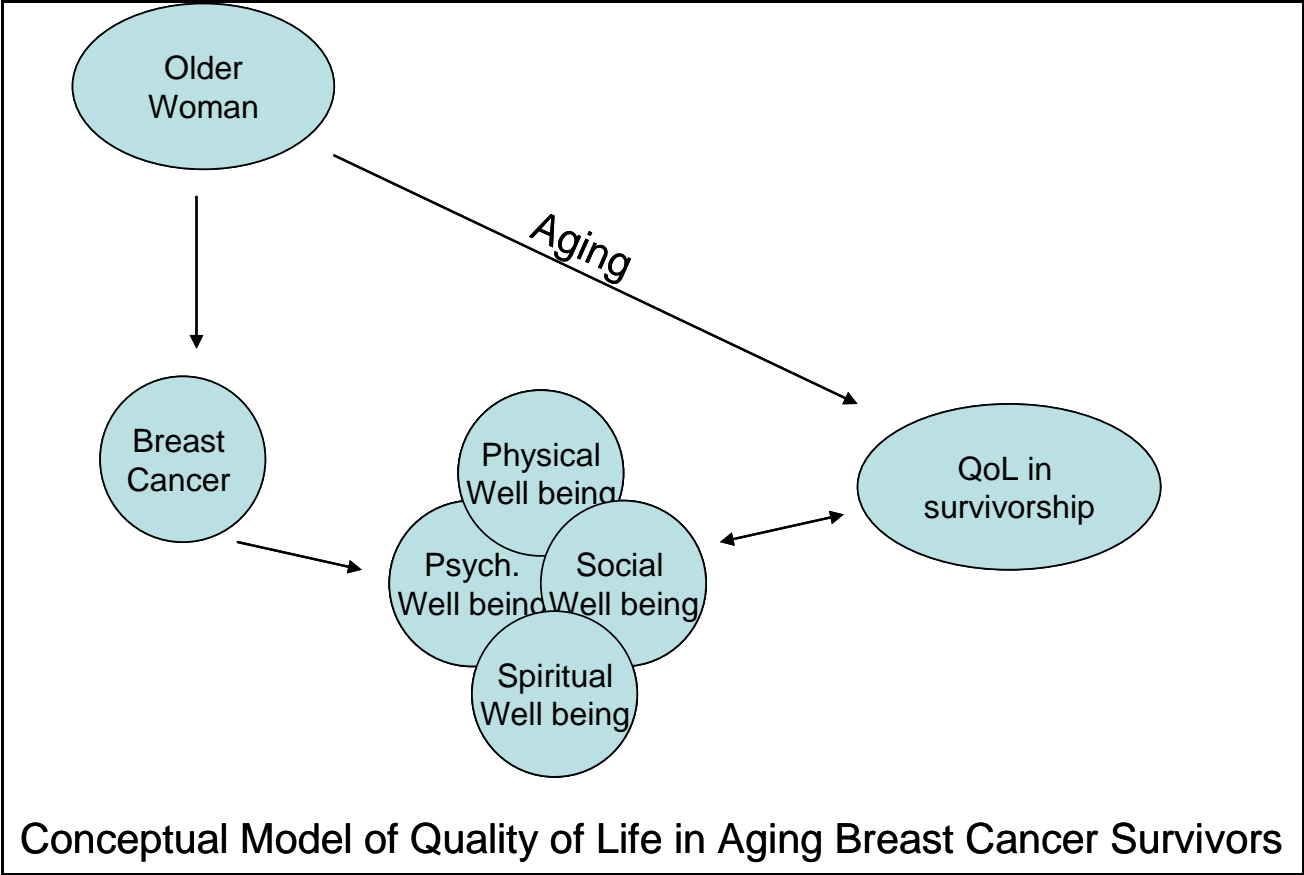
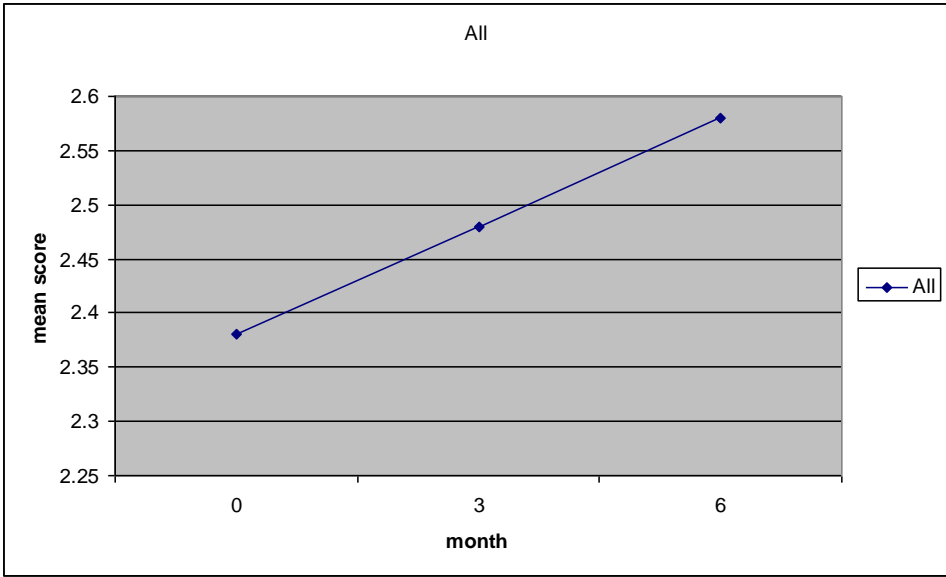
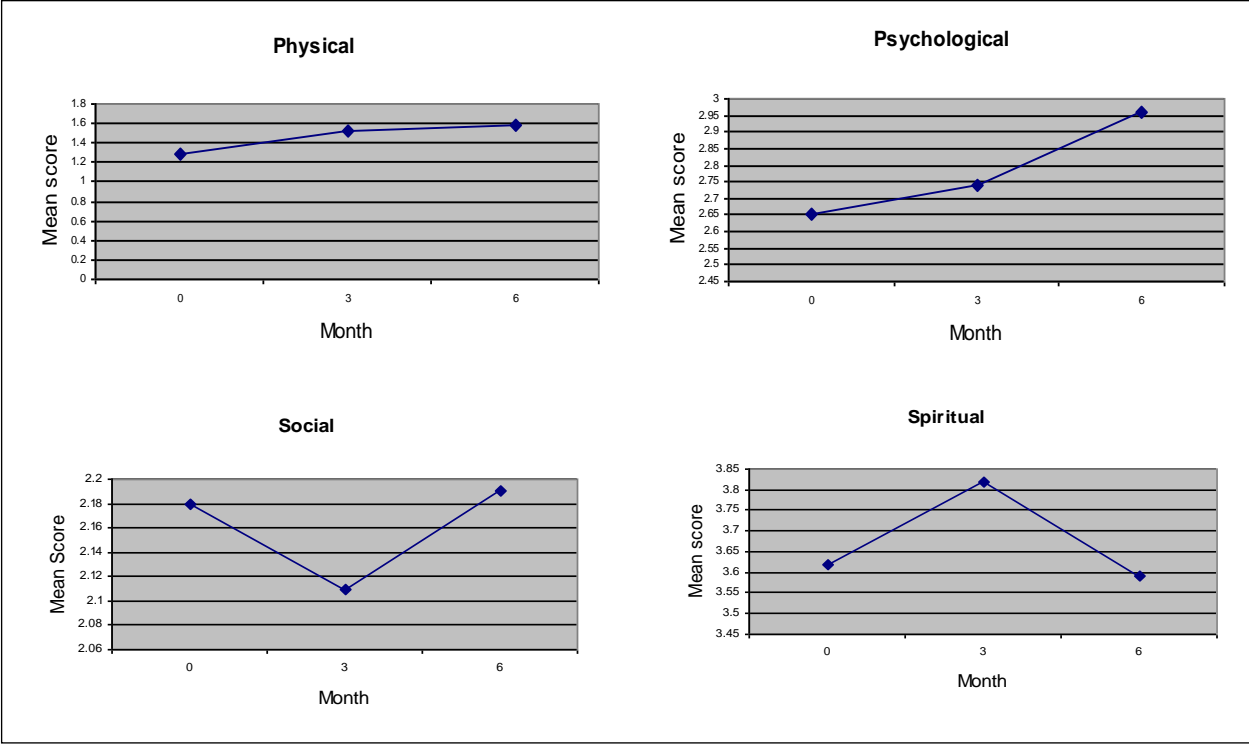


Figure 1: Conceptual Model of Quality of Life in Aging Breast Cancer Survivors



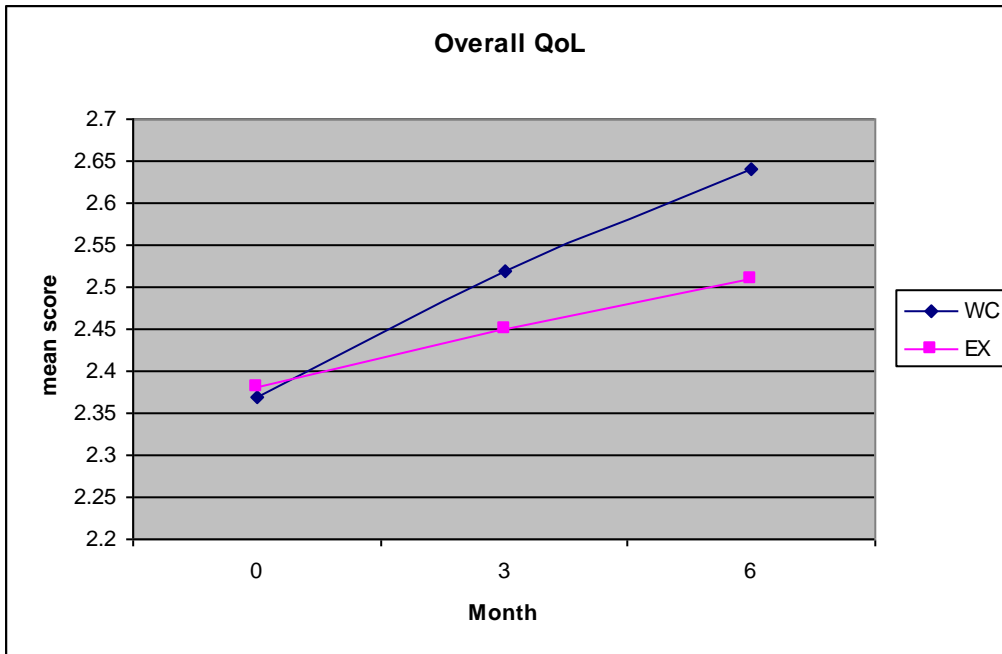
**Figure 2: Plot of means for whole group: Overall QoL**

Note: the higher the score, the worse the QoL



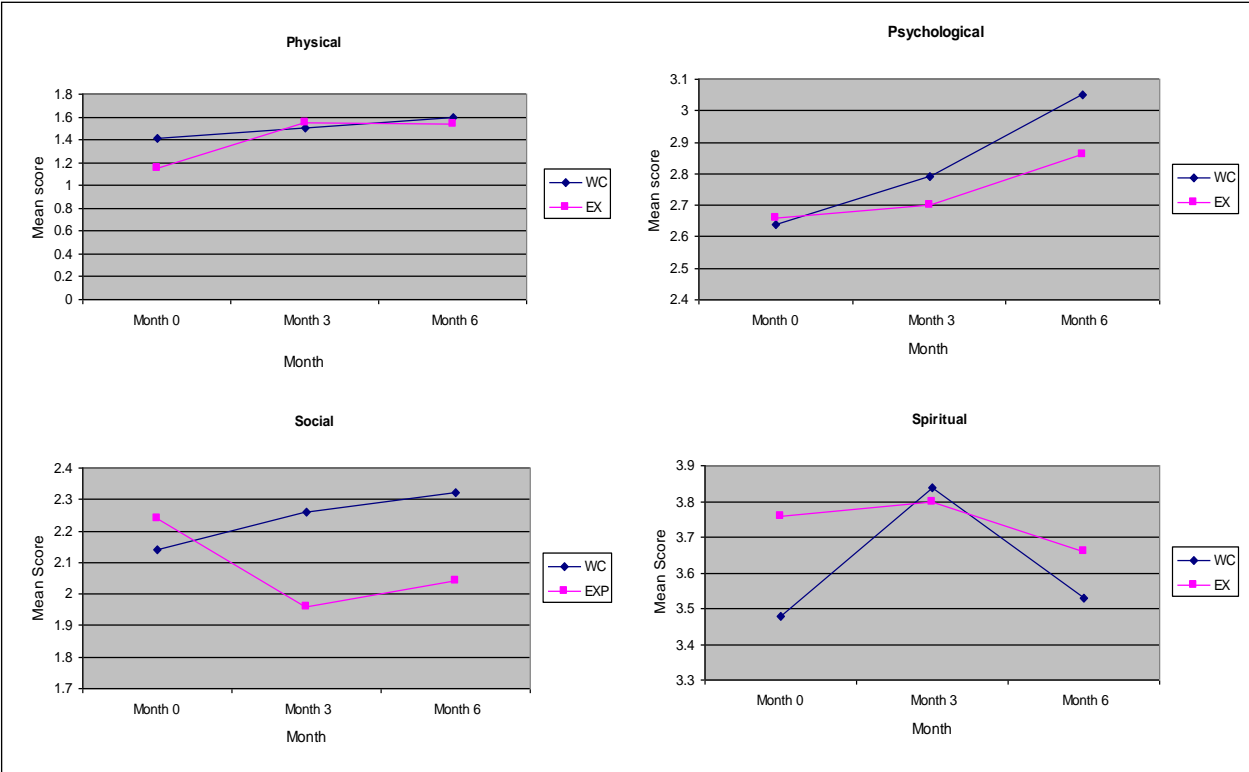
**Figure 3: Plot of means for whole group: QoL domains**

Note: the higher the score, the worse the QoL



**Figure 4: Plot of means for Overall QoL for WC and EX Groups**

Note: The higher the score, the worse the QoL



**Figure 5: Plot of mean scores for WC and EX Groups for QoL domains**

Note: The higher the score, the worse the QoL



## **APPENDIX C: DISSERTATION PROPOSAL**

## Abstract

**Background:** There are over 10 million cancer survivors alive today. In 2006, approximately 1.4 million people will be diagnosed with cancer and 565,000 are expected to die from their cancer.<sup>1</sup> Currently, 57% of all new cancer diagnoses and 71% of deaths occur in people age 65 and older.<sup>2</sup> Little is known about how cancer affects this elderly population.

**Aims:** The overall purpose of this research is to examine quality of life in women with early stage breast cancer who are age 65 or older and are within the first year of cancer survivorship. Women of all ages diagnosed with breast cancer share common concerns, but also have unique needs. The specific aims of this dissertation are to: 1) Describe the overall quality of life of female breast cancer survivors age 65 or older; 2) Describe quality of life within the domains of physical, psychological, social and spiritual well-being in female breast cancer survivors age 65 or older and; 3) Describe additional current life experiences that may relate to quality of life in older breast cancer survivors.

**Research Design and Methods:** A descriptive design for analysis using mixed methods will be used. Data will be obtained from a pre-existing data set, the Breast Cancer Education Intervention (BCEI) a longitudinal, psychoeducational Quality of Life (QoL) intervention for 256 breast cancer survivors in the first year of survivorship. This sample included an experimental (EX) group and a Wait Control (WC) group. QoL was measured over time. This dissertation will focus on the subset of older women (age 65 and older) surviving with breast cancer. Quantitative analysis of surveys using parametric and non-parametric statistics and qualitative analysis of field notes and narrative responses on surveys will occur.

**Relevance to Healthcare:** The goal of this dissertation research is to add to the body of knowledge in research concerning older women with breast cancer. Information concerning the quality of life in older women with breast cancer may help form guidelines for treatment and follow-up care in this population during cancer survivorship.

# Quality of Life in Older Breast Cancer Survivors: A Descriptive Study

## Specific Aims

There are over 10 million cancer survivors alive today. In 2006, approximately 1.4 million people will be diagnosed with cancer and 565,000 are expected to die from their disease.<sup>1</sup> Currently, 57% of all new cancer diagnoses and 71% of cancer deaths occur in people age 65 and older.<sup>2</sup> Little is known about how cancer affects this elderly population.

This dissertation will focus on an understudied population in cancer care: older women with breast cancer. Older or elderly women will be defined as being 65 years or older. Approximately 212,920 new cases of invasive breast cancer will be diagnosed in 2006 and 41,430 women will die of this disease<sup>1</sup>. Within these new cases, it is estimated that women over that age of 65 will constitute over 88,000 of these new diagnoses and account for approximately 23,000 of the deaths attributed to breast cancer.<sup>3</sup>

The overall purpose of this research is to examine quality of life in women with early stage breast cancer who are age 65 or older and are within the first year of cancer survivorship. Data will be drawn from an existing cohort of women who participated in the Breast Cancer Education Intervention (BCEI), a longitudinal, psychoeducational Quality of Life (QoL) intervention for 256 breast cancer survivors in the first year of survivorship. This sample included an Experimental (EX) group and a Wait Control (WC) group. QoL was measured over time.

**Aim #1:** Describe the overall quality of life of female breast cancer survivors age 65 or older.

**Research Question #1.1:** What is the QoL of older breast cancer survivors at baseline?

**Research Question #1.2:** How does QoL change over time?

**Research Question #1.3:** How does QoL compare between groups over time?

**Aim #2:** Describe quality of life within the domains of physical, psychological, social and spiritual well-being in female breast cancer survivors age 65 or older.

**Research Question 2.1:** What is the QoL of older breast cancer survivors within the domains of physical, psychological, social and spiritual well-being at baseline?

**Research Question # 2.2:** How does QoL within these domains change over time?

**Research Question # 2.3:** How does QoL with these domains compare between groups over time?

**Aim #3:** Describe additional life experiences that may relate to quality of life in female breast cancer survivors age 65 and older.

**Research Question #3.1:** Describe other life experiences of older breast cancer survivors as described by research nurses.

**Research Question #3.2:** Describe the types of medication used by older breast cancer survivors age 65 and older.

This research is relevant for several reasons. Little is known about older women with early stage breast cancer, especially during survivorship. These women have been largely understudied and are apt to be under-diagnosed, under-treated and under-appreciated once treatment has ended and survivorship begins. This in turn makes older women susceptible to late physical and psychosocial effects often encountered in survivorship. With an increase in the population of older people on the horizon, guidelines for all aspects of cancer need to be developed in order to properly care for this population. The dissertation seeks to increase the body of knowledge concerning older women with early stage breast cancer in order to assist in the development of guidelines and interventions appropriate for the unique needs of this growing population.

### **Background and Significance**

Today, there are more than 2.3 million women surviving with breast cancer.<sup>3</sup> Currently, women have a one in 8 chance of developing breast cancer in their lifetime. Incidence of breast cancer increases with age. Within the next 10 years of their age, A 20 year old woman has a 1 in 1,985 chance of being diagnosed with breast cancer while a 70 year old woman has a 1 in 24 chance of being diagnosed with breast cancer. This probability changes depending on the presence of risk factors unique to each woman.<sup>3</sup> Fifty percent of women diagnosed with breast cancer are 61 years old or older<sup>3</sup>.

While there is ample evidence that cancer and its treatment affect quality of life in breast cancer survivors, the impact of cancer and its treatment on the quality of life in older women surviving with breast cancer is unclear. Research is often conflicting as some studies have concluded that quality of life in older women with breast cancer is poor while others conclude older women surviving with breast cancer suffer little negative effect from treatment.<sup>4-13</sup>

The recognition of the need to focus on older populations is not new.<sup>14</sup> The burden of cancer due to aging is now imminent and little is known about cancer in this population as a whole or within the specific cancers such as breast cancer.<sup>2, 15, 16</sup> Further research is needed across all areas of cancer care and the elderly including screening, diagnosis, treatment, survivorship and quality of life. Several organizations support this need for research.

The National Institute of Aging (NIA) has compiled the *Action Plan for Aging Research: Strategic Plan for Fiscal Years 2001-2005*<sup>17</sup> which recognizes the need to address knowledge deficits regarding the elderly, disease and aging. One of the primary goals is to improve the health and quality of life in older people. To meet this goal, the NIA has developed research initiatives for studying diseases such as cancer focusing on older individuals.

The Institute of Medicine's (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*<sup>18</sup> describes the survivorship phase of cancer as neglected in research. The IOM proposes essential components of survivorship care as: 1) prevention of new and recurrent cancer as well as late effects; 2) surveillance of new, recurrent and metastatic cancer as well as side effects; 3) interventions for the effects of cancer and its treatment; and 4) coordination of care between specialist and primary care providers to meet all the needs of the cancer survivor. In addition, the IOM report

suggests developing a “Survivorship Care Plan” to meet the needs of cancer patients after treatment. This Care Plan would summarize treatment, guide follow-up, suggest preventive practices for maintaining health, provide information of employment and health insurance, and detail the availability of psychosocial services within the patient’s community. An additional recommendation is to encourage health care providers to use “systematically developed evidence-based clinical practice guidelines” (p5) to help manage cancer and its effects. Guidelines concerning cancer care in older adults do not exist at this time.

Quality of life in survivorship has been recognized as an important outcome of cancer treatment. The National Cancer Institute’s (NCI) *Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer*<sup>19</sup> includes improving the quality of care and quality of life in those affected by cancer and encourages the use of quality of life endpoints in NIH funded clinical trials. To further emphasize the outcomes of research, the NIH has developed the Outcomes Research Branch to help define the emerging field of outcomes research. This field looks at relevant endpoints of treatments and interventions. The endpoints include: survival, health-related quality of life, healthcare and economic burden.<sup>20</sup>

This dissertation research involving older breast cancer survivors is significant for several reasons: *First*, Americans are aging. In 2000, 14.3% of women in the U.S. were over the age of 65. By 2050, 22.6% of all women are projected to be over the age of 65.<sup>21</sup> *Second*, incidence of cancer increases with age. People over the age of 65 have nearly 10 times the risk for developing cancer than those younger than 65.<sup>22</sup> Due to growth and aging of our population, the number of cancer cases is expected to double from the current rate of 1.3 million to 2.6 million by the year 2050.<sup>15</sup> Currently, the mean age of all women diagnosed with breast cancer is 61 while women age 75 to 79 have the highest incidence rate.<sup>3</sup> As more women reach this age group, incidence rates will also increase. Additionally, many women will approach old age with a personal history of breast cancer. Risk for recurrence will remain as well as risk for developing a second breast cancer.<sup>23</sup> The cancer burden will substantially increase over the next 30 years.<sup>22</sup> *Third*, the sheer number of older people who will be diagnosed with cancer will increase the demand for health care services.<sup>23</sup> Healthcare professionals will be unprepared to appropriately care for these aging women.<sup>24, 25</sup> *Fourth*, co-morbid conditions increase with age and this will impact care.<sup>23</sup> The Centers for Disease Control<sup>26</sup> (CDC) estimates that the average 75 year old has 3 chronic illnesses and uses 5 prescription medications. It is unclear how these illnesses and medications impact or interact with treatment for cancer. *Fifth*, women of different ages have different concerns and needs.<sup>27, 28</sup> Due to the lack of research concerning older women with breast cancer, these needs are largely unknown.

In summary, little is known about older women with breast cancer. The current need for research is intensified by the fact that the already large number of older women surviving with breast cancer will dramatically increase in the near future.

## **Literature Review**

The goal of this literature review is to support the importance of this dissertation research in adding to the body of knowledge in nursing concerning older women with breast cancer. This literature review will focus on several areas: 1) aging, 2) breast

cancer, 3) survivorship, 4) quality of life, and 5) methods of research. All of these topics will support the need for this research study.

## AGING

### Changing Demographics

The demographics of America are changing and soon, more elderly people will be alive and living longer than ever before. According to population projections, there is about to be a large increase in the number of elderly people in the United States. As of

	2000	2030	2050
<b>Total population</b>	282 million	364 million	420 million
<b>Number of Americans age of 65 or older</b>	35 million (12%)	72 million (20%)	87 million (21%)
<b>Men</b>	14.4 million		
<b>Women</b>	20.6 million		
<b>Number of Americans age 85 or older</b>	3.6 million	9.6 million	18.2 million
<b>Number of Centenarians</b>	81,000		800,000

2003, 35 million Americans were over the age of 65 (men: 14.4 million, women: 20.6 million) representing over 12% of the population in the United States. By the year 2030, the number of older Americans will grow to be 72 million representing approximately 20% of the total population.<sup>2, 30</sup> In

the year 2050, it is projected that 87 million people will be over the age of 65, representing 21% of the nations population.<sup>31</sup>

The most rapidly growing group are Americans over the age of 85.<sup>29, 32</sup> In 1995, those over the age of 85 were numbered at 3.6 million. This number is expected to double by 2025 and increase 5 fold by 2050 totaling 18.2 million adults over the age of 85. The numbers of centenarians are also increasing. By 2050, estimates project 800,000 people will be 100 years old or older compared to the 81,000 centenarians living in the 2000.<sup>29</sup> Please refer to Table 1 for a summary.

Life expectancy has also improved over time.<sup>30, 31</sup> In 2000, the average life expectancy was 76.0 years (men: 74.1 years, women: 79.5 years). Currently, the average 65 year old can expect to live 17.9 more years (men: 16.3, women: 19.2), the average 75 year old can expect to live an additional 11.3 years (men: 10.1, women 12.1), and an 85 year old has an additional life span of 6.3 years (men: 5.6, women: 6.7).<sup>30</sup> By the year 2050, the average person is expected to have an average life expectancy between 82 and 84 years (see Table 2).<sup>30</sup> Both the increase in the number of older people and the projected longevity of their lives over the next several decades support the importance of better understanding the needs of older cancer survivors in order to reduce adverse effects experienced in survivorship.

	2000	2050
Average life expectancy (at birth)	76 years Men: 74.1 years Women: 79.5 years	82-84 years (projected)
Life expectancy for 65 year old	Men: 16.3 years Women: 19.2 years	
Life expectancy for 75 year old	Men: 10.1 years Women: 12.1 years	
Life expectancy for 85 year old	Men: 5.6 years Women: 6.7 years	

### Demographic Differences between Elderly Men and Women

The elderly are not a homogenous population. Many differences exist

between elderly men and women. Women make up approximately 59% of the population over the age of 65. Older women are less likely to be married than men (44% compared to 75%) and more likely to be divorced or widowed. Older women are also less likely to remarry after a divorce or the death of a spouse. Forty percent of women over the age of 65 live alone while 41% live with a spouse. At age 85, 60% of women live alone.

Older Americans represented 3.3% of the overall workforce in 2003 and are projected to be 5% of the workforce in 2020. Women over the age of 65 continue to work. Thirty five percent of women age 65 and older remain in the workforce compared to 59% of men of the same age.<sup>32</sup>

Poverty rates for adults over the age of 65 has recently declined from 10.2% to 9.8%.<sup>33</sup> Older women are more likely to be poor compared to men of the same age. Elderly women have a 12.2% rate of poverty compared to men at 7.5%. Fewer older women achieve economic security because they were more likely to either not work outside the home or work at jobs that do not allow them to collect the maximum benefit from Social Security (SS). In addition, women are only able to collect 2/3rds of their husbands benefit if they are widowed.

Social support for older women is also limited. Since older women are likely to live alone, they must depend on other people for support instead of spouses. The most likely caregiver or support person for older women is children living nearby. Older women are also more likely to enter a nursing home than older men.<sup>32</sup>

As a group, older people spend a considerable amount of money on healthcare. It is estimated that 12.5% of expenditures are health-related. This is more than double the amount spent by the average consumer. The majority of these costs are for insurance (55%), medications (24%), medical care (17%) and medical supplies (4%).<sup>34</sup> Almost all older people not living in an institution receive Medicare (96%) however Medicare only pays approximately half of medical costs. Over 87% of elderly persons have some type of supplemental coverage. Individuals living in nursing homes are usually covered by Medicaid (58%).<sup>34</sup>

### Chronic Disease in the Elderly

Many older adults experience healthy aging but most will eventually experience illness and chronic disease. Illnesses that contribute to morbidity and mortality include cerebrovascular disease, cancer, chronic lower respiratory diseases, pneumonia/influenza, diabetes, arthritis, and Alzheimer's disease. Many older

Americans chronically suffer from one or more of these illnesses prior to their death. Chronic co-morbidities often seen in elderly populations include: gastrointestinal problems<sup>35</sup>, hypertension, heart conditions, cancer, chronic obstructive pulmonary disease (COPD), arthritis and diabetes.<sup>35, 36</sup> Eighty percent of older Americans over the age of 65 have at least one chronic illness and 50% have 2 or more chronic conditions.<sup>37</sup> The presence of co-morbidities increases with age.<sup>36, 38</sup> At the time of diagnosis, it is likely that cancer is not a person's first chronic illness.<sup>2</sup>

*Cancer:* Cancer is a major consideration in adults. Currently, 57% of all new cancer diagnoses and 71% of deaths occur in people age 65 and older.<sup>2</sup> Cancer is the second most common cause of death in persons age 65 and older following heart disease.<sup>30</sup>

Overall	57%
Breast	47.5%
Uterine	55.4%
Ovarian	45.9%
Colon	73.9%
Lung	65.8%

Approximately 1.4 million persons will be diagnosed with cancer in 2006.<sup>1</sup> The cancers with the highest incidence in men are prostate, lung, colon and bladder cancer. In women, breast, lung, colon and uterine cancer have the highest incidence.<sup>1</sup> Overall, 76.9% of prostate cancer, 73.9% of colon cancer, 65.8% of lung cancer, 45.9% of ovarian and over 47.5% of breast cancer diagnoses occur in individuals over age 65. In addition, 55.4% of women diagnosed with uterine

cancer are age 65 or older (see Table 3).<sup>2, 38</sup> Due to advances in cancer treatment, early detection and screening, cancer is considered a chronic illness contributing to morbidity and mortality in later life.<sup>36</sup> As our population continues to grow, more older Americans will be diagnosed with cancer and need to be managed within the context of their cancer diagnosis and other co-morbid illnesses they most likely will be experiencing.<sup>36</sup>

*Comorbidity and Cancer:* The presence of co-morbidities affects many aspects of cancer beginning with screening and diagnosis of cancer. Heflin and colleagues<sup>39</sup> found that the relationship between the number of co-morbid conditions and the use of screening tests varied widely in older populations. Additionally, screening rates decreased as age increased. Compared to those without a co-morbid condition, women with hip fractures were less likely to receive mammograms; people with cognitive impairment were less likely to receive fecal occult blood testing; and those with hypertension experienced higher rates of clinical breast exams, Pap tests, FOBT and higher trends toward mammography. Overall, co-morbid conditions were not related to lower incidence of cancer screening, however age was a determining factor in whether or not elderly people received screening for cancer. Using age as a determining factor for screening is worrisome since many elderly are healthy and may be good candidates for cancer screening tests. Using age as the determining criteria means many older adults may not receive the benefit of cancer screening when they are otherwise healthy. Conversely, many fear that older people with multiple co-morbid conditions may experience harm by participating in cancer screening activities.

Comorbidity has also been associated with later diagnosis of cancer and greater mortality. Although people with co-morbid illnesses have more exposure to physicians for the treatment of their illnesses, cancer screening may not be considered as important as the illnesses already being managed.<sup>40</sup> Additionally, the symptoms of cancer may



not be recognized by patients or practitioners or attributed to pre-existing conditions leading to missed or delayed cancer diagnosis.<sup>41</sup>

Treatment of cancer is also affected by the presence of co-morbidities. The National Comprehensive Cancer Network has published clinical practice guidelines for the detection and treatment of many common cancers. These guidelines reflect what experts believe are appropriate practice in the treatment of cancer. However, in the National Report to the Nation on the Status of Cancer, 1975-2002, Edwards and colleagues<sup>42</sup> recognize age-related disparities for the treatment of cancer. Cancer patients age 65 and older were treated below guidelines (less than was recommended) for breast, colorectal, lung, and ovarian cancer. The presence of co-morbid illnesses influenced treatment decisions.

The impact of co-morbidity on cancer treatment is of great concern to many involved in the care of older adults.<sup>39, 43-48</sup> Many healthcare professionals are concerned that treatment for cancer may be too dangerous or debilitating depending on the number and type of co-morbidities a person has when they are diagnosed with cancer. People with cancer who have either multiple or severe co-morbidities may experience poorer survival compared to patients with no co-morbidities. The presence of co-morbidities can also have a negative impact on quality of life in persons diagnosed with cancer.<sup>46, 47</sup> People with a history of cancer tend to rate their health lower and their disability higher than those without a cancer diagnosis. When another co-morbid illness is present, the chance a person will rate their health as poor increases 5 to 10 times what which would be expected.<sup>49</sup>

In the future, it will be necessary to consider these co-morbid illnesses more closely to reduce morbidity.<sup>36, 49</sup> Many researchers and health care professionals that work with the elderly are concerned with the inevitable increase in cancer diagnosis in the elderly over the next several decades. They advocate for comprehensive geriatric assessment of older people diagnosed with cancer to determine the appropriateness of any given cancer treatment.<sup>46</sup> It is agreed that age should not be the sole determining factor concerning treatment decisions.<sup>41, 50</sup> Many older adults may be healthy enough to undergo standard treatments for cancer. The goal of the geriatric assessment is to identify medical, functional and psychological problems that may be present in the older adult diagnosed with cancer and to develop a comprehensive care plan.<sup>46</sup> Geriatric assessment is multidimensional and includes assessing function (activities of daily living and functional status), co-morbidity (number of illnesses and severity), socioeconomic issues (living conditions, presence of a caregiver, transportation), geriatric syndromes (dementia, depression, fall history, osteoporosis), medications (number of prescriptions and potential drug interactions), and nutritional status.<sup>24, 41, 50</sup> Using a geriatric health assessment may more accurately allow physicians to identify frail patients<sup>24</sup> and estimate risk associated with treatment for cancer and avoid treatments that may lead to functional disability.<sup>46</sup> Balducci and Stanta<sup>24</sup> also recommend asking several questions in addition to the geriatric assessment. These question include: Will the patient die from the cancer?; Will the patient experience cancer-related morbidity? and; Will the patient be able to tolerate treatment without life-threatening complications? These questions and a comprehensive geriatric assessment may help patients, family members and health care providers determine the best course of action for elderly people with cancer.

*Ageing Summary:* The number of older Americans will double by the year 2030. While some will remain healthy, most will experience co-morbid illness including cancer at some point in their lifetime. Age coupled with the presence of co-morbid illness impacts decisions concerning cancer screening and treatment. Comprehensive assessments of the elderly should be incorporated into decisions related to cancer in this population. For women, considerations involving breast cancer heighten the need for such assessment.<sup>51</sup>

## BREAST CANCER

Breast cancer is the most common cancer diagnosed in women.<sup>1</sup> Risk factors for breast cancer are well known and include: age, family history, age at first full-term pregnancy, length of menstrual history, post menopausal obesity, oral contraceptive and postmenopausal hormone use, high alcohol intake and low physical activity.<sup>3</sup> Currently, women have a 1 in 8 chance of developing breast cancer in their lifetime. Incidence of breast cancer increases with age. Fifty percent of women diagnosed with breast cancer are 61 years old or older<sup>3</sup>. Women age 75 to 79 years old have the highest incidence rate (496.6 per 100,000 women) and women age 20-24 have the lowest rate of incidence (1.3 per 100,000 women). Although white women have higher incidence of diagnosis after the age of 35, African American women have a higher mortality rate from breast cancer which is consistent across all age groups.<sup>3</sup>

### Incidence and Survival

Incidence is defined by the National Cancer Institute (NCI) as the “number of new cases

<b>Survival at 5 years</b>			
Overall 88%			
<b>Local Disease</b>	98%	<b>Age 40 and younger</b>	82%
<b>Regional Disease</b>	81%	<b>Ages 40-74</b>	89%
<b>Distant Disease</b>	26%	<b>Age 75 and older</b>	88%

of a disease diagnosed each year.”<sup>52</sup> The incidence of breast cancer rose 4% yearly from 1980 to 1987 most likely due to increase screening efforts. Since 1988, rates have

continued to rise but at a much lower rate of 0.3% per year. Recently, women between the ages of 40 and 49 experienced a slight decline in incidence but women over the age of 50 continue to experience this slight increase in incidence.

Mortality from breast cancer has been decreasing. A mortality rate is defined by NCI as “the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year.”<sup>53</sup> From 1990 to 2002, mortality rates (the number of people who died from an illness) decreased 2.3% each year. However, this reduction in mortality has mostly benefited white women.<sup>3</sup> Several factors have been seen to influence survival at 5 years: age and stage at diagnosis. The overall rate of survival at 5 years is 88% however this survival rate changes according to extent of disease and are as follows: local (98%), regional (81%) and distant (26%). Age differences also impact 5 year survival rates. Women diagnosed with breast cancer at age 40 or younger have an

82% survival rate, women ages 40 to 74 have an 89% survival rate and women age 75 or older have an 88% chance at survival (see Table 4).<sup>3</sup>

## Screening

Screening entails checking for a disease when there are no symptoms.<sup>52</sup> Increased screening for breast cancer has led to tumors being found in early and localized stages. The American Cancer Society recommends that women age 40 and older receive an annual mammogram and an annual clinical breast exam. The recommendation for a monthly breast self exam (BSE) was recently eliminated because it is recognized that many women find a lump outside of a structured self exam and awareness of changes in the body is more important than conducting a structured breast exam. However, women should still be educated about the benefit and technique of the breast self exam so they can perform one if they are interested in incorporating this into their monthly routine.<sup>3</sup>

There has been a marked increase in mammography use over the past decade. In 2000, approximately 70% of women reported that they had been recently screened for breast cancer with mammography. Screening rates varied per ethnic group: White (72%); Black (68%); Hispanic (63%), Asian/Pacific Islander (57%) and American Indian/Alaskan Native (52%).<sup>54</sup> Annual screening rates also differ according to age. Women receive mammography and a clinical breast exam (CBE) at the following rates: age 40 (54.1%), 40-64 (54.9%), and 65+ (52.3%). Rates are lower if women do not have a regular healthcare provider or are uninsured.<sup>3</sup> Sixty four percent of women over the age of 65 receive screening by mammogram only and do not receive routine CBE.<sup>3</sup>

Even though older woman are more likely to be diagnosed with breast cancer, controversy exists concerning the efficacy of screening for breast cancer in older populations.<sup>45, 55-57</sup> This controversy exists because there is little research involving older women and screening for breast cancer.<sup>55</sup> Screening rates have been shown to decline with age and physicians base their decision to screen women on an assessment of risk and benefit.<sup>57</sup> Additionally, physician recommendation for screening varied widely according to age. In women between the ages of 50 and 74, providers recommended mammography at least every other year (51%) and yearly (45%). In women over age 75, screening was recommended annually for 80% of the women, 5% of the physicians did not recommend screening and 10% had no policy regarding screening.<sup>56</sup> Physicians reported that issues such as cost, comorbidity, functional status of the women, lack of guidelines, questionable value of the test and patient resistance as influencing their decision to recommend screening.<sup>56</sup>

The National Comprehensive Cancer Network's (NCCN) *Breast Cancer Screening and Diagnosis Guidelines*<sup>58</sup> support the ACS recommendations on breast cancer screening and offers considerations for screening the elderly. As older women are more apt to develop breast cancer, screening guidelines should apply to all women. However, if an elderly woman has serious co-morbid conditions that would preclude treatment, screening for breast cancer should not be used.

McPherson and colleagues<sup>45</sup> specifically studied the effect of mammography on survival in older women with co-morbidity and breast cancer. Results showed a significant reduction in mortality for all older women, even those who had mild or moderate co-morbidity. However, for older women with multiple or severe co-morbid illnesses, survival was not improved. These findings suggest that it may not be effective

to screen older women with the presence of severe co-morbidity who may not benefit from detection of breast cancer and treatment. But treating older women, regardless of age may be effective if their level of co-morbidity is low.<sup>45, 57</sup>

## **Diagnosis**

The NCCN has published guidelines concerning the diagnosis of invasive breast cancer.<sup>59</sup> Invasive cancer is defined as cancer that has spread beyond its point of origin and into neighboring tissues.<sup>52</sup> Current guidelines for the diagnosis of invasive breast cancer includes: diagnostic mammography, pathology review, evaluation of estrogen (ER) and progesterone (PR) receptor status, Her-2 receptor status and various blood chemistries.<sup>59</sup>

Differences have been noted in the use of these guidelines in younger and older women. Compared to younger women, older women receive fewer diagnoses by mammogram and needle localization.<sup>60</sup> Some older women had no histological assessment of their disease. Estrogen receptor status was also unknown in 74% of the population.<sup>61</sup>

Overall, the presentation and nature of breast cancer at diagnosis in older women is blurred. While some researchers have reported that older women have more advanced disease at diagnosis,<sup>60, 61</sup> others have found that women over the age of 70 had similar disease characteristics as younger women, but more favorable histological characteristics with lower grade disease and less negative ER-receptor status.<sup>62</sup> Gennari and colleagues<sup>63</sup> compared the presentation of elderly postmenopausal women with younger postmenopausal women. Older women had larger tumors and greater lymph node involvement than younger women. Elderly women also demonstrated more ER/PR positivity, less tumor vascularization and less Her-2 neu expression than younger women.

Singh and colleagues<sup>64</sup> examined the natural history of breast cancer in women who did not receive systemic therapy. No difference in tumor size was noted between age groups; however, women over the age of 70 had less lymph node involvement. It is also reported that older women have fewer lymph nodes removed. Controversy exists over the benefit of axillary lymph node dissection in older women with breast cancer. In early stage disease, there was no significant difference in mortality, recurrence and survival between older women (mean age 70 years) who had an axillary lymph node dissection and those who did not. Additionally, no evidence was found to support some views that breast cancer in the older woman was more indolent than in younger women.<sup>65</sup>

## **Treatment**

According to guidelines published by the National Comprehensive Cancer Network treatment for breast cancer is dependent on tumor size, lymph node involvement, estrogen receptor (ER), progesterone receptor (PR) and Her-2 status, and the presence of metastatic disease.<sup>59</sup> Women with early stage invasive breast cancer can opt for total mastectomy or breast conservation therapy which includes lumpectomy and radiation therapy. The extent of radiation therapy and the receipt of adjuvant chemotherapy are dependent on axillary nodal involvement, size of the tumor and ER/PR status. Adjuvant hormonal therapy depends on ER/PR status. In addition,

women who are Her-2 neu positive should receive trastuzumab. The NCCN guidelines do not make recommendations regarding chemotherapy in women over the age of 70 stating that data were insufficient to make a determination regarding the safety and efficacy of chemotherapy in this population. The guidelines state that use of chemotherapy in older women should be individualized and co-morbid conditions should be taken into consideration.<sup>59</sup> Women with advanced disease also receive a combination of the treatments already mentioned however, breast conservation therapy is not recommended.<sup>59</sup>

Overall, it is agreed that older women have more variable treatment than younger women and are often under-treated or treated with less than standard treatment for their disease.<sup>60, 61, 66-72</sup> Bouchardy and colleagues<sup>61</sup> noted no standardization of treatment in older women. Women opted for no treatment (12%); Tamoxifen only (32%); breast conservation surgery and radiation (7%) and mastectomy (14%). Tamoxifen was given to women regardless of their estrogen receptor status. These researchers determined that 50% of these women had suboptimal treatment which contributed to increased mortality related to breast cancer. In this sample, forty seven percent (47%) of older women (age 80 and older) received standard treatment compared to 91% of women age 50 to 79 years. In a study to determine concordance with established guidelines, Giordano and colleagues<sup>68</sup> determined that age was associated with under-treatment. Older women were less likely to receive definitive surgery, post-lumpectomy radiation, adjuvant chemotherapy and hormonal therapy. Women age 75 and older were particularly vulnerable to not being treated according to guidelines.

*Surgery:* In a study that examined factors associated with surgical options for breast cancer, Chagpar and colleagues<sup>73</sup> found that age was an independent predictor of surgery type. Women over the age of 55 were more likely to receive mastectomy compared to breast conservation therapy. If older women received breast conserving surgery, they were also less likely to receive radiation therapy.<sup>60, 63</sup>

*Chemotherapy:* The use of chemotherapy in older women with breast cancer is inconsistent. Du and colleagues<sup>74</sup> noted a decrease in the use of chemotherapy with age. Women age 65-69 received chemotherapy 54% of the time while women over the age of 85 received chemotherapy 3% of the time.<sup>74</sup> In this study, chemotherapy was noted to significantly reduce mortality in women age 65 to 69, but have little impact in women over age 70.<sup>74</sup> The reason for this difference is unknown.

Muss and colleagues<sup>75</sup> demonstrate that there is a survival benefit for older women who are healthy and receive chemotherapy. Benefit was comparable to that of younger women. However, overall survival was worse for women over age of 65 due to death from causes other than breast cancer.

Woodward and colleagues<sup>70</sup> also observed that older women were less likely than younger women to receive chemotherapy as part of their treatment. Women age 50 to 65 were 6 times as likely not to receive chemotherapy and women over the age of 65 were sixty two times as likely not to receive chemotherapy when compared to women under age 50. They concluded that age bias contributed to the under-treatment of this patient population.

Older women also receive fewer referrals to medical oncologists. Thwin and colleagues<sup>71</sup> report that 79% of women over the age of 65 were referred to a medical

oncologist compared to 88% of younger women. Health status evaluated by the surgeon was associated with referrals. Women perceived to have poor health status received fewer referrals.

*Hormonal therapy:* Tamoxifen may be the only consistent treatment given to women over the age of 65.<sup>76</sup> However, older women with co-morbid conditions and estrogen receptor (ER) negativity were less likely to have discussed this option with their doctors.<sup>77</sup> In one study, women over age 70 were less likely to receive chemotherapy but more likely to receive hormonal therapy.<sup>62</sup> Interestingly, women who were neutral or negative in their belief that Tamoxifen was beneficial often stopped taking it before the end of 5 years. Women were at risk for stopping the drug if they held these beliefs and if they had 4 or more positive lymph nodes.<sup>78</sup>

Aromatase inhibitors instead of or in combination with Tamoxifen have also been used as adjunct therapy in older women.<sup>79</sup> Mouridsen and Chaudri-Ross<sup>80</sup> demonstrated the effectiveness of the aromatase inhibitor letrozole compared to Tamoxifen. Letrozole was as effective as Tamoxifen in postmenopausal women of all ages. However, older women (age 70 or older) who took letrozole had more benefit as time to progression was significantly longer in this group (12.2 months) compared to the Tamoxifen group (5.8 months). Older women in the letrozole group also experienced significantly longer survival compared to the Tamoxifen group.

No information was found concerning the use of trastuzumab specifically in older women. NCCN guidelines do not restrict its use in older women.<sup>59</sup>

*Misperceptions regarding breast cancer in older women:* Many of the variances in diagnosis and treatment can be attributed to misperceptions of health care professionals and the patients themselves. These include beliefs that: breast cancer in the elderly is less aggressive; the elderly have limited life expectancy due to other chronic co-morbid conditions; and breast cancer is not as big of a problem compared to other causes of mortality.<sup>60</sup> Other misperceptions include beliefs that older women accept cancer as a part of life and expect to experience losses related to cancer, older women would be better off with surgeries such as mastectomy, and the loss of breast tissue is not significant to older women.<sup>81</sup>

Additionally, many health professionals assume older women could not or do not want to make healthcare decisions.<sup>81</sup> Another assumption is that elderly women are frail and can not handle standard treatments. Contrasting views exist in the literature. Cameron and Horsburgh<sup>28</sup> compared issues faced by younger and older breast cancer survivors and found that older women were more hesitant and less likely to investigate changes they found in their breasts. Older women also delayed talking with a doctor about new or unusual findings in the breast and were less involved than younger women in making treatment decisions. Older women often did what the doctor told them needed to be done and did not remember being given choices for treatment. Younger women were more apt to want to discuss treatment options and participate in decision making.

Crooks<sup>81</sup> found divergent results in her study. Older women stated they were interested in participating in their healthcare, but communicating with physicians was often challenging. Women felt that surgeons and oncologists did not have the time to answer their questions or address their concerns and they did not feel educated enough about treatment options. Older women did want to be involved in decision making, but

were often not given the chance. It was noted that choices for treatment decreased as women aged. The option for mastectomy versus lumpectomy decreased the older the woman was. Interestingly, women remembered being given information to read to help make decisions however older women perceived the written material without a verbal explanation as a lack of interest in them as a person and did not review the materials.

*Summary:* Older women receive different treatment than younger women and are often under-treated or treated with less than standard treatment for their breast cancer. Older women are more likely to receive mastectomy compared to breast conservation therapy (BCT) however, when they do receive BCT, they are less likely to receive radiation therapy. Older women are also less likely to receive chemotherapy. Older women did receive hormonal therapy however; older women with co-morbid conditions were less likely to have this treatment.

### **Surveillance**

Surveillance and follow-up occurs after treatment for disease in order to monitor for side effects and recurrent disease. Current surveillance guidelines established by the NCCN include a history and physical every 4 to 6 months for the first 5 years; mammogram every 12 months (6 to 12 months post radiation therapy is breast conservation therapy was used), pelvic exam every 12 months if a uterus is present and for women on aromatase inhibitors bone health should be monitored.<sup>59</sup> No exceptions were made for older women.

Discussion of surveillance in the literature was limited to follow-up mammography. In 2001, Lash and Silliman<sup>82</sup> investigated the medical surveillance of women over the age of 55 who had early stage breast cancer. Surveillance at the time of this study included annual physical exams and mammography. Results showed that older women (age 75 to 90) were less likely to receive appropriate follow-up and surveillance tests after treatment than younger women.<sup>82</sup> In addition, the farther a woman was from treatment, the less likely she was to continue with follow-up. Women age 75 to 90 were more likely to receive less than 4 years of continuous follow-up compared to women age 55 to 64. Doubeni and colleagues<sup>83</sup> also report differences in surveillance based on age. Older women (age 75 +) were less likely to receive annual mammography than younger women especially if the older women had co-morbid illnesses. Co-morbid illnesses did not have a significant impact on the use of mammography in younger women.

*Breast Cancer Summary:* Age related differences related to screening, diagnosis, treatment and surveillance exist in regards to breast cancer. Older women have a higher likelihood of being under-screened, improperly diagnosed, and under-treated. Older women also receive inconsistent follow-up after treatment compared to younger women. This review of the literature indicates a discrepancy between standardized treatment and practice in older populations. Reasons for this disconnect have been suggested however more research is needed with this older population of women. Research based evidence is clearly more desirable than professional opinion or speculation.<sup>51</sup>

### **CANCER SURVIVORSHIP**

Anyone living with a history of cancer is a survivor. Today, there are more than 10 million cancer survivors in the United States <sup>1</sup> including 2.3 million women surviving with breast cancer.<sup>3</sup> The National Cancer Institute's Office of Cancer Survivorship states

that individuals are considered “a cancer survivor from the time of diagnosis, throughout the balance of his or her life.” Since family member’s, friends and caregivers are impacted by cancer and the survivorship experience, they are included in this definition.<sup>84</sup>

While survival is often associated with survival rates at 5 years often equating with cure of disease, it has also come to be known as a continuum in which patients with cancer experience physical and psychosocial issues after the acute phase of illness.<sup>85-91</sup> Physical effects in survivorship are numerous and include: fatigue<sup>92</sup>, pain, cognitive changes,<sup>92</sup> lymphedema, sexual effects, pulmonary, neurologic, gastrointestinal,<sup>87</sup> and cardiac effects.<sup>87, 93, 94</sup> Psychosocial effects of survivorship include: fear of recurrence, depression, uncertainty in illness, and finding meaning in illness.<sup>90</sup>

The survivorship literature shows how cancer survivors go through changes due to the experience of having cancer and these changes remain with them the rest of their lives. One of the first people to explore survivorship in cancer was Mullan<sup>95</sup> who describes “seasons in survival.” These seasons are identified as: 1) acute survival, 2) extended survival and, 3) permanent survival. Each season has its own struggles for the cancer patient. The acute survival phase is focused on diagnosis and treatment of the disease. Individuals are confronted with their own mortality and are focused on coping with and managing the effects from treatments. The extended survival phase begins after treatment when the cancer patient has less contact with their oncology team. Patients experience a multitude of physical and psychological effects as they try to reenter the world and often begin a “watchful waiting” period that is dominated by fear of recurrence. The permanent phase of survival begins when the cancer patient can reasonably consider themselves cured or the chance of the disease coming back is remote. In this phase, the survivor may become comfortable with the changes that have occurred but may also experience long-term effects.

Dow<sup>96</sup> expands on Mullan’s seasons of survival and discusses the adjustments survivors must make after treatment. The immediate period after treatment is characterized as one of lessening acute side effects, and it is also a dynamic process which holds unique challenges for the survivor. After diagnosis and treatment, support from health care professionals may not be readily available however; this is a time when survivors may need support most. In addition, returning to “normal” may not be possible due to all the physical and psychological changes that have occurred. Fear of recurrence may be extremely prominent for cancer survivors. Lack of education concerning what signs to look for may be prevalent in this population. Uncertainty is also an important factor for survivors. On the positive side, cancer patients are often able to put their experience in perspective and move from surviving to “thriving.” Some survivors find or renew faith and feel confident about the changes in their life. These survivors do not define themselves by their cancer, but return to previous roles as wives, sisters and mothers. Hopefully individuals adjust to the new physical, psychosocial and spiritual changes that occur in survivorship.

Zebrack<sup>89</sup> discusses the potential for cancer survivors to develop a new identity after the cancer experience. As cancer patients integrate the experience of having cancer into their self-concept it may renew or change a person’s sense of self. This new sense of self is challenged in survivorship during times of distress when survivors either meet or fall short of the expectations they have for themselves and their role in society. Meeting



expectations leads to better quality of life while falling short of expectations lowers quality of life. In addition, cancer survivors encounter situations everyday which can be reminders of their own experience with cancer and can reinforce or upset the new sense of self.

Little, Paul, Jordens and Sayers<sup>97</sup> also believe that surviving cancer changes personal identity. Identity is defined in their study as the “sense” of being a certain type of person and includes “future memory” which people construct for themselves as life proceeds. Cancer has the potential to interrupt this identity and future memories due to all the changes it brings both physically and psychosocially. Some people are able to resume lives within the context of their new reconstructed identity others are unable to construct new identity and meaning into their lives leaving them feeling isolated.

Deimling and colleagues (2006) examined the impact of cancer-related worries and psychological distress among cancer survivors and found that for many survivors cancer-related worries persisted for years after treatment. In a sample of older adults with breast, prostate and colorectal cancers, who were an average of 10 years from diagnosis, survivors still worried about their cancer returning (32.5%), symptoms that might indicate recurrence (37.25%), a new type of cancer (30.5%) and future diagnostic tests that might lead to the diagnosis of another cancer or recurrence (39.5%) well after the 5 year “cure” date.

Personal accounts from cancer survivors focus on finding a new balance after treatment. Jenkins<sup>98</sup> describes cancer as an event which has a great potential for learning and growth as well as a time for obstacles. She describes the difficulty of returning to a “normal” life and the persistence of fear of recurrence.

Other researchers have looked at the meaning of quality of life in survivorship. Dow and colleagues<sup>99</sup> identified themes that depict the meaning of quality of life in the eyes of cancer survivors. These themes include: finding a balance between independence and dependence; achieving a sense of wholeness which restores life purpose; search for meaning; managing physical symptoms; facing losses; controlling life instead of being controlled by the cancer; contrast between focusing on the now versus the future; survivorship viewed as a trajectory and dynamic concept; altered meaning of health; and survivorship as a family experience. These themes demonstrate the complexity of the cancer survivorship experience and the potential for different issues to be important at different phases of survivorship.

*Summary:* Anyone living with a history of cancer is a survivor. Cancer survivors go through phases of survivorship, experience changes in their self-concept, reconstruct their identity and experience late physical and psychosocial effects. Survivorship is a unique and often complex experience in which quality of life is an important aspect. An aspect of survivorship that is lacking in the literature concerns differences between older and younger cancer survivors. It is unknown if survivorship issues are the same for these different populations. Research is needed to investigate survivorship in different populations.

## **QUALITY OF LIFE**

Quality of life is an important aspect of survivorship and was first discussed in the literature in 1953. This concept gained rapid popularity in the 1970’s and 1980’s and now over 92,000 articles in PubMed use “quality of life” as a keyword. Quality of life is

a term that is used by both patients and health professionals. It is recognized as a multidimensional concept with perception based on the subjective experiences of the individual assessing it.<sup>100-104</sup> However, despite its extensive use in research, King and colleagues<sup>102</sup> suggest that there are “gaps in theory, research and practice” (p.27) related to quality of life. Lack of a uniform definition of QoL may be the basis for these issues.

Meeberg<sup>105</sup> defines quality of life as a subjective experience that defines a feeling of overall life satisfaction. The World Health Organization<sup>106</sup> defines QoL as “an individuals perception of their position in life in the context of the culture and value system in which the live and in relation to their goals, standards, and concerns”. Ferrans and Powers<sup>107</sup> define QoL as “the persons sense of wellbeing that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.” Ferrell and colleagues define quality of life as a personal sense of wellbeing which encompasses physical, psychological, social and spiritual dimensions.<sup>108-110</sup>

In many instances the concept of QoL is clarified by researchers through “domains” or dimensions which are used to measure the concept. Different researchers measure the concept in different ways. Ferrell and colleagues<sup>108-113</sup> use 4 domains to help define the concept: physical, psychological, social and spiritual well-being. Ferrans<sup>114</sup> uses similar domains of health and functioning, socioeconomic, psychological/spiritual and family. Other researchers such as Cella and Tulsky<sup>101</sup> use the domains of physical concerns, functional ability, family well-being, emotional well-being, spirituality, treatment satisfaction, future orientation, sexuality/intimacy, social functioning and occupational functioning to describe QoL. Aaronson<sup>100</sup> uses physical functioning, disease symptoms and treatment side effects, psychological status, social functioning, general health perceptions, physical suffering, self-care activities, outlook on life, meaningful activities and social relationships to describe QoL. Measurement tools exist that correspond to each of these researchers conceptualization of quality of life.<sup>102</sup> These tools enable researchers to look specifically at the QoL of patients on both individual group levels.<sup>103</sup> The different domains examined by researchers demonstrate the multidimensionality of the concept and the uniqueness of its conceptualization.

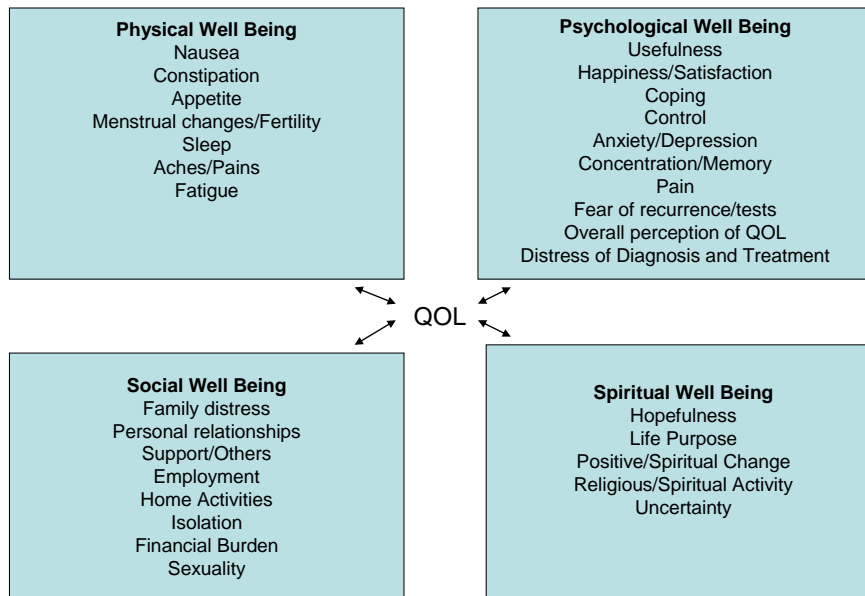
King and colleagues<sup>102</sup> suggest that the concept of quality of life may be discipline specific and concept analyses may need to take place in each discipline and then compared in order to determine how the term is used across disciplines. In addition, King and colleagues<sup>102</sup> suggest that QoL is dynamic and changing. QoL should be measured on a continuum as QoL at one time point may not predict QoL at subsequent time points. The evaluation of QoL takes place in social context and is only reflective of the appraiser’s cognitive view of their life at the time of the survey.<sup>104</sup>

The conceptual framework for this dissertation is based the Conceptual Model for Quality of Life in Breast Cancer survivors (QoL-BC) that was developed by Ferrell and colleagues in 1996. The QoL-BC model was adapted from previous conceptual models developed by Ferrell and colleagues that had been used in cancer survivors.<sup>112</sup> While examining quality of life in long-term cancer survivors through the use of both qualitative and quantitative methods, the researchers were able to identify aspects of cancer that were specific to breast cancer survivors.<sup>111</sup> This led to the development of the Quality of Life-Breast Cancer instrument and the conceptual model for Quality of Life in Breast Cancer survivors (QoL-BC).

This conceptual model (QoL-BC) consists of quality of life interacting with and being influenced by the domains of physical well-being, psychological well-being, social well-being and spiritual well-being (See below). Each domain has been defined by the researchers and describes “concepts” or factors that influence the overall domain. The definitions for the domains are as follows:

*Quality of life:* Quality of life is a personal sense of wellbeing which encompasses physical, psychological, social and spiritual dimensions.<sup>108-110</sup>

*Physical well-being:* “The control or relief of symptoms and the maintenance of function and independence.”<sup>115</sup>



Original Quality of Life Model for Breast Cancer Survivors

Concepts within this domain include: nausea, constipation, appetite changes, fertility and menstrual changes, sleep, pain, and fatigue.

*Psychological well-being:* “Seeking a sense of control in the face of life threatening illness characterized by emotional distress, altered life priorities, and fears of the unknown, as well as positive life changes”<sup>115</sup> Concepts within this domain include: fear of

recurrence and tests, usefulness, happiness and life satisfaction, coping, being in control, anxiety, depression, cognitive changes, distress from treatment and an overall perception of QoL.

*Social well-being:* “a way to view not only the cancer or its symptoms, but also the person surrounding the tumor; it is the means by which we recognize people with cancer, their roles, and relationships.”<sup>115</sup> Concepts within this domain include: family distress, personal relationships, support, employment and financial burden, sexuality, isolation and activity at home.

*Spiritual well-being:* “the ability to maintain hope and derive meaning from the cancer experience that is characterized by uncertainty. Spiritual well-being involves issues of transcendence and is enhanced by one’s religion and other sources of spiritual support.”<sup>115</sup> Concepts within this domain include having hope, purpose in life, uncertainty, and religious and spiritual changes/ activity.

The Quality of Life Model for Breast Cancer Survivors is a framework that is applied to all women with breast cancer. At this time, it is unclear what concepts within each domain are relevant to older women with breast cancer. This framework will be modified for this dissertation. Future research may examine how this framework directly applies to older women with breast cancer.

## **Rationale for a Quality of Life Framework**

Quality of life is a valid theoretical/conceptual framework for nursing to apply to many populations including older women with breast cancer because it is a holistic approach to assessing and evaluating the lives of these women after cancer. Additionally, a quality of life framework fits this student's interests and research questions developed for the dissertation research.

Many of the strengths of a quality of life construct for older women with breast cancer lie in its uses and are important for many reasons. *First*, with cancer now being classified as a chronic illness, focus on outcomes of treatment has changed from quantity of life to quality of life. Discomfort and disability due to treatments in a life that may extend many more years is simply unacceptable. Quality of life is a self-reported measure that can compliment the clinically derived mortality rates used to determine if treatments are appropriate in cancer care. In addition, research involving quality of life in older women with breast cancer can impact the development of treatment guidelines for this ever-growing population. *Second*, older women comprise the largest group of women with breast cancer. Due to the lack of knowledge previously mentioned concerning diagnosis and treatment in this population, quality of life in clinical trials and other research is an important outcome to determine best practice for these older women. Older women treated for their breast cancer will be surviving with cancer and are at risk for long-term side effects. It is crucial that quality of life in these women become a focus so they can live their lives independently and with as few side effects as possible. *Third*, quality of life outcomes can provide a patient focused perspective of QoL after treatment and help guide the development and effectiveness of interventions designed to improve the lives of older women after treatment for breast cancer.

The remainder of this literature review will focus on quality of life in cancer survivorship using the domains established by Ferrell and colleagues.

## **Quality of Life in Cancer Survivorship**

This review of the literature intends to provide the state of the science concerning issues related to quality of life in older women surviving with early stage breast cancer. An overview of quality of life issues will be provided and when available, information specific to women age 65 and older will be discussed.

The literature that discusses quality of life (QoL) in older breast cancer survivors is far from comprehensive. Many studies that examine QoL report the average age of the participants as being near 50 years.<sup>108, 111, 112, 116-122</sup> Unfortunately, these data can not be generalized to an older sample. Some studies have looked at differences between quality of life in younger and older women and provide information in regards to women in specific age groups.<sup>4, 5, 11, 116, 123-126</sup> Other studies have focused specifically on older women with breast cancer<sup>6, 9, 127-134</sup>. Exclusion or lack of participation of older women in clinical trials has led to a knowledge deficit in many areas regarding the older women with breast cancer.

**Overall Well-Being:** Quality of life is often reported in relation to symptoms being experienced by survivors compared to controls. For example: women who

continue to experience symptoms such as fatigue and menopausal symptoms reported poorer quality of life than non-cancer controls.<sup>135</sup>

Health-related quality of life (HRQoL) has also been compared to the general population. Bardwell and colleagues<sup>136</sup> noted that breast cancer survivors who averaged 2 years from diagnosis reported high health-related QoL that was comparable to controls. Poor physical HRQoL was related to poor psychosocial functioning, poor sleep quality, less physical activity and obesity. Poor mental HRQoL was related to poor sleep quality, pain, gastrointestinal symptoms and more life events.

Arndt and colleagues<sup>137</sup> also compared QoL of breast cancer survivors to controls at 1 and 3 years post-diagnosis. At 3 years, the overall QoL in breast cancer survivors was comparable to controls. Women with breast cancer reported slightly worse physical functioning but larger deficits in role, emotional, social and cognitive functioning. Symptoms that persisted at 3 years included fatigue, pain, insomnia and shortness of breath. These symptoms were more severe in younger age groups.

Vinokur and colleagues<sup>138</sup> examined physical and psychological functioning and adjustment in breast cancer survivors. They were surprised to find that women with early stage disease who had survived over 5 years show positive adjustment to disease. Compared to controls without a history of breast cancer, they had the same levels of physical functioning and reported similar psychological and social well-being as the control group. Interestingly, these survivors rated their breast cancer experience as “a little” stressful compared to non-cancer controls who rated their most stressful condition to date as “somewhat” stressful. The researchers speculate that it is the low severity of disease (early stage) that led to the excellent adjustment.

Additionally, how women with breast cancer perceive the side effect burden affects quality of life. Longman, Braden and Mishel<sup>139</sup> looked at psychological adjustment, side effect burden and quality of life in breast cancer survivors over time. The study demonstrated that negative feelings such as depression and anxiety persist and are burdensome for survivors. This negatively impacts quality of life. This finding was consistent at all time points in the study.

Vacek and colleagues<sup>12</sup> also looked at factors that influenced quality of life in breast cancer survivors. This study compared women treated for breast cancer with a group that had benign breast biopsies. This study was conducted over time to ascertain trends. Using the Quality of Well-Being Instrument, quality of life declined over time for the breast cancer survivors. Presence of co-morbidity was related to significantly lower QoL scores. Survivors who were married showed a slower decline in quality of life. Older survivors had a more rapid decline in their quality of life scores.

On the contrary, Kenefick<sup>9</sup> reported that older women have better global quality of life scores than younger women and experience less symptom distress. Quality of life in older women has been shown to improve over time as well.<sup>5,9</sup>

Overcash<sup>140</sup> conducted interviews with older women with breast cancer which resulted in descriptive qualitative data reflecting quality of life in these women. Eight major themes emerged: importance of God, importance of a positive attitude; no alteration in lifestyle; physician trust; caregiver to others; need to protect family; importance of health and importance of family. Additionally, many of the women who participated in the study had active lives despite diagnosis and treatment. Overall, women were able to maintain their activity level in spite of breast cancer and being ill at

times. This study emphasized that preconceived notions of older women being ill and dependent are exaggerated as older women are able to keep up with their active lifestyle despite having cancer.

*Summary:* Women of all ages diagnosed with breast cancer share common concerns but also have unique needs. Due to the heterogeneity of women, age related differences related to breast cancer occur from diagnosis into survivorship. Overall, QoL seems positive. Sammarco<sup>141</sup> states that every woman will adapt to breast cancer and make choices based on their own personal history, psychosocial stage and current concerns based on their stage in life. Survivors who are able to adjust to having cancer often have comparable QoL to non-cancer peers. As a group, older women adjust well to breast cancer and often report better QoL scores than younger women. However, those with co-morbid illnesses may report lower QoL. Older women remain active after diagnosis despite treatment and side effects and long-term effects.

**Physical Well-being:** Any cancer survivor may experience a wide range of symptoms and side effects after diagnosis and treatment. Physical well-being is defined as “the control or relief of symptoms and the maintenance of function and independence.”<sup>115</sup>

*Fatigue:* Fatigue is one of the most frequently reported symptoms.<sup>4, 6, 9, 13, 109, 111, 120, 142-146</sup> Fatigue has been noted to be a problem for breast cancer survivors both immediately after treatment<sup>145</sup> and over time.<sup>9, 111, 146, 147</sup> Ferrell and colleagues<sup>111</sup> studied a group of cancer survivors an average of 6.6 years after diagnosis and noted that fatigue was the top physical issue for these survivors. Servaes and colleagues<sup>146</sup> also noted long-term fatigue in breast cancer survivors. In a sample of women who completed treatment an average of 29 months previously, 38% stated they were severely fatigued. Compared to survivors that did not have severe fatigue, these patients reported worse physiological well-being, more functional impairment, more sleep concerns, lower physical activity, poorer social support and social functioning. No association was made between prior treatment received and current level of fatigue.

Fan and colleagues<sup>135</sup> also noted fatigue in long term breast cancer survivors compared to controls. Hormonal therapy had a small effect on fatigue levels. Women taking hormonal therapy tended to be more fatigued at 2 years but this effect was not statistically significant. In addition, an association was found between fatigue and the severity of menopausal symptoms.

Fatigue has been shown to decrease over time. Fatigue has been reported as most severe during treatment but decreases one year after treatment.<sup>147</sup> Fatigue affects overall quality of life and domains of quality of life. Using the Medical Outcomes Study Short Form General Health Survey, Byar and colleagues<sup>147</sup> noted that fatigue affected the physical, social, bodily pain, mental, vitality and general health domains.

While looking at patterns of symptom distress in older women (mean age of 68 years) after surgical treatment for breast cancer, Kenefick<sup>9</sup> noted fatigue to be a persistent problem and the number one distressing symptom at each time point in the study. Fatigue distress was measured after discharge and at 3 and 6 months. Fatigue related distress did improve over time most notably from discharge to 6 months. Fatigue was also repeatedly correlated with concentration over time.

*Pain:* Pain is one of the most frequently reported symptoms.<sup>5, 6, 9, 10, 13, 121, 133, 143</sup> Pain in breast cancer survivors can be due to surgery,<sup>148-150</sup> lymphedema<sup>151</sup> or co-morbid conditions such as arthritis<sup>8, 133</sup>

Post-mastectomy pain (PMP) can be experienced by women with breast cancer well into survivorship. MacDonald and colleagues<sup>150</sup> examined women with chronic PMP approximately 9 years after their surgery. Over half of their sample reported the persistence of PMP. Younger women were particularly at risk. Women who experienced PMP reported functional limitations and difficulty with activities of daily living as well as lower quality of life scores. Pain can also be present in women who receive lumpectomy and breast conservation therapy and in women who elect breast reconstruction.<sup>148</sup>

In comparative studies, it has been noted that both younger and older women experience pain<sup>124</sup>, but older women experience more pain.<sup>4, 5</sup>

*Lymphedema:* Lymphedema (LE) and arm symptoms are frequently reported side effects of breast cancer treatment<sup>5, 10, 142, 143, 151-155</sup> Women with any type of lymph node removal are at risk for LE however, those who receive axillary lymph node dissection experience more symptoms of LE than women with sentinel lymph node biopsies. Symptoms may include: numbness and tingling, firmness or tightness in the arm and larger arm size.<sup>155</sup> Women with LE report frustration, anxiety, depression, changes in role functioning, pain, disability and poor social support.<sup>156</sup>

Ridner<sup>153</sup> found that women with lymphedema consistently scored lower on multiple QoL instruments compared to women without LE. Symptoms associated with LE in this group included: altered limb sensation, decreased physical activity, presence of fatigue, psychological distress and loss of confidence in the body. Additionally, women's perception of limb size, not objective or measured limb size, influenced the experience of having LE.

Armer and Fu<sup>151</sup> have studied the occurrence of lymphedema (LE) in older breast cancer survivors. Incidence of LE for older women was lower (31%) when compared to incidence in younger women (41%). The difference in incidence may be due to less extensive surgery in older women. Women with and without documented diagnoses of lymphedema reported experiencing symptoms such as numbness, tenderness and aching in the affected arm. Older women had a tendency to report these symptoms less than younger women. With the projected number of older women that will be diagnosed with breast cancer over the next several decades there is a risk for both under-diagnosis and under-treatment of lymphedema in this growing population.<sup>152</sup>

*Menopausal Symptoms:* Symptoms of menopause have been reported as a concern of women treated for breast cancer.<sup>135, 157-160</sup> Fan and colleagues<sup>135</sup> report that women who received chemotherapy (n=104) experienced more menopausal symptoms than the non-treated control group. In this sample, the use of hormonal therapy did not impact menopausal symptoms. However, more women were treated for hot flashes as time progressed.

Carpenter and Andrykowski<sup>158</sup> also examined the presence and severity of menopausal symptoms in breast cancer survivors and its impact on quality of life. The most commonly reported and most severe symptoms were: joint pain, fatigue, trouble sleeping and hot flashes/night sweats. Other symptoms reported were vaginal dryness and painful sexual intercourse. The total number of symptoms was related to years in

post-menopause. Women who experienced fewer years of menopause reported more symptoms. Sixty percent of this sample reported 6 or more symptoms of menopause. Additionally, the more symptoms a women experienced and higher the severity of symptoms, the lower women rated their physical and emotional QoL.

The presence of menopausal symptoms in breast cancer survivors has been compared to non-cancer controls and found to be similar in both groups.<sup>159, 160</sup> Schultz and colleagues<sup>160</sup> concluded that breast cancer and menopause were 2 separate issues and the menopausal symptoms women experienced may not have been breast cancer related.

Hot flashes have also been noted in older breast cancer survivors.<sup>6</sup> In a sample consisting of women over the age of 65 with a history of breast cancer, hot flashes were repeatedly named as one of the top ten symptoms experienced up to a year after diagnosis. Out of 246 women, 3.3% ranked hot flashes as a concern.<sup>6</sup>

*Weight gain:* Weight gain and weight changes have been linked to developing breast cancer<sup>161, 162</sup> and to higher rates of recurrence and mortality in breast cancer.<sup>163, 164</sup> Risk factors of weight gain in breast cancer survivors include time since diagnosis, receipt of adjuvant chemotherapy and high body mass index at time of diagnosis. Additionally, women who did not exercise gained more weight.<sup>165</sup>

Weight gain has been a reported concern of breast cancer survivors.<sup>93, 162-169</sup> Weight gain can begin during chemotherapy<sup>167</sup> and continue into survivorship as women take endocrine therapy.<sup>93, 168, 170</sup> McInnes and Knobf<sup>169</sup> analyzed weight gain and QoL in women who received adjuvant chemotherapy for early stage breast cancer. In their sample, 78% had gained weight (average 9 lbs.) one year after treatment. Women maintained this weight gain at 3 years. Greater weight gain was seen in pre-menopausal women. Women who took Tamoxifen gained more weight than women who did not, but this result was not statistically significant. Although, weight gain did not affect overall QoL, women were distressed by the gain.

Weight gain has been noted as a problem in older breast cancer survivors. Heidrich and colleagues<sup>8</sup> reported that weight gain was one of the 10 most distressing symptoms for older women after breast cancer however, none of the women in this sample attributed their weight gain as being cancer related. Instead weight gain was attributed to chronic illness or the aging process.

*Insomnia:* Insomnia and sleep disturbances have been examined in breast cancer survivors. Disturbances in sleep often begin in treatment and persist into survivorship.<sup>147, 171</sup> Savard and colleagues<sup>171</sup> conducted a randomized clinical trial to evaluate the effectiveness of Cognitive Behavioral Therapy for insomnia in women with breast cancer. Women who received the intervention reported better sleep than controls. In addition, treated women also reported using less sleep medication, had decreased anxiety and depression and better global QoL than the control group.

Women who report sleep disturbances also report more symptom distress. Pain, fatigue, bowel problems, and lack of concentration were associated with insomnia.<sup>9</sup> Older women were noted to experience sleep changes however the literature does not go into great detail concerning this issue. 4, 6, 9, 172

*Physical Functioning:* Physical functioning in breast cancer survivors is usually comparative and results vary widely. Schroevers and colleagues<sup>126</sup> found that women of any age with cancer experience difficulty with physical functioning. However, at 8 years



after diagnosis, older cancer survivors were more likely to have more physical symptoms and limitations than younger women. In addition, younger survivors were more likely to appreciate themselves and believe that life was more fulfilling compared to older survivors.<sup>126</sup>

In a study looking at physical functioning in older cancer survivors, Cimprich and colleagues<sup>4</sup> noted that older women report lower physical functioning compared to middle aged women and men of different ages. Older women reported more problems with fatigue, pain, constipation and sleep changes while younger women have more problems with menstrual and fertility issues. The number of co-morbid illnesses also correlated to lower physical functioning.

In a different study, Satariano and colleagues<sup>11</sup> compared the functional status of women with breast cancer (ages 55 to 84) to controls without breast cancer using the Instrumental Activities of Daily Living (IADL) survey. The IADL evaluates transportation, housekeeping, meal preparation and grocery shopping. Results showed that women with cancer, ages 55 to 74, had the most problems with functioning compared to controls within that age group. The oldest women in their sample (age 75 and older) reported the fewest functional problems compared to similar aged controls. Breast cancer in the oldest age group was not associated with poorer functioning. Interestingly, physical impairments and deficits in functioning were not always perceived by older breast cancer survivors as being attributable to having breast cancer. Aging and chronic illness were often reported as the cause of current symptoms.<sup>8</sup>

In a study that looked at quality of life in long-term breast cancer survivors, women who were older at diagnosis reported worse physical functioning and more pain compared to younger women at both 7 and 12 years from treatment. Older women also noted more arm symptoms than younger women. However, global quality of life increased for older women at 12 years.<sup>5</sup>

Wenzel and colleagues<sup>117</sup> reported that older women reported more health problems that were unrelated to their cancer and higher quality of life than younger women.

*Summary:* Physical problems are common in breast cancer survivors. Women experience fatigue, pain, LE, insomnia, weight gain, menopausal symptoms and decreases with physical functioning. Older women report that fatigue persists over time, have more pain than younger women, fewer menopausal symptoms and more issues with physical functioning. Age and chronic illness seem to be negatively associated with physical functioning however the data on physical functioning has shown conflicting results and may be sample specific.

**Psychological Well-being:** Psychological well-being is defined as “seeking a sense of control in the face of life threatening illness characterized by emotional distress, altered life priorities, and fears of the unknown, as well as positive life changes”<sup>115</sup>

*Fear of Recurrence:* Fear of recurrence is extremely common among breast cancer survivors.<sup>10, 110, 111, 133, 143, 173, 174</sup> In a study focusing on breast cancer and psychosocial well-being in early stage breast cancer survivors, Spencer and colleagues<sup>174</sup> report that fear of recurrence is the number one concern of survivors. Ferrell and colleagues<sup>110</sup> report that even though women fear recurrence, they are able to balance hope with these fears. Women were hopeful that new treatments would be available if their cancer

returned. Other fears such as fear of more treatment and instances of poor health have also been described by survivors.<sup>175</sup>

While women with breast cancer share concerns with fear of recurrence,<sup>10, 143</sup> older women seem to have less fear.<sup>10</sup> Older survivors may experience these fears many years after diagnosis. Gil and colleagues<sup>133</sup> studied older women 5 to 11 years after treatment and found that on average, older women have 1.8 experiences per month that trigger feelings of uncertainty and fears of recurrence. The most common trigger was hearing of some one else being diagnosed with cancer. Other triggers included: new aches and pains or physical symptoms, information from the media and environmental factors that remind the survivor of their experience. Uncertainty regarding breast cancer lasts well into survivorship.

*Cognitive changes:* Cognitive changes have been reported as a problem for breast cancer survivors<sup>4, 123, 135, 172</sup> Cimprich and Ronis<sup>172</sup> compared attention and symptom distress in women with and without breast cancer. When comparing attention in these groups at baseline, the breast cancer group had lower attentions scores than the control group. At 3 months, the breast cancer group had gradually improved their attention scores. However, loss of concentration was still a distressful symptom for breast cancer survivors even though their overall attention scores had improved.<sup>172</sup>

Cognitive changes (loss of concentration) also occur in older breast cancer survivors.<sup>123, 172</sup> Cimprich<sup>123</sup> stated that the normal processes of aging results in the lowered ability of women to focus and concentrate. As a result, older women are more at risk for attention fatigue after treatment for breast cancer. In this study, older women had lower attention scores and lower attention performance over time compared to younger women, Older women who received mastectomy were most affected by these cognitive changes.

*Depression:* Depression impacts women with cancer in several ways. Badger and colleagues<sup>176</sup> specifically looked at the effect of depression burden and psychological adjustment and quality of life in women with breast cancer over time. Women who reported a higher level of depression burden at baseline experienced poor psychological adjustment than women with low levels of depression burden. In addition, women with high levels of depression reported lower overall quality of life. Women with high levels of depression benefited from an intervention and were able to report improved quality of life compared to women who did not receive an intervention.

Goodwin and colleagues<sup>166</sup> looked at the effects of depression on diagnosis, treatment and survival of older women with breast cancer. Results of their study showed that women who had a diagnosis of depression prior to the diagnosis with breast cancer were less likely to receive definitive treatment and had poorer survival rates. The reasons for the poorer survival rates are unknown but may be due to adherence to appropriate screenings and medical recommendations.

*Effect of Symptom Distress:* When studying the psychological well being of older women with chronic illnesses (breast cancer or osteoarthritis) Heidrich<sup>7</sup> found that women with arthritis reported more symptoms and functional health problems than did women with breast cancer. Women with arthritis also viewed their chronic illness as more severe, less controllable and more chronic than women with breast cancer. Women with arthritis were more bothered by symptoms and portrayed their physical health more negatively than women with breast cancer. Women also compared

themselves with other women they knew and were able to make upward and downward comparisons. These comparisons influenced psychological well-being.

When comparing older women with and without breast cancer Heidrich and colleagues<sup>8</sup> noted that both groups of women reported multiple symptoms but had low levels of symptom distress. In addition, women with breast cancer rarely associated their symptoms with breast cancer but instead attributed symptoms to aging and other chronic illnesses. Women often rated the cause of their symptoms as unknown and this correlated with poorer social functioning and mental health, less energy, lower perception of purpose in life, and higher levels of depression and anxiety negatively impacting quality of life.

*Summary:* Women with breast cancer often continue to fear recurrence, have cognitive changes, depression and symptom distress. Older women seem to fear recurrence less than younger women. Older women experience more cognitive changes possibly due to the changes of aging. Depression has been linked to lower QoL in women with breast cancer and with poorer survival rates in older women. Compared to controls, older women with breast cancer seem to have better QoL than some women with other chronic illnesses such as osteoporosis and often fail to associate “symptoms” with their breast cancer, instead attributing symptoms to age and other chronic illnesses.

**Social Well-being:** Social well-being is defined as “a way to view not only the cancer or its symptoms, but also the person surrounding the tumor; it is the means by which we recognize people with cancer, their roles, and relationships.”<sup>115</sup>

Thewes and colleagues<sup>143</sup> compared the psychosocial needs of older and younger breast cancer survivors and found that younger women had more unique needs. Younger women were more concerned with their careers and had a greater number of concerns about relationships, sex and fertility. Younger women were more likely to want and seek out additional support from professionals than older women. Older women discussed not wanting information about their treatment as a way lessening anxiety. Finally, younger women spoke about feeling very isolated as a young woman with breast cancer due to its rarity in women their age.

*Body Image:* The effects of breast cancer on body image have been reported in the literature. Ganz and colleagues<sup>124</sup> found that women who received breast conservation treatment had significantly fewer problems with their body image compared to women who received mastectomy or reconstruction. Pinto and Trunzo<sup>122</sup> looked at body esteem among breast cancer survivors. Women who exercised reported better body esteem and better mood states (less confusion, fatigue, and depression and higher vigor) than survivors who did not exercise.

Although King and colleagues<sup>10</sup> reported that older women have better body image than younger women, older women are still concerned about body image. Figueiredo and colleagues<sup>128</sup> found that body image was important for 31% of their sample (mean age 74 years) when making treatment decisions. At 2 years after treatment, older women who had breast conservation surgery had better body image than women who received mastectomy. Additionally, women who wanted breast conservation treatment and received mastectomy had the poorest body image. Other studies have also shown that body image for the older woman improves over time.<sup>5</sup>

*Employment:* Concerns regarding work and employment are most likely experienced by younger breast cancer survivors due to their age. Maunsell and colleagues<sup>177</sup> used qualitative methods to explore work problems after breast cancer in a small sample (n=13) of survivors. Several concerns emerged from the interviews. Women worried about returning to work. Some feared not being able to perform the tasks they did prior to treatment and others worried that the changes in their physical appearance would cause co-workers to look closely at their bodies. Some women experienced changes in their job that they did not ask for. Women were demoted, given modified tasks or lost their jobs. Others felt their relationship with their boss and co-workers changed. Many women felt they had a decreased ability to do their jobs and cited fatigue and arm problems as the cause. Work also became less of a priority after treatment and returning to work. Bloom and colleagues<sup>178</sup> also found that continuing to work created conflicts for women. Due to fatigue, some women were too tired to work during treatment. Some women found they had unsympathetic employers. Other women quit their jobs and made a career change.

In other studies, women used the return to work to gain a sense of normalcy and to relieve financial burdens incurred due to the breast cancer diagnosis.<sup>109</sup>

Generally, it has been shown that older women have less concern over employment, work, and financial issues compared to younger women.<sup>5, 27</sup>

*Sexuality and Sexual Functioning:* Ganz and colleagues<sup>124</sup> examined sexual functioning in breast cancer survivors. The majority of the sample was sexually active at the time of their participation in the study (60%). The women at greatest risk for sexual dysfunction were post-menopausal women under the age of 50 and those who received chemotherapy. Tamoxifen was not noted to significantly contribute to sexual dysfunction in breast cancer survivors over the age of 50.

Speer and colleagues<sup>130</sup> also looked at sexual functioning in long-term (mean: 4.4 years) breast cancer survivors. Sexual functioning was not linked to type of treatment or hormone levels but, sexual functioning was significantly poorer in survivors compared to controls. Survivors who were depressed had lower levels of sexual desire and survivors who had relationship distress reported poor arousal, lubrication, orgasm and sexual satisfaction. In addition, survivors with poor body image also had low levels of sexual satisfaction.

Information concerning the impact of breast cancer on sexuality in older women is uncertain. Wyatt and Friedman<sup>13</sup> report that sexual concerns were the highest reported quality of life concern among midlife and older women. Cimprich and colleagues<sup>4</sup> report that although breast cancer impacts sexuality, that impact is low in older women. Spencer and colleagues<sup>174</sup> also report that older women had less concern over sexual issues and partner related concerns than younger women.

*Relationships, Support and Social Functioning:* The impact of breast cancer on relationships has been reported. Holmberg and colleagues<sup>119</sup> explored the impact of breast cancer on relationships and found breast cancer caused both physical and psychological changes in women impacted their relationships. Women felt shame, undignified and embarrassed by the changes in their bodies and had difficulty looking at themselves. Psychologically, they did not feel adequate in their role as woman or partner. Women looked at themselves differently after breast cancer. Women also

reported fatigue, vaginal dryness, loss of libido, and depression which they attributed to their decrease in desire and sexual response.

Partners of the women with breast cancer expressed less concern over their partner's appearance but more concern over their partner's survival. Partners also expressed concern over reconstructive surgery fearing that it was an unnecessary operation or that it might cause their wife more pain and discomfort.

Women without partners reported negative comments about their physical appearance from prior partners and feared these responses from future partners. Unpartnered women also found that breast cancer did not strengthen their relationships but may have hastened the demise of troubled relationships. Partnered women believed cancer strengthened their relationships with their spouses.

The changes in how women viewed themselves affected their sexual relationships as well as other relationships. Friendships sometimes changed as women found close friends becoming more distant however, women were able to draw support from other friends and new relationships. Variable responses from employers and co-workers were discussed. Most women were supported, however some lost their jobs due to cancer related side effects and time needed off from work.

Ganz and colleagues<sup>124</sup> found that younger women encountered more difficulty in relationships than older women. In addition, younger un-partnered women were very concerned about dating issues such as telling a date about their cancer or beginning a sexual relationship.<sup>119, 124</sup>

It has been reported that older women have better social functioning compared to younger women.<sup>10 134</sup> Partners and adult children were found to be important sources of support for women. Families that were able to adjust to the breast cancer predicted better mental health (less depression and anxiety) for the cancer survivor.<sup>179</sup> Older women with limited social support were less satisfied with their lives<sup>180</sup> Sammarco<sup>134</sup> reported that older women who have better social support also rate their overall quality of life as better. Social support was correlated with less disease related uncertainty. Social support was also seen to lessen as women got older.

*Summary:* Women with breast cancer experience similar issues and concerns related to body image, employment, sexuality, relationships and support. Older women seem as concerned with body image and sexuality as younger women, but less concerned with employment issues. Physical and psychological issues do impact relationships and younger women who do not have partners experience anxiety over future relationships. Older women report equal if not better support than younger women and this support correlates to overall quality of life.

**Spiritual Well-being:** Spiritual well-being is defined as “the ability to maintain hope and derive meaning from the cancer experience that is characterized by uncertainty. Spiritual well-being involves issues of transcendence and is enhanced by one's religion and other sources of spiritual support.”<sup>115</sup>

*Religion and spiritual beliefs:* When exploring the impact of breast cancer on spiritual well-being, Ferrell and colleagues<sup>110</sup> found using formal religious practices and having spiritual beliefs helped support women in survivorship. Women in their study were concerned with uncertainty and hope and discussed how cancer altered their priorities and life meaning.<sup>110</sup> Cotton and colleagues<sup>181</sup> also noted that having an active

religious life was significantly associated with spiritual well-being. However, this study noted no significant difference in QoL between women who did and did not actively practice religion.

Women also discussed having a relationship with God and being able to rely on God for support and guidance. The presence of God was felt by many women in their lives and this made women feel supported. Women used activities such as prayer, either their own prayers or prayers from others to help them cope with their illness.<sup>182</sup>

Spiritual well-being has also been examined in relation to symptom distress. Manning-Walsh<sup>120</sup> looked at psychospiritual well-being and symptom distress in cancer survivors. Although symptom distress was reported as low by this sample, there was an inverse relationship between symptom distress and psychological, spiritual, and psychospiritual well-being. In addition, younger women had significantly lower psychospiritual well-being compared to older women.

Manning-Walsh<sup>183</sup> also examined spiritual struggle and its relation to quality of life. Women who had greater spiritual struggles reported lower quality of life and lower life satisfaction.

Fehring and colleagues<sup>184</sup> examined spiritual well-being, religiosity, hope, depression and mood states in older people with cancer. Being highly religious was found to be positively related to hope, mood and spiritual well-being and negatively related to depression and negative mood states. Older cancer survivors used religion and spiritual beliefs to cope and keep life in perspective.

Feher and Maly<sup>127</sup> also found that religion and spirituality helped older women to cope. Women felt that their religious and spiritual faith helped give them the emotional support they needed in order to cope with the breast cancer and make meaning in their illness. Their faith gave them a sense of companionship and being taken care of. Faith gave older women emotional support, helped them control fears, take comfort and have a sense of well-being. Older women also used their connections to the church to keep a social connection with others. Being associated with a church or religious community allowed women to keep in touch with others through volunteer work and their relationship with the leader of their church. Women also liked being prayed for by others. Women felt protected, loved and unafraid due to the presence of God in their lives.

*Meaning:* Meaning has been examined in several ways: meaning in life and meaning in illness. Gall and Cornblat<sup>182</sup> examined meaning in breast cancer survivors and found that many women believed their cancer was serving a Divine purpose. Albaugh<sup>185</sup> also found that some women viewed breast cancer as a wake up call so they could find out what was really important in their lives. Others thought God was asking something of them. Some believed cancer was just a part of life and did not know why they got the cancer, but life had meaning despite this. Meraviglia<sup>186</sup> noted that meaning in life for breast cancer survivors was positively related to psychological well-being and negatively related to symptoms and physical well-being.

Utley<sup>131</sup> looked at meaning in illness in older long-term breast cancer survivors. Women were found to go through 3 distinct phases of meaning. The first phase viewed cancer as sickness and then death. In this phase women talked about expecting to feel sick if they had cancer and how their expectation did not correlate with how they really felt. The second phase viewed cancer as an obstacle and something they had to get over.

In this phase they realized cancer was something they could live with. In the third phase, cancer was viewed as transforming. Women realized that their lives had changes and could see how cancer benefited them and their lives.

Through grounded theory, Crooks<sup>81</sup> developed the theoretical model of *Living Day by Day* in which older women went through several phases before coming to terms with and finding meaning in their disease. Initially, women “faced the music” by finding out about their diagnosis and taking action against it (treatment). “Getting back to normal” after treatment was a considerable task for older women. In this phase, women acknowledged the physical changes they experienced such as pain or the loss of a breast and strategized to assimilate these changes into their lives. In addition, older women were able to realize that having cancer changed how other people viewed them as individuals. This caused older women to protect family members by downplaying their own fears and concerns and sharing information about themselves with others in similar situations or with those who were perceived as caring about their situation. “Getting perspective” is the third phase in which older women sought perspective on both their disease and life expectancy. Women made decisions for themselves based on their analysis or perspective. Older women compared themselves to other women in similar situations and with different illnesses to determine if their problems were more or less significant compared to other women. Older women used this strategy to affirm that their previous decisions were correct and to determine how much effort should be given to concerns about the diagnosis and fears of recurrence. Finally, “being different than before” was acknowledged by older women. Women became aware of the isolation or aloneness caused by the diagnosis and the need for time to make sense of the changes that have occurred. Older women also examined their belief systems and the important things in life were stressed. Ultimately, this process of finding meaning in illness and the outcomes and changes it caused allowed women to reach a different level of living in which each day was lived to its fullest possible potential.

*Summary:* Women who are religious use their faith as a source of support during all phases of cancer survivorship. Higher faith often correlated with lower distress. Additionally, women often found meaning in their having breast cancer which led to a purpose in life. Older women seemed to go through “stages” in order to find meaning in illness and could often see the benefit cancer had brought to their lives.

## RESEARCH METHODS

This section of the literature review discusses the methods to be used in this dissertation research. This dissertation will be conducted using secondary analysis and mixed methods.

**Secondary Analysis:** Conducting original research from existing data is recognized as an important and legitimate method for conducting scientific inquiry.<sup>187-189</sup> Searches in national databases such as PubMed and CINHALL using the keywords “secondary analysis” reveal over 6,000 research studies in several disciplines conducted using secondary analysis. Recognizing the utility of sharing research data, the National Institutes of Health (NIH) has implemented a policy concerning data sharing.<sup>190</sup> The purpose of data sharing is to help expedite “translation of research results into knowledge, products, and procedures to improve human health.”

Using pre-existing data is a rigorous undertaking that requires astute research planning and data analysis.<sup>187</sup> Pre-existing data can be used to answer questions other than those of the original study. Answering questions developed during an original study or that focus on a subset of a population are also appropriate uses.<sup>191</sup> Existing data can be combined with other data sets to more thoroughly investigate a problem.<sup>189, 192, 193</sup> Using pre-existing databases is also a means to answer policy questions and influence policy decisions concerning healthcare.<sup>192</sup> Some researchers advocate pairing data mining with secondary analysis in order to make new discoveries in patterns, correlations and trends.<sup>192</sup>

Secondary analysis can be conducted from both quantitative and qualitative data.<sup>191, 194-196</sup> Advantages to conducting research using existing data are numerous. A primary advantage is resource savings. Conducting research using independent data collection may not be feasible due to limitations in funding and resources.<sup>189</sup> Using an existing data set requires less research funding due to lower staff needs and less time needed to conduct original research.<sup>189, 191</sup> Research using pre-existing data eliminates the need for a researcher to affiliate with a large organization in order to receive the support needed to collect data from an adequate sample. Using a pre-existing data set eliminates data collection problems and can be used with a variety of research designs.<sup>189, 196</sup> Additionally, quality issues and threats to reliability and validity in large well-known data sets are usually known by the primary researchers and documented. The length of time it takes to report results is also shortened.<sup>192</sup>

Limitations of secondary analysis also exist. The researcher needs to remember that the original data were collected for different purposes. The existing data set must “fit” with the current research problem.<sup>187, 191</sup> Methodological issues will exist if the secondary study or studies that are being combined are not theoretically or conceptually congruent with each other or the primary study.<sup>193</sup> There may also be restraints on the amount of creativity a secondary analysis may provide due to limited available variables.<sup>189</sup> Additionally, the quality of the data may be unknown.<sup>189</sup> Missing data and other inaccuracies may affect the outcome of further analysis.<sup>189, 191</sup> It is important to know how the data were collected and what limitations are present within the database so the researcher can determine if the database is appropriate to use for their own research purposes.<sup>192</sup> Additionally, a historical bias may exist in the data. Outdated data or changes in treatment patterns can impact the results of a secondary analysis and threaten internal validity.<sup>191, 192, 193</sup>

Other threats to reliability and validity involve the sample. In large data sets, the sample may not be random.<sup>192</sup> In addition, the desired population may be underrepresented in the existing data set<sup>189</sup> or fundamentally different when looking to combine studies.<sup>193</sup> Several issues regarding analysis are also discussed in the literature. Samples in the larger databases may be weighted leading to inaccurate conclusions. Researchers may need to seek advice concerning analytical approaches to evaluate their research questions.<sup>188</sup> Other disadvantages include the time frame to gaining access to existing data, lack of existing data in a particular area of interest and a reluctance of researchers to share their hard-earned data.<sup>189</sup> Finally, not understanding the nuances of the data being used in analysis can also be considered a weakness in secondary analysis.<sup>51</sup>



*Summary:* Secondary analysis is a rigorous undertaking that uses pre-existing data sets in order to answer new research questions. Although limitations exist, this student’s familiarity with the pre-existing data set is an advantage for the dissertation research. In addition, the current research questions and conceptual framework fit well with data collected in the parent study, the BCEI.

**Mixed Methods:** Mixed method design includes both quantitative and qualitative methods in the research design and in data analysis.<sup>197-199</sup> Using mixed methods can be used to answer different types of research questions in one study.<sup>197</sup> It can also be used for a variety of research goals that include: developing instruments, explicating and validating constructs, generating hypothesis, illustrating, clarifying or amplifying analysis, understanding causal relationships and building, testing and refining theory.<sup>199</sup> Triangulation has also been associated with mixed methods however, Williamson<sup>200</sup> discusses triangulation as not being exclusive to mixing qualitative and quantitative methods, but with combining 2 of “something” such as 2 different studies using the same method or using 2 different researchers to collect and interpret data. For this reason, the use of the word “triangulation” will be specifically avoided to limit confusion.

Much of the discussion concerning the use of mixed methods centers around the possible incompatibility of paradigms each method is based in (see Table 5).<sup>201-205</sup> However, since the paradigm debate is not the purpose of this literature review, the controversy will be noted, but not discussed in detail. Recognizing this debate, Giddings<sup>201</sup> asserts that there is no need for methods (or researchers) to compete, but researchers need to integrate and carry out multi-methodological studies that meet their needs. Freshwater<sup>206</sup> also supports mixed methods and states the goal is to find the best approach to answer the research question.

<b>Assumption</b>	<b>Quantitative (Positivist)</b>	<b>Qualitative (Naturalistic)</b>
<b>Ontologic</b> (What is the nature of reality?)	Reality exists. Real world is driven by natural causes	Reality is subjective and constructed by individuals
<b>Epistemologic</b> (How is the researcher related to subjects?)	The researcher is independent from those being researched	The researcher interacts with research subjects. Interactive process
<b>Axiologic</b> (What is the role of values in inquiry?)	Objectivity is the goal. Values and biases are controlled	Subjectivity is desired. Values come into play
<b>Methodologic</b> (How is the knowledge obtained?)	-Deductive -Emphasizes discrete concepts  -Results verify researchers “hunches”  -Fixed, tightly controlled design -Emphasizes statistical analysis -Aims to generalize findings	-Inductive -Emphasizes the entirety of a phenomenon  -Results are grounded in subjects experiences  -Flexible and context driven design -Emphasizes narrative information -Aims to find patterns in the data

Polit and Beck<sup>199</sup> support the use of mixing methods for several reasons. *First:* the mixed method approach is complementary in research because integrating multiple methods can overcome weaknesses of using a single research design. *Second:* mixed methods may enhance theoretical insights given that qualitative and quantitative methods reflect different ways of viewing the world. *Third:* mixed methods may provide an incremental approach in the research process in which feedback loops are used to create a body of evidence. *Fourth:* mixed methods may enhance validity of study findings. Cross validation can occur by using qualitative methods to confirm quantitative results. *Fifth:* if results are incongruent, new research ideas and questions can emerge.

Considerations for using mixed methods include: paradigm incompatibility, cost, researcher training, analytical challenges and publication biases.<sup>199</sup> As discussed, researchers need to be aware of the paradigmatic differences between qualitative and quantitative research. High cost and limited funding may prohibit the use of mixed methods. Funding agencies may need to be educated on the benefits of this type of research.<sup>199</sup> Finally, the researcher or research team should have expertise in both methods in order to be successful and be able to combine the data from both methods.<sup>197, 199</sup>

Creswell and colleagues<sup>198, 208</sup> acknowledge that using mixed methods is a rigorous undertaking and several methodological decisions need to be made. Collecting the data is only the first step in using mixed methods. Researchers need to state a logical reason for wanting to use multiple methods. In addition, researchers need to determine when to use these methods in their study: concurrently or sequentially. In a sequential approach, one method acts a basis for the next method of data collection or analysis. In a concurrent approach, all data are collected at the same time and combined for results. When to integrate the data also needs to be decided.

The use of mixed methods has already contributed to nursing research. Ferrell and colleagues<sup>108-113, 121, 209</sup> combined both quantitative and qualitative methods throughout the development of a series of Quality of Life Conceptual Models and empiric measurement tools to examine quality of life in numerous groups of cancer survivors. Cancer patients were asked about their experiences which led to the development of conceptual frameworks and quality of life measurement tools. Subsequently, quantitative data was used to develop cancer specific conceptual models such as the Quality of Life- Breast Cancer conceptual model. Their work continually validated and refined the content domains of both the models and empirical measurement tools.

Rees and Bath<sup>210</sup> also have used mixed methods to examine information sources for partners of women with breast cancer. Subjects were interviewed; data was transcribed and interpreted by the researchers. Subsequently, subjects were given surveys to complete; this quantitative data was then analyzed. Their qualitative findings were supported by the quantitative data. According to the researchers, the use of mixed methods created a “fuller picture” of the research topic than either method would have achieved on their own. This study listed financial constraints as one of the limitations which prohibited the use of more than one researcher in the data analysis phase.

Schulmeister and colleagues<sup>211</sup> also used mixed methods to examine quality of life in patients receiving autologous stem cell transplant in an outpatient facility. Telephone interviews were conducted and patients were asked to complete a QoL survey. Results

showed that QoL initially decreased in these patients but rebounded to at least pre-treatment levels at 6 months. The researchers state that their use of mixed methods gave them a greater understanding of the patient's treatment experience which could lead to appropriate individualized nursing interventions.

According to Zebrack,<sup>104</sup> in order to capture the true essence of QoL in an individual, using standardized quantitative instruments may not be enough. Methods that capture the subjective experience are also needed. Powel and Clark<sup>212</sup> also advocate for methods that enable patient experiences to be captured more thoroughly. Allowing open ended questions allows patients to tell their story and presents a more complete picture of the experience for researchers.

This dissertation will use mixed methods in order to capture issues that could not be captured on quantitative surveys. It is expect that older women surviving with breast cancer also have other experiences that occur during this period of their lives that may affect their quality of life. Qualitative analysis of field notes will aim to identify these experiences.

*Summary:* Using mixed methods in research provides several advantages. Using both quantitative and qualitative methods may give a fuller picture of quality of life in older woman surviving with breast cancer.

**Literature Review Summary:** This review of literature supports the urgency for research involving older women with cancer as our population ages and the number of breast cancer diagnoses in women is expected to dramatically increase. It shows that women with breast cancer are a heterogeneous group and women of different ages have unique needs and concerns after being diagnosed with breast cancer that continue into survivorship and affect quality of life. These differences are demonstrated in the often sparse or conflicting information related to older women surviving with breast cancer and the quality of their lives found in the literature. This literature review also supports using secondary analysis for this dissertation and the benefit of using mixed methods in the research design. Older women with breast cancer are not necessarily a more important group than others. However, the paucity of research and empirically-based understanding of how to best meet the needs of this group make the topic and population a very important foci of study.<sup>51</sup>

## **Preliminary Studies**

None

## **Dissertation Research Design and Methods**

The overall purpose of this research is to examine quality of life in early stage breast cancer survivors, age 65 and older, who are within the first year of survivorship. This student's dissertation research will use a descriptive design for analysis using mixed methods. Data will be drawn from a pre-existing data set, the Breast Cancer Education Intervention (BCEI) and will focus on the subset of older women (age 65 and older) surviving with breast cancer. Please see the letter of permission from the BCEI Principal

Investigator (Appendix A). The quantitative analysis of surveys and qualitative analysis of field notes will be used to answer the research questions. Assumptions that will be the basis for this study stem from the literature review and include:

1. Risk for breast cancer increases with age
2. Older women may develop co-morbid illnesses as they age and cancer may not be their first illness
3. Survivorship begins once a woman is diagnosed with cancer, however many people view “survivorship” as beginning after treatment
4. The path from cancer screening to survivorship is variable in older women and this can impact quality of life in survivorship
5. Survivorship is a complex time in which women with cancer may experience physical and psychosocial late effects from illness
6. Women of different ages may have unique needs- older women are no exception
7. Changes in well-being may constantly fluctuate depending on a woman’s current situation or experiences and this influences quality of life
8. Older breast cancer survivors eventually adapt to having had breast cancer
9. Quality of life related to having breast cancer influences quality of life of the aging woman which continues in survivorship

**The Parent Study- The Breast Cancer Education Intervention (BCEI):** The parent study conducted by Dr. Karen Dow and colleagues established the effectiveness of the Breast Cancer Education Intervention (BCEI) in improving the QoL in early stage breast cancer survivors.<sup>213</sup> This study used a randomized, two-group, longitudinal experimental design. A total of 261 subjects enrolled and 256 completed the study. *Subject Enrollment:* Subjects were recruited through several means. Most subjects were referred from local cancer centers and community oncology offices. A small number of subjects were self-referred to the study. A total of 261 women were enrolled into the study. Four women in the experimental group withdrew from the study during the study intervention, one subject in the waiting control group died prior to receiving the intervention due to causes unrelated to the study. *Inclusion/Exclusion criteria:* Eligibility was based on the following criteria: female age 21 or older; histologically confirmed early stage breast cancer (Stage 0-II) with no evidence of a second primary cancer or metastatic and recurrent disease; completion of treatment for their early stage breast cancer with the exception of hormonal treatments such as Tamoxifen or Arimidex and anti-HER2 therapy; live within 50 miles of their referring cancer center and be willing and able to participate in the BCEI. *Intervention description:* Experimental subjects (EX) received 3 face to face Education and Support sessions, reinforcing written and audio materials followed by both telephone and face to face follow-up support sessions. The Waiting Control (WC) group received 4 attention control telephone calls, 1 to 3 face to face Education and Support Sessions, reinforcing written and audio materials and 1 face to face follow-up support session. The domains of interest for this study included overall quality of life, physical, psychological, social and spiritual well-being, mood and pain. *Sample characteristics:* The mean age was 54.4 years (sd 11.58). Eighty two percent of the subjects were Caucasian, 8.8% African-

American/Black, 5.7% were Hispanic and 3.5 % were Asian, Middle Eastern or Native American. English was the primary language (94.6%) followed by Spanish (3.8%). The majority of subjects were either married or living with a partner (68.2%). Sixty two percent were employed either full or part-time and 55% had an annual income of \$50,000 or more. 47.5% were college educated. 60.5% of subjects received a lumpectomy, 69.3% received radiation therapy, 54% received combination chemotherapy, and 75.5% were on hormonal therapy. No significant differences were noted between groups except the WC group had statistically higher college education ( $p < .05$ ) compared to the EX group.

### **Dissertation Aims and Research Questions**

**Aim #1:** Describe the overall quality of life of female breast cancer survivors age 65 or older.

**Research Question #1.1:** What is the QoL of older breast cancer survivors at baseline?

**Research Question #1.2:** How does QoL change over time?

**Research Question #1.3:** How does QoL compare between groups over time?

**Aim #2:** Describe quality of life within the domains of physical, psychological, social and spiritual well-being in female breast cancer survivors age 65 or older.

**Research Question 2.1:** What is the QoL of older breast cancer survivors within the domains of physical, psychological, social and spiritual well-being at baseline?

**Research Question # 2.2:** How does QoL within these domains change over time?

**Research Question # 2.3:** How does QoL with these domains compare between groups over time?

**Aim #3:** Describe additional life experiences that may relate to quality of life in female breast cancer survivors age 65 and older.

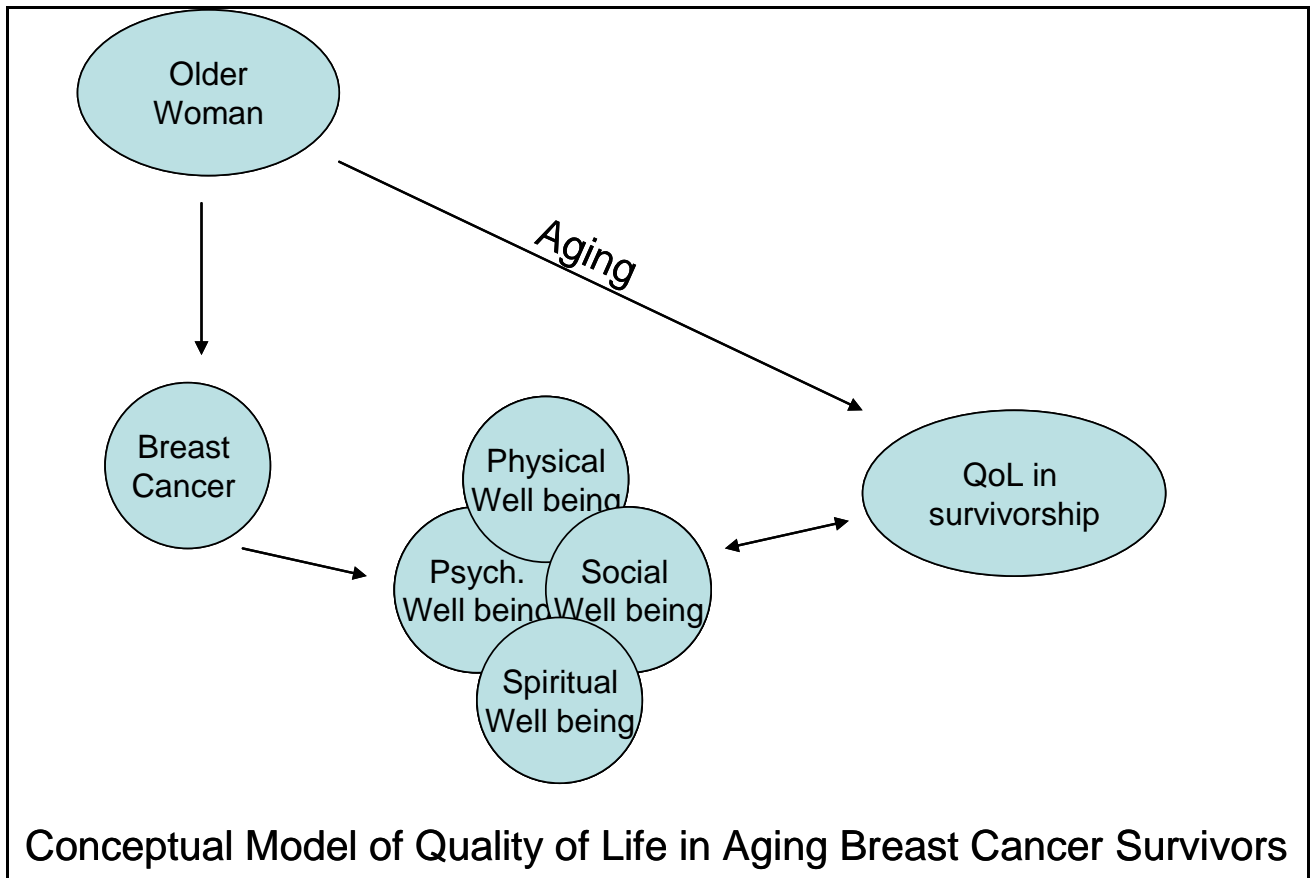
**Research Question #3.1:** Describe other life experiences of older breast cancer survivors as described by research nurses.

**Research Question #3.2:** Describe the types of medication used by older breast cancer survivors age 65 and older.

### **Conceptual Model and Framework**

Conceptual models form a context for most studies, including those directed toward nursing.<sup>214</sup> According to Polit and Beck<sup>214</sup>, conceptual models are more loosely constructed than theories but provide a “perspective regarding interrelated phenomenon” (p.116) A conceptual model presents a “broad understanding of the phenomenon of interest and reflects the assumptions and philosophic views of the model’s designer (p.116). Conceptual models are often accompanied by a visual framework to illustrate the conceptual linkages. Fawcett<sup>215</sup> states that the distinction between a theory and a conceptual model is the level of abstraction. Conceptual models are more abstract than a theory. Conceptual models also provide general guidelines for researchers to follow. A model specifies a phenomenon by “identifying relevant concepts and by describing the connections among them” (p.88). In addition, conceptual models can evolve either intuitively or deductively.

The Conceptual Model of Quality of Life in Aging Breast Cancer Survivors (see below) is intuitively developed and based on the experience of the investigator and the Quality of Life Model in Breast Cancer Survivors developed by Ferrell and colleagues. The new model maintains that quality of life is a personal sense of wellbeing which encompasses physical, psychological, social and spiritual dimensions.<sup>108-110</sup> The literature review for this dissertation and the investigator's own clinical and research experiences form the basis for the assumptions for this conceptual model.



When an older woman is diagnosed with breast cancer several things influence how they will perceive their quality of life in survivorship. This includes both aging and the domains of physical, psychological, social and spiritual well being. Changes in the domains of well being may occur and continue to influence quality of life in survivorship.

The assumptions for this model include:

1. Quality of life is multi-dimensional, subjective and dynamic
2. The domains of quality of life are interactive with each other and one concept within a domain often influences another domain
3. Aging influences perception of quality of life in survivorship

#### 4. Perception of physical, psychological, social and spiritual well-being influences QoL in survivorship

Although Ferrell and colleagues have defined and described the domains of physical, psychological, social and spiritual well-being in their conceptual model, this new model of Quality of Life in Aging Breast Cancer Survivors does not include the concepts within each domain. For example, the physical domain includes concepts of fertility and menstrual issues which may not affect older women with breast cancer. It is unclear if the concepts within the domains of well-being set forth by Ferrell and colleagues apply to an older population of women surviving with breast cancer.

#### Sample Size

This dissertation research will be conducted using a pre-existing data set to study a specific population of older women surviving with breast cancer. The original BCEI obtained a

	3 <sup>rd</sup> Month-baseline			6 <sup>th</sup> Month-baseline		
	WC	EX	Effect Size	WC	EX	Effect Size
Overall QoL			0.313			0.209
mean	0.042	-0.309		-0.162	-0.405	
s.d.	0.752	0.834		0.765	0.879	

sample of 261 women who were randomly selected to be in an Experimental (EX) group or a Wait Control (WC) group. Randomization was paired and 129 women were placed in the EX group and 132 in the WC group. For example, when one woman was placed in the EX group- her “pair” was automatically assigned to the WC group. The groups are not exactly equal because women were randomized primarily due to age and race and sampling was not purposeful in order to achieve the same number of women for age or racial groups. Women over the age of 65 were included in the randomization process and will become the sample of “older women” for this dissertation resulting in a convenience sample of 50 older women consisting of 24 EX subjects and 26 Wait Control subjects. None of the women lived in a nursing home, all were community dwelling.

Effect size was calculated during data analysis of the BCEI and indicated a small effect at both 3 and 6 months of the study (See Table 6).<sup>213</sup>

#### Data Collection Procedures

This dissertation will use the data set of the BCEI experimental research study. The Principal Investigator (PI) for the BCEI was contacted about sharing the data collected during the BCEI. After discussion concerning the importance/relevance of studying the sub-population of older women- women age 65 and older (n=50) with breast cancer, the PI consented to share the de-identified data pertaining to women age 65 and older with this doctoral student. This student was involved in the BCEI as the Project Director and has first hand knowledge concerning data collection, entry and cleaning.

Data was collected during face to face and telephone interviews using a paper and pencil format. Subjects recorded their own answers on the surveys. Research Nurses and an Administrative Assistant double checked all forms for missing data prior to data entry. If missing items were identified, the subject was immediately contacted for the

information. All raw collected data was kept in a locked file cabinet in the UCF BCEI research office.

Data was entered into SPSS v11 and v12 by graduate research assistants as the data became available. Several of the surveys (Demographics, POMS, BPI, QoL-BC) were double-checked for accuracy by another research assistant who did not do the original entry. Initial data check included checking 25% of the data. This number was adjusted based on the findings. If an unacceptable number of errors were found, an additional percentage of the sample was checked for errors. If the error rate was acceptable, fewer subjects were double-checked. Initially a data accuracy threshold was set at 95% however, due to the volume of data points per patient this could have resulted in accepting an unacceptable high number of actual errors. The criterion for accuracy was subsequently changed to 99%.<sup>216</sup>

Due to the complexity and clinical interpretation needed for some forms such as the BCEI Finances Form, a Research Nurse completed 100% data-checks on this dataset and completed the primary data entry for questions which involved qualitative answers concerning current medications and out of pocket costs for those medications. Another RN subsequently double-checked this data as well. Overall, data was found to be over 0.99% accurate.

Data cleaning took place once all data was collected and entered. Initially, the data files were constructed by a designee of the study statistician. These files were not descriptively labeled and were recoded during the initial data cleaning stage so variables represented the questions being asked of the subjects. Data consists mostly of discrete, categorical and dichotomous variables. Descriptive frequencies were run on all data files to find missing data, outliers and problematic data. Only .02% of the data was missing. Outliers and extreme values exist on some surveys which asked for qualitative data such as current medications and cost of the medications. Extreme cost-related values were noted on the BCEI Finances Form however this data is not needed for this dissertation. Nonsensical data was noted and corrected by referencing the original raw data.

Data files were labeled according to the data collection instruments used. Large data sets were separated into subscales so each subscale has its own data file. For example, The Quality of Life- Breast Cancer instrument was divided into 4 files according to the subscales of physical, psychological, social and spiritual well-being. 10 quantitative files will be used and are listed as follows: Demographics (1), POMS (1), BPI (1), QOL-BR (4), and BCEI Finances Form (3).

Field notes written by the research nurses will also be used in data analysis but were not part of the initial data cleaning process.

### **Data Collection Instruments** (see Appendix B)

**BCEI Demographics Tool:** Demographic information is important to describe the sample. Information concerning age, religion, marital status, income, occupation, and treatment variables were collected.

The BCEI Demographic Tool has 17 items that include both closed (n=14) and open (n=3) ended questions. Several closed ended questions also include an opportunity for an “other” answer in which subjects could state an answer if none of the given answers were acceptable. This was included in items asking about ethnicity, primary language,



religious affiliation, specific chemotherapy, hormonal and fatigue related drugs. Open ended questions were for age, occupation and describing other cancers the subject may have had in the past.

**Profile of Mood States-Short Form:** The Profile of Mood States- Short Form (POMS-SF) was used in the BCEI to measure mood disturbance. The POMS- SF contains 37 items and asks subjects to rate how certain descriptive words such as “fatigued”, “hopeless”, and “furious” describe them at the present time. Subjects were asked to think about the past week (present time) and state if the given descriptive words describes them on a scale of “0- not at all” to “4- extremely well”.

Both the original Profile of Mood States (POMS) and the POMS-SF have been used in cancer patients. Normative data for both forms has been reported.<sup>217-222</sup> The POMS was developed by McNair and colleagues<sup>220</sup> to identify and measure transient and fluctuating mood states. The POMS has been translated into several languages and is used in multiple populations. There are six factorially-derived mood states. These include: tension-anxiety; depression-dejection; anger-hostility; vigor-activity; fatigue-inertia; and confusion-bewilderment. Normative data for the original POMS was based on 235 normal college students and 1000 outpatient psychiatric patients.<sup>220</sup> No further information is available. Internal consistencies for this scale range from .84 to .95 among the 6 factors. Test-retest reliability ranged from .65 to .74 among the 6 factors. Concurrent validity was supported by comparisons with normative samples for the MMPI-2 and the Hopkins Symptom Distress Scale.

Cassileth and colleagues<sup>218</sup> used family members of cancer patients as the normative sample in their study. Although total scores for the POMS can range from -32 to +200, scores can be reported as mean scores. Higher scores mean greater disturbance in mood. In these samples, mean scores for patients were 20.1 and mean scores for family members was 14.5. The researcher’s state that this contrasts sharply with the norms reported by McNair in the POMS manual in which mean scores of college students were 43.3 and mean scores for psychiatric patients was 77.5. These researchers believe it is important to evaluate cancer patients against more normative norms such as general populations instead of extreme populations.

A short form (POMS-SF) was developed by Shacham<sup>221</sup> and norm referenced in cancer patients with pain. The short form contains 37 items. Each of the original subscales was shortened by 2 to 7 items and internal consistency was retained. Cronbach’s alphas ranged from 0.80 to 0.91 for the subscales on the new short form. The short form also had high correlation to the original form (all reliability coefficients above  $r=.95$ ).

Baker and colleagues<sup>217</sup> also psychometrically evaluated the POMS-SF in 428 cancer patients waiting for bone marrow transplantation. Reliability analysis showed Cronbach’s alpha of .78 to .91 among the 6 subscales.<sup>217</sup> This compared favorably to the Cronbach’s alpha’s reported by Shacham (.80 to .91 among the 6 subscales). Convergent and discriminate validity was also shown through patterns of correlations between the subscales and other well known measures such as the CES-D. Confirmatory factor analysis supported the 6 factors for the POMS items.<sup>217</sup> These researchers concluded the POMS-SF developed by Shacham was an acceptable alternative to the original 65 item form.

DiLorenzo and colleagues<sup>219</sup> compared the POMS and the POMS-SF in a sample of breast cancer patient undergoing chemotherapy compared to a group of healthy women. Again, the POMS-SF highly correlated to the full-length POMS (range:  $r = .93$  to  $.99$ ). In addition internal consistency was similar to the full-length POMS for both the breast cancer and healthy groups. Cronbach's alpha's ranged from  $.73$  to  $.97$  in the healthy group and from  $.62$  to  $.93$  in the breast cancer group.

Finally, the POMS-SF was used in the BCEI and the Cronbach's alpha ranged between  $0.95$  and  $0.99$  for this scale<sup>213</sup> (see Table 7).

The POMS is a very easy form to complete. One limitation is that subjects may not be familiar with all the descriptive words they are asked to describe themselves with. Words such as "peevish" and "weary" may be difficult to score if subjects do not know how to define these words in order to determine if they describe how they are feeling.<sup>223</sup>

**BCEI Brief Pain Inventory:** Pain was measured in the BCEI using a modified version of the Brief Pain Inventory (BPI). The BPI is a well established pain measure (originally known as the Wisconsin Brief Pain Questionnaire) that evaluates the intensity of pain and how it interferes in the life of the person experiencing it. Pain relief is also addressed. The patient is asked to think about the last 24 hours when answering the questions. The 14 items used in the BCEI asks subjects if they are currently having pain related to their cancer (yes/no), the intensity of the pain (0-10 scale), treatments/medications they currently take for their pain and how pain interfered with everyday activities such as walking, enjoyment of life, and everyday activities (0-no interference, 10-extreme interference). Demographic questions and diagrams for describing pain were eliminated in the modified version. Questions that asked patients to "check" adjectives to describe their pain and reasons for pain were also eliminated

The original BPI was specifically designed for use in people with cancer and other diseases. The original survey has 23 items.<sup>224</sup> Reliability was assessed using test-retest with 2 samples. Reliability was higher when the interval between completing the surveys was short (range of  $r = 0.59$  to  $0.93$ ). Validity was supported by correlating the amount of medications taken to higher pain ratings.<sup>225</sup>

The BPI has been used to address pain specifically in breast cancer survivors after surgery<sup>226</sup> and in other patients with cancer pain.<sup>227-229</sup> Tittle and colleagues<sup>229</sup> validated the BPI for use with surgical patients with cancer. In a mixed sample of surgical and medical patients ( $n=388$ ), the BPI correlated with the Visual Analogue Scale for both populations (range  $r=0.71$  to  $0.73$ ). Alpha coefficients for reliability were high for both groups ( $r = 0.95$  for medical group and  $r = 0.97$  for the surgical group).<sup>229</sup>

The BPI has good test-retest reliability over short intervals.<sup>224</sup> Cleeland states that using the BPI may reduce response bias,<sup>224</sup> however, bias may occur in samples of older women because older women may not want to "complain" about their pain for fear of being prescribed pain medication.

The Cronbach's alpha for subjects using this form in the BCEI was  $-0.85$  to  $0.95$ <sup>213</sup> (see Table 7).

A limitation to using the modified BPI with an older sample of women with breast cancer is that the questionnaire is specific to cancer pain and does not allow the woman to identify the source of pain. Many older women may experience pain for reasons other than cancer. This could not be captured on the modified BPI.<sup>223</sup>

**Quality of Life- Breast Cancer:** The Quality of Life Instrument- Breast Cancer (QoL-BC) version is a 50 item scale that specifically measures quality of life in women with breast cancer based on a conceptual model of quality of life in breast cancer survivors using the domains of physical, psychological, social and spiritual well-being.<sup>108</sup> It was adapted from the Quality of Life-Cancer Survivors (QoL-CS) scale. Subjects are asked to use a scale from 0 to 10 to describe current problems and levels of distress within the domains of quality of life. For example: “To what extent is fatigue a problem for you?” 0=no problem, 10= severe problem, and “How much anxiety do you have?” 0= none at all, 10= a great deal. Questions also address having hope and perception of positive changes due to cancer. Patient were asked to think about the last week or so (the present time) before answering.

Reliability was established on the original QoL-CS using test-retest and internal consistency measures. Test-retest reliability was  $r=0.89$ . Overall reliability was established with a Cronbach’s alpha of 0.93. Alpha coefficients for the subscales were acceptable at: physical well-being 0.77, psychological well-being 0.89, Social well-being 0.81 and spiritual well-being 0.71.<sup>108</sup>

Reliability for the QoL-BC scale was established in the BCEI. Cronbach’s alpha’s were 0.99 for overall QoL, 0.99 for physical subscale, 0.93 to 0.99 for psychological subscale, 0.71 to 0.99 for social subscale and 0.70 to 0.99 for the spiritual subscale<sup>213</sup> (see Table 7).

Content validity was supported by using expert nurses and quality of life researchers to review the tool. Pearson’s correlations were also used to gauge the tool compared to the already established FACT-G tool. Correlation was high in the subscales for physical, psychological and social well being.<sup>108</sup>

One limitation to this form is that although it has been successfully used in populations that include older women, it is uncertain to what extent the components of each domain (physical, psychological, social and spiritual) represent concerns of older (over age 65) women with breast cancer. Domains such as physical functioning are not represented in this measurement and issues such as fertility and menstrual changes may not apply.

Another limitation to the tool is that some questions ask about change, but do not ask if the item has changed for the better or worse. For example, one question asks “How much has your spiritual life changes as a result of your diagnosis?” and asks the subject to rate from 0= no change to 10= a great deal. Another questions asks “Has your illness or treatment caused changes in your self concept (the way you see yourself)?” but again does not allow the subject to state if these changes were positive or negative.<sup>223</sup>

**BCEI Finances Form:** A Finances Form, based on a measurement by Given, Given and Stommel,<sup>230</sup> focuses on the financial burden of the woman with cancer and her family due to cancer related expenses. Forty four questions ask subjects to report information on insurance, time off from work, out of pocket costs for breast cancer related expenses are collected and actions such as selling a house or filing for bankruptcy they have had to do in order to cover breast cancer related expenses.

Information concerning out of pocket costs for prescription and over the counter medications is also collected. Subjects are asked first to answer questions based on their expenses since diagnosis, but in M3 and M6, they are asked only to report new expenses and experiences.

In the 1994 study by Given, Given and Stommel<sup>230</sup>, family and patient out of pocket costs are evaluated for women with breast cancer. Either patients or caregivers of deceased patients were interviewed. Patients and family members were asked to report expenses that were non-reimbursable for the 3 months prior to the interview. In addition, family labor costs based on the number of hours caregivers spent giving care were calculated. Researchers then estimated the cost of care. No evidence of psychometric evaluation, reliability or validity can be found in the literature. This information seems to have been garnered from interviews and an original survey instrument for reporting finances does not seem to exist. The reliability measures for the BCEI Finances Form ranged from Cronbach's alpha .45 to .86<sup>213</sup> (see Table 7).

<b>Variables</b>	<b>Measurement Tool</b>	<b>Cronbach's Alpha</b>
<b>Overall Quality of Life</b>	QoL-BC total score	.93
<b>Physical Well-being</b>	QoL-BC Physical subscale score	.99
<b>Psychological Well-being</b>	QoL-BC Psych subscale	.93-.99
<b>Social Well-Being</b>	QoL-BC Social subscale items	.71-.99
<b>Spiritual Well-Being</b>	QoL-BC Spiritual subscale	.70-.99
<b>Psychological distress</b>	POMS	.95-.99
<b>Pain</b>	BPI	-.85-.91
<b>Finances/ Medications</b>	Work, Finances, Insurance Tool	.45-.86

Limitations to this tool used in the BCEI exist. This tool requires recall of dollar amounts for specific items which may be difficult to remember. In the parent study, many women had difficulty estimating the amount of money spent per month on breast cancer related costs. Reasons for poor recall included buying medications in bulk or infrequently, using credit cards, ordering by mail or having husbands who

tended the finances. In future studies, this information could be captured differently. If determining financial burden and not actual out of pocket costs is the goal, the form can be simplified to replace the reporting of out of pocket costs for each breast cancer related item with subjective questions regarding the subjects perception of overall financial burden. An estimation of out of pocket costs can also be garnered by asking for a "ballpark" figure as opposed to exact amounts.<sup>223</sup>

### **Data Management and Integrity**

Once this study gains IRB approval, this doctoral student will obtain de-identified data from the Principal Investigator. De-identified data is data that is anonymous and does not contain information that can identify a subject. This is important to maintain the privacy of the subjects in the BCEI. This de-identified data will include SPSS files for the Demographic, POMS-SF, BPI, QoL-BC and BCEI Finances Form surveys and field notes in the form of Word documents/files. A copy of the SPSS data files will be downloaded onto single read-only CDs so data can not be overwritten. Data will then be transferred and stored on the student's home computer and the "master copy" will be placed in a fire-proof safe in the student's home. Data analysis will take place only on

the student’s computer. A back-up copy of the working SPSS files will be placed on a portable “jump” drive and stored in the fire-proof safe. Password protected files will also be used.

Field notes in the form of Word documents will also be copied and placed on read-only CD’s. These files will be downloaded onto the student’s home computer for analysis in Ethnograph- a qualitative software program. Back-up copies of the working files will also be kept on a portable jump drive and stored in a fire-proof safe.

Files will be backed-up each time a new file is created or a current file altered.

## Data Analysis Plan

The overall purpose of this research is to examine quality of life in a group of early stage breast cancer survivors, age 65 and older, who have recently completed treatment for their cancer. This student’s dissertation research will use a descriptive design for analysis using mixed methods. Data will be drawn from a pre-existing data set, the Breast Cancer Education Intervention (BCEI) and will focus on the subset of older women (age 65 and older) with early stage breast cancer. Quantitative analysis of surveys and qualitative descriptive and content analysis of field notes will be used to answer the research questions. The main research variables are listed in Table 8.

### Pre-analysis data screening:

Data will be screening to assess accuracy, missing data, outliers, and assumptions of fit (normality, linearity and homoscedasticity).

*Data accuracy, missing data and outliers:* Data will be examined using descriptive statistics. Frequencies will be run on all variables to evaluate completeness of the data. The

original BCEI reported a missing data rate of 0.2%, so missing data is not expected to be an issue. Outliers are also not expected to be an issue since the surveys used had very few open ended questions or those questions that contained open ended answers such as financial data are not included in the research questions and will not be considered for data analysis.

*Assumptions of fit:* Data will be explored to consider normality, linearity and homoscedasticity. Descriptive statistics will be run. Normality will be examined using histograms, normality plots and the Kolmogorov-Smirnov test. Homoscedasticity

Table 8: Main Research Variables and Data Source	
Main Research Variables	Data Source
Overall QoL	QoL- BC
Physical Well-being	QoL- BC subscale
Fatigue	POMS subscale
Pain	BPI
Psychological Well-being	QoL- BC subscale
Psychological Distress	POMS subscale
Social Well-being	QoL- BC subscale
Spiritual Well-being	QoL- BC subscale
Current Life Experiences	Field Notes
Medications	BCEI Finance Form

(homogeneity of variance) will be evaluated when comparing groups using Levene's test for equal variances.

*Reliability analysis:* Reliability of the measures used in this sample of older women with breast cancer will be evaluated using Cronbach's alpha. Cronbach's alpha is a measure of internal consistency and indicates if an instrument is measuring one or more traits. The range for this measure is between .00 and 1.00 with higher scores indicating higher internal consistency.<sup>231</sup> SPSS software will be used to calculate Cronbach's alpha. Each instrument will be assessed as a whole for internal consistency. Additionally, tools such as the QoL-BC tool will be assessed for consistency within each subscale.

*Power Analysis:* The power of a statistical test indicated the "probability that it will yield statistically significant results (p.1).<sup>232</sup> Power analysis is a method to reduce the risk and estimate the occurrence of Type II errors (accepting a false null hypothesis). The 4 components of power analysis are: 1) significance criterion ( $\alpha$ ); 2) the sample size; effect size ( $\gamma$ ) and power ( $1-\beta$ ).<sup>233</sup> For this dissertation, several of these components are known. The *significance criteria* which signifies the probability of rejecting a true null hypothesis (Type I error) is set at  $\alpha = 0.05$ . This means that in a sample of 100, the null hypothesis would be rejected 5 times when it is true. The *sample size* is  $N=50$ , with  $Ex= 24$  and  $WC = 26$ . Although an *effect size* can not be calculated for this dissertation at this time, the effect size for the BCEI was .313 at 3 months. It is expected that the effect size for the sample of older women used in this dissertation study will be different from that found in the BCEI. Since a premise of this study is that women of different ages have unique needs, the probable difference in effect size may be due to the overall samples used in each study. The BCEI had a large sample consisting of 261 women ages 28 to 83. This dissertation will focus on a specific subset of women ( $N=50$ ) ages 65 to 83. The effect size is likely to change based on the overall differences inherent to each sample which may include perception of quality of life and report of symptoms. Older women (age 65 and older) are likely to be different from younger women or a sample of women who average age is approximately 54 years old. Once an effect size for the dissertation study can be calculated, a power analysis will be conducted during the data analysis phase of the proposed research.

**Data analysis of specific research questions:** Analysis of the research questions will be conducted using parametric and non-parametric statistics (See Table 9).

*Demographics:* Demographics contain nominal data and will be evaluated using descriptive statistics and frequencies for the overall sample and the 2 groups (EX and WC). Comparisons between the EX group and WC group will be done using Chi Square test.

*Research Questions:* The measurement tools contain both ordinal and interval data.

**Aim #1:** Describe the overall quality of life of female breast cancer survivors age 65 or older.

**Research Question #1.1:** What is the QoL of older breast cancer survivors at baseline?

**Research Question #1.2:** How does QoL change over time?

**Research Question #1.3:** How does QoL compare between groups over time?

- 1.1 The goal of this research question is to describe how older women with breast cancer report their quality of life after being treated for early stage breast cancer. The global measure of QoL contained in the QOL-BC tool will be averaged (*mean score*) at M1 to determine overall QoL for the sample. Score range will also be determined.
- 1.2 This research question will describe how overall QoL changes over time. The entire sample will be examined as a group and QoL scores at M3 and M6 will be compared to baseline. *Paired t-tests* will be used to compare baseline QoL scores to QoL scores at M3 and M6. If needed, non-parametric statistics may be used such as the *Wilcoxon signed-rank test*.
- 1.3 This research question will describe how overall QoL compares between a group who received an intervention (EX) and a group who did not (WC). Repeated Measure Analysis of Variance (*RM-ANOVA*) will be used to determine group differences over time (M3 and M6). If needed, non-parametric tests such as the *Kruskal-Wallis test* will be used.

**Aim #2:** Describe quality of life within the domains of physical, psychological, social and spiritual well-being in female breast cancer survivors age 65 or older.

**Research Question 2.1:** What is the QoL of older breast cancer survivors within the domains of physical, psychological, social and spiritual well-being at baseline?

**Research Question # 2.2:** How does QoL within these domains change over time?

**Research Question # 2.3:** How does QoL within these domains compare between groups over time?

- 2.1 The goal of this research question is to determine how older women with breast cancer report their QoL within the domains of the quality of life at M1. Scores for each item in each subscale in the QoL-BC will be calculated as an average (*mean score*). The scores within each subscale will then be added to make a total subscale score. Ranges will also be computed. In addition, within each subscale, items will be ranked according to level of concern (high to low concern).
- 2.2 This research question will describe changes in the subscale scores within the entire sample over time. Subscale scores within the entire sample at M3 and M6 will be compared to baseline subscale scores. *Paired t-tests* will be used. If needed, non-parametric statistics such as the *Wilcoxon signed-rank test* will be used.
- 2.3 This research question will describe how changes in subscale scores compare between 2 groups (EX vs. WC) over time (M3 and M6). *RM-ANOVA* will be used to determine group differences over time. If needed, non-parametric tests such as the *Kruskal-Wallis test* will be used.

**Aim #3:** Describe additional life experiences that may relate to quality of life in female breast cancer survivors age 65 and older.

**Research Question #3.1:** Describe other life experiences of older breast cancer survivors as described by research nurses.

**Research Question #3.2:** Describe the types of medication used by older breast cancer survivors age 65 and older.

- 3.1 The goal of this research question is to describe other life experiences of older breast cancer survivors as they related to quality of life. Data will be obtained from field notes documented by research nurses throughout the duration of the study.
- 3.2 The goal of this research question to describe the types of medication used by older breast cancer survivors age 65 and older. Data will be obtained from the BCEI Finances Form. Frequencies will be used to describe this data.

**Qualitative Data Analysis Procedure:** The goals of the research questions presented in Aim #3 are largely descriptive. As posed, the questions do not lend themselves to one of the well-known methods of qualitative analysis such as phenomenology, grounded theory or ethnography. During this analysis there will be no attempt to determine the lived experience of older women with breast cancer, provide a holistic view of that population's culture or determine the social processes within a social setting. Instead, this dissertation will use qualitative description<sup>234, 235</sup> and qualitative content analysis is used to discover themes in the research nurses field notes.<sup>236, 237</sup> Qualitative description is used when straight description of a phenomenon is desired.<sup>235</sup> One characteristic of using qualitative description is that it is a low-inference procedure meaning the "facts" are presented in everyday language as opposed to other methods such as phenomenology, ethnography or grounded theory that present or interpret events in other terms.<sup>235</sup>

*Process for content analysis of field notes:* Qualitative content analysis of field notes will be based on a systematic process set forth by Schilling<sup>238</sup> in which there are 5 levels of analysis that include turning transcripts into raw data, condensing records, developing a preliminary category system, formally defining the categories and analyzing and interpreting data. Due to the nature of the field notes as being a second hand account (nurse observations) of patient experiences, the steps will be modified. The following describes the process for analyzing the field notes for this dissertation:

- 1) Field notes will be entered into Ethnograph and used as raw qualitative data.
- 2) Data will be read thoroughly prior to coding. Since the field notes are not a traditional narrative (in the subjects own words) and are expected to be brief, data will not be further reduced.
- 3) Themes or events will be generated from the data and codes will be applied that describe the theme using language closely reflecting the language used by the nurses in the field notes. For example, if the nurse observed and noted that the patient was concerned with an ill family member, recently experienced the death of their spouse, or was worried over a follow-up appointment, the codes used to describe the experience will specifically state the event i.e., "concerned with husband's illness", "spouse recently died", or "worried about follow-up mammogram." Codes and themes will reflect the actual event or experience noted by the research nurse in the field note.
- 4) Categories will be developed and defined and the previously used codes will be placed in these categories. For example, a several subjects may be worried about the



health of family members; hence, the overall category may be “worried about the health of family member.”

5) These themes and categories will be used describe other life experiences that may relate to quality of life in older breast cancer survivors.

Consistent with basic content analysis, reliability will be verified by either a fellow doctoral student who is naive to the data or a member of the dissertation committee. The procedure for reliability is to 1) review 5 field notes, 2) compare the themes and codes identified by the doctoral researcher with the actual field notes.

<b>Research Questions</b>	<b>Goals</b>	<b>Analysis Method</b>
1.1	<ul style="list-style-type: none"> <li>• Within group- Overall QoL score</li> </ul>	Means
1.2	<ul style="list-style-type: none"> <li>• Within group changes- Overall QoL score</li> </ul>	Paired T-tests/ Wilcoxon signed rank test
1.3	<ul style="list-style-type: none"> <li>• Between group changes- Overall QoL score</li> </ul>	RM-ANOVA/ Kruskal-Wallis test
2.1	<ul style="list-style-type: none"> <li>• Within group- QoL subscale score</li> <li>• Within group- Item scores within subscales</li> </ul>	Means Means
2.2	<ul style="list-style-type: none"> <li>• Within group changes- QoL subscale scores</li> </ul>	Paired T-tests/ Wilcoxon signed rank test
2.3	<ul style="list-style-type: none"> <li>• Between group changes- QoL subscale scores</li> </ul>	RM-ANOVA/ Kruskal-Wallis test
3.1	<ul style="list-style-type: none"> <li>• Within group- Current life experiences</li> </ul>	Qualitative Content Analysis
3.2	<ul style="list-style-type: none"> <li>• Within group- Medications</li> </ul>	Means

### **Study Limitations**

Several limitations exist for this dissertation research.

*Secondary Analysis:* The primary limitation of this dissertation is that the data set was originally intended for different research questions. However, a strength of this dissertation research is that the data set “fits” the current set of research questions and the overall conceptual framework used in the BCEI is suitable for examining quality of life in older breast cancer survivors.

Additionally, using a preexisting data set may cause a researcher to question the integrity and quality of the data. Fortunately, this student is very familiar with data set and was involved in data management and cleaning procedures. The student is confident that the data set is sound and few instances of missing data exist.

*Sample Size:* This dissertation will be using a subset of a larger population of early stage breast cancer survivors. The sample of women age 65 and older is small. Data from 50 older women will be analyzed and statistical significance is not guaranteed. However, both parametric and non-parametric statistical procedures are available and worked into the data analysis plan to provide the most rigorous data analysis possible with the limited sample size.

*Reliability of Measurements:* While the tools used in the original study (BCEI) have been used in populations with breast cancer, their reliability specifically in older women has not been reported. For example, the Quality of Life- Breast Cancer instrument has not been used specifically in a population of older women and it is uncertain if the items

contained within each domain is relevant to a population of older women surviving with breast cancer.

In addition, the content of the field notes taken by the Research Nurses during the BCEI is unknown. These notes have not been examined prior to this study. These notes were originally written to document face to face visits and telephone calls between nurses and subjects. Notes were also used to document specific issues subjects were encountering and interventions suggested by the Research Nurses during the course of the study. The contents of these notes may vary in quality and usability.

*Generalizability:* The results of this research will not generalizable outside of the setting in which it was collected. However, it is hoped that this research will foster new research questions concerning older women with breast cancer and lead to intervention testing in future research endeavors.

### Summary of Research Design and Methods

The overall purpose of this research is to examine quality of life in women with early stage breast cancer who are age 65 and older and are within the first year of survivorship. This student’s dissertation research will use a descriptive design for analysis using mixed methods. Parametric and non-parametric statistical tests will examine QoL in this sample of older women surviving with breast cancer. Thematic analysis of field notes will investigate additional life experiences experienced by older breast cancer survivors.

### Timetable- (See Table 10)

Month	Tasks
August 2006	<ul style="list-style-type: none"> <li>• Prepare research protocol</li> </ul>
Sept 2006	<ul style="list-style-type: none"> <li>• Defend Dissertation Proposal</li> </ul>
October 2006	<ul style="list-style-type: none"> <li>• Submit to UCF IRB</li> </ul>
November 2006	<ul style="list-style-type: none"> <li>• Begin data analysis</li> </ul>
December 2006	<ul style="list-style-type: none"> <li>• Complete data analysis</li> </ul>
January 2007	<ul style="list-style-type: none"> <li>• Begin writing of results, findings, conclusions</li> <li>• Elicit dates for dissertation defense from committee</li> <li>• Request Dissertation Defense date no later than March 2nd</li> </ul>
February 2007	<ul style="list-style-type: none"> <li>• Continue writing of results, findings, conclusions</li> <li>• Begin development of papers for publication</li> </ul>
March 2007	<ul style="list-style-type: none"> <li>• Complete dissertation within parameters of UCF Dissertation guidelines</li> <li>• Write abstracts of 3 papers for publication and submit to journal editors</li> <li>• Complete writing of results, findings, conclusion</li> </ul>
April 2007	<ul style="list-style-type: none"> <li>• Defend Dissertation no later than April 6</li> <li>• Complete changes and modifications requested by Dissertation Committee</li> <li>• Submit hard copies to dissertation committee</li> <li>• Complete all final reports required by SON and UCF</li> </ul>
May 2007	<ul style="list-style-type: none"> <li>• Graduation</li> </ul>

## **Human Subjects Research**

### **Protection of Human Subjects**

Approval for this dissertation research will be obtained from the University of Central Florida Institutional Review Board (IRB) prior to the start of any research activities.

### **Potential risks**

No risk to the subject can be predicted at this time. This dissertation research will use de-identified quantitative and qualitative data.

### **Protection against risks**

Not Applicable

### **Importance of knowledge to be gained**

This dissertation research is important because little is known about quality of life in older breast cancer survivors. Although the sample for this study is small, it may help clarify some of the ambiguity concerning older women with breast cancer found in the literature. The results of this research are expected to contribute to the limited knowledge concerning older breast cancer survivors to gain a better understanding of this population and their concerns and needs after being treated for early stage breast cancer.

### **Inclusion of Women and Minorities**

Women are the focus of this research and minority women are included. The parent study achieved an 18% minority participation rate. The sample of older women will also be examined for minority participation.

### **Inclusion of Children**

No children under the age of 21 were included in the original BCEI.

### **Data Safety and Monitoring Plan**

According to the NIH Policy for Data and Safety Monitoring<sup>240</sup> a data safety and monitoring plan is needed for clinical trials (intervention studies) to ensure the safety of research participants as well as the integrity and validity of data in clinical trials supported by the NIH. The data and monitoring safety board functions separately from the Institutional Review Board. This dissertation will not employ a DSMB because of the inherent low risk to subjects involved in an analysis of pre-existing de-identified data. There will be no recruitment of subjects, no opportunity for significant adverse events involving subjects and no patient contact. In the event that an adverse event (AE) that had not been previously discovered in the BCEI is found, the Principal Investigator of the BCEI will be notified so the AE can be reported to the UCF IRB.

### **Vertebrate Animals**

Not Applicable

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**APPENDIX D: LETTER OF PERMISSION TO USE BCEI DATA FOR SECONDARY  
ANALYSIS**



School of Nursing

October 10, 2006

Victoria Loerzel, MSN, RN, OCN  
Doctoral Student  
UCF School of Nursing

Dear Vicki:

Thank you for your request to use de-identified data from our Breast Cancer Education Intervention (BCEI) Study funded by the National Institute of Nursing Research (NINR) and the Office of Cancer Survivorship at the National Cancer Institute (NCI). I am happy to honor your request for one time use of de-identified data from our population of older women over the age 65 years for use in your dissertation research.

There are a few stipulations for use of the data and are as follows:

1. Only de-identified quantitative and qualitative data from the BCEI is allowed.
2. Data analysis must be confined to your approved dissertation aims. All other requests for additional analysis must be submitted in writing to me.
3. Forward a copy of all publication resulting from your data analysis.
4. Any publication resulting from your work must include an acknowledgment of study support from NIH.

If you agree to the above stipulations, you have my approval for use of the data. Your research interest in the needs of older women with breast cancer is very important work. Best wishes.

Sincerely,

Karen Dow Meneses PhD, RN, FAAN  
Professor, Kahli Endowed Chair in Oncology Nursing

**APPENDIX E: LETTER OF IRB APPROVAL**



Office of Research & Commercialization

November 1, 2006

Karen Dow, Ph.D. &  
Victoria Loerzel, M.S.N.  
University of Central Florida  
School of Nursing  
OTC6 267  
Orlando, FL 32816-2211

Dear Dr. Dow & Mrs. Loerzel:

The University of Central Florida's Institutional Review Board (IRB) received your protocol IRB #06-3926 entitled "**Quality of Life in Older Breast Cancer Survivors: A Descriptive Study**". The IRB Chair reviewed the study on 10/31/2006 and did not have any concerns with the proposed project. The Chair has indicated that under federal regulations (Category #4, research involving the use of existing data, documents, and records, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifies linked to the subjects) this research is **exempt** from further review by our IRB, so an approval is not applicable and a renewal within one year is not required. The data is public information.

Please accept our best wishes for the success of your endeavors. Should you have any questions, please do not hesitate to call me at 407-823-2901.

Cordially,

A handwritten signature in cursive script that reads "Joanne Muratori".

Joanne Muratori  
(FWA00000351 Exp. 5/13/07, IRB00001138)

Copies: IRB File

JM:jt

12201 Research Parkway • Suite 501 • Orlando, FL 32826-3246 • 407-823-3778 • Fax 407-823-3299

An Equal Opportunity and Affirmative Action Institution

**APPENDIX F: CERTIFICATE OF COMPLETION- PROTECTION OF HUMAN RIGHTS**



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## Human Participant Protections Education for Research Teams

### Completion Certificate

This is to certify that

**Vicki Loerzel**

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 02/18/2006.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health  
<http://www.nih.gov>

**APPENDIX G: LETTER REQUESTING BIostatistician CONSULTATION**

Victoria Loerzel

May 2, 2007

Dr. Xiaogang Su  
University of Central Florida  
Statistics & Actuarial Science  
4000 Central Florida Blvd.  
Orlando, FL. 32816

Dear Dr. Su,

I would like to ask you if you would be a statistical consultant for my doctoral dissertation entitled: Quality of Life in Older Breast Cancer Survivors. Your assistance with analysis, especially with Generalized Estimating Equation methods, would be an invaluable asset to my dissertation.

If you have any questions, please do not hesitate to contact me.

Thank you for your consideration.

Sincerely,

Vicki Loerzel  
Doctoral Candidate  
College of Nursing  
University of Central Florida  
407-823-0762  
vloerzel@mail.ucf.edu



**APPENDIX H: RESPONSE FROM REQUEST FOR BIostatistician  
CONSULTATION**

Novell WebAccess - Windows Internet Explorer

http://gw4.mail.ucf.edu:8080/gw/webacc?action=Item.Read&User.context=ir5iv1Xr0%0f%5Mu8&Item.drn=96951z24z08&merge=msgitem&Url.Folder.type=Folder.UNIVERSAL

### Mail Message

Reply Read Later

Mail Properties

From: Xiaogang Su  
To: vloerzel@mail.ucf.edu  
CC: kdow@mail.ucf.edu  
Subject: Re: request for statistical consultation for dissertation

Wednesday - May 2, 2007 11:18 PM

Hi, Vicky,

Yes, please. Would love to. I will send out the results that you requested last time in a little bit.

Thanks,  
Xiaogang

=====  
Xiaogang Su, Assistant Professor  
Department of Statistics and Actuarial Science  
University of Central Florida  
Orlando, FL 32816  
(407) 823-2940 [O]  
xiaosu@mail.ucf.edu  
<http://pegasus.cc.ucf.edu/~xsu/>  
>>> Victoria Loerzel 05/02/07 7:41 AM >>>  
Hi Dr. Su.

I hope all is well with you.

As Karen had mentioned in a previous meeting, we would like to include you as a statistical consultant on my dissertation. I have been asked to send you a formal letter with this request. It is attached and will be included in the appendices of my dissertation manuscript.

I will need a response from you to include in my dissertation manuscript as well. Karen has indicated that this can be an e-mail from you stating that you will serve as a consultant.

If you could reply via e-mail, I would appreciate it.

If you have any questions, please let me know.

Thanks again for providing the GEE analysis for the senior subjects on the BCEI. This information has proved to be an invaluable part of my dissertation.

Vicki

Done

Internet 100%

start Loerzel Quan 5-3... dissertation worki... Novell WebAccess... Novell WebAccess...

10:09 AM

## **APPENDIX I: CURRICULUM VITAE**

**University of Central Florida School of Nursing:**

**Home:**

P.O. Box 162210

Orlando, FL 32816-2210

--Office

--Fax

- Fax

Email: [vloerzel@mail.ucf.edu](mailto:vloerzel@mail.ucf.edu)

**I. EDUCATION**

<b>Year</b>	<b>Degree</b>	<b>Institution</b>	<b>Major</b>	<b>Role Preparation</b>
2003- 2007	PhD	University of Central Florida, Orlando, FL.	Nursing	Doctoral Preparation
1993-1997	MSN	Case Western Reserve University, Frances Payne Bolton School of Nursing, Cleveland, OH.	Nursing	Clinical Specialist
1990-1993	BSN	Florida Atlantic University, Boca Raton, FL	Nursing	Clinical Practice
1985-1989	BA	Rollins College, Winter Park, FL.	History	

**II. LICENSURE/CERTIFICATION**

RN	Florida	3079232
OCN®	Oncology Certified Nurse	1996- present

**III. EMPLOYMENT**

***ACADEMIC APPOINTMENTS:***

2002- 2007	<b>Research Project Director</b> (2003-2005), Quality of life intervention for breast cancer survivors (NR-RO1-5332-04), National Institute of Nursing Research, National Cancer Institute, National Institutes of Health, Dr. Karen H. Dow, PI (\$1.6 million).
2005-2007	<b>Adjunct Instructor.</b> University of Central Florida School of Nursing, College of Health and Public Affairs, Orlando.
1996	<b>Clinical Instructor.</b> Case Western Reserve University, Frances Payne Bolton School of Nursing, Cleveland, OH.

#### ***CLINICAL APPOINTMENTS:***

- 1997 -2002           **Cancer Care Coordinator.** M. D. Anderson Cancer Center Orlando, Orlando, FL.
- 1997                   **Staff Nurse.** Oncology, Orlando Regional Medical Center, Orlando, FL.
- 1993- 1996           **Staff Nurse.** Bone Marrow Transplant Unit, The Cleveland Clinic Foundation, Cleveland, OH

#### **IV.                    HONORS and AWARDS**

- 2006                   Pegasus Award Nominee, College of Public Health Affairs, University of Central Florida
- 2005                   Graduate Poster Award, (\$50). 13<sup>th</sup> Annual Research Day, Sigma Theta Tau International, Theta Epsilon Chapter.
- 2003-2004            Merit Fellowship, (\$5,000). Graduate Studies, University of Central Florida.

#### **V.                     RESEARCH EXPERIENCE**

- 2004                   Consultant. Fertility after breast cancer: A web-based program. Susan G. Komen Breast Cancer Foundation, Dr. Karen H. Dow, PI (\$250,000).
- 2002- 2007           Project Director. Quality of life intervention for breast cancer survivors (NR-RO1-5332-04), National Institute of Nursing Research, National Cancer Institute, National Institutes of Health, Dr. Karen H. Dow, PI (\$1.6 million).
- 1996                   Research Assistant. Effects of virtual reality on symptom distress in children receiving cancer chemotherapy, American Cancer Society, Dr. Susan Schneider, PI.

#### **VI.                    PUBLICATIONS**

##### ***REFEREED NATIONAL/INTERNATIONAL JOURNALS:***

1. McNees, P., Dow, K.H., & **Loerzel, V.W.** (2005). Application of the CuSum technique to evaluate changes in recruitment strategies. *Nursing Research*, 54(6), 399-405.
2. **Loerzel, V.W.**, & Bushy, A. (2005). Interventions that address health disparities in women. *Family and Community Health Journal*, 28(1), 79-89.
3. **Loerzel, V.W.**, & Dow, K.H. (2004). Male breast cancer. *Clinical Journal of Oncology Nursing*, 8(2), 191-192.
4. **Loerzel, V.W.**, & Dow, K.H. (2003). Cardiac toxicity related to cancer treatment. *Clinical Journal of Oncology Nursing*, 7(5), 557-562.
5. **Wochna, V.** (1997). Anxiety, needs and coping in family members of the bone marrow transplant patient. *Cancer Nursing*, 20(4), 244-250.

**NON-REFEREED NATIONAL/INTERNATIONAL:**

6. **Loerzel, V.W.**, & Dow, K.H. (2005). Study explores lymphedema incidence, knowledge, and prevention of early stage breast cancer. *Lymphedema Management- Special Interest Group Newsletter*, 16(2). 3.

**BOOK CHAPTERS:**

7. **Loerzel, V.W.** (2006). Hidden populations of women. In Karen H. Dow (Ed.), *Nursing care of women with cancer*. St. Louis, Missouri, Elsevier.
8. Dow, K.H., & **Loerzel, V.W.** (2005). Cancer survivorship: A critical aspect of care. In Yarboro, C. H., Frogge, M. H., & Goodman, M., (Eds.), *Cancer principles and practice* (pp.1665-1675). Sudbury, Massachusetts. Jones and Bartlett Publishers.
9. **Loerzel, V.W.** (2005). Bleeding. In M. Hickey and S. Newton (Eds.), *Telephone triage for oncology nurses* (pp. 75-78). Pittsburg, Pennsylvania, Oncology Nursing Society Press.
10. **Loerzel, V.W.** (2005). Fever with neutropenia. In M. Hickey and S. Newton (Eds.), *Telephone triage for oncology nurses* (pp.125-127). Pittsburg, Pennsylvania, Oncology Nursing Society Press.
11. **Loerzel, V.W.** (2003). Late physical effects of treatment. In Karen H. Dow (Ed.), *Contemporary issues in breast cancer, 2<sup>nd</sup> Ed.* (pp. 263-280). Boston, Massachusetts. Jones and Bartlett Publishers.
12. **Loerzel, V.W.** (2003). Support and survivorship issues. In Karen H. Dow (Ed.), *Contemporary issues in breast cancer, 2<sup>nd</sup> Ed.* (pp. 313-322). Boston, Massachusetts. Jones and Bartlett Publishers.

**ACCEPTED FOR PUBLICATION**

13. Meneses, K., McNeese, P., **Loerzel, V.W.**, Su, X, Hassey, L. Transition from treatment to survivorship: Effects of a psychological intervention on quality of life in breast cancer survivors. *Oncology Nursing Forum*, Accepted for publication.

**PEER REVIEWED PUBLISHED ABSTRACTS:**

14. Powel, L., Dow, K.H., McNeese, P., & **Loerzel, V.W.** (2007). Early use of qualitative techniques to improve intervention integrity. *Oncology Nursing Forum*, 34(1), 246.
15. **Loerzel, V.W.**, Dow, K.H., & McNeese, P. (2007). Data Integrity: The value of clinical context in data preparation and entry. *Oncology Nursing Forum*, 34(1), 245.
16. Dow, K.H., McNeese, P., & **Loerzel, V.W.** (2006) Effectiveness of psychoeducational interventions for breast cancer survivors: An interim analysis. Conference Proceedings, American Psychosocial Oncology Society 3<sup>rd</sup> Annual Conference.
17. McNeese, P., Dow, K.H., Spellman, S., Lerz, R., McNeese, C., & **Loerzel, V.W.** (2006). Fertility and cancer project: Psychoeducational and psychosocial research in an electronic environment. Conference Proceedings, American Psychosocial Oncology Society 3<sup>rd</sup> Annual Conference.
18. **Loerzel, V.W.**, Dow, K.H., & McNeese, P. (2006). Why women with breast cancer use or don't use lymphedema prevention and management strategies. Conference Proceedings, American Psychosocial Oncology Society 3<sup>rd</sup> Annual Conference.
19. Dow, K.H., McNeese, P., **Loerzel, V.W.**, & Zhang, Y. (2006). Tailored breast cancer education intervention (BCEI) for breast cancer survivors: An interim analysis. 20<sup>th</sup> Annual Conference Proceedings, Southern Nursing Research Society.
20. **Loerzel, V.W.**, Dow, K.H., & McNeese, P. (2006). Tools for managing patient recruitment: Evolving strategies in longitudinal research. 20<sup>th</sup> Annual Conference Proceedings, Southern Nursing Research Society.

21. Dow, K.H., McNees, P., & **Loerzel, V.W.** (2006). CuSum technique: A tool to evaluate change in referral and enrollment. 20<sup>th</sup> Annual Conference Proceedings, Southern Nursing Research Society.
22. McNees, P., Dow, K.H., Ramaswamysanthanam, R., Subramanian, G., & **Loerzel, V.W.** (2006). Tools and processes for improving research data integrity. 20<sup>th</sup> Annual Conference Proceedings, Southern Nursing Research Society.
23. Dow, K.H., McNees, P., & **Loerzel, V.W.** (2005). The internet as a comprehensive environment for quality of life research: Challenges, strategies and tactics. *Quality of Life Research*, 14(9), 1990.
24. McNees, P., Dow, K., & **Loerzel, V.W.** (2005). Live Item index technique (LIITE) in longitudinal quality of life clinical trials. *Quality of Life Research*, 14(9), 2017.
25. **Loerzel, V.W.**, Dow, K.H., & McNees, P. (2005) Incidental findings related to lymphedema incidence and prevention in quality of life research. *Quality of Life Research*, 14(9), 2039.
26. Dow, K.H., **Loerzel, V.W.**, Zhang, Y., & McNees, P. (2005). A targeted breast cancer education intervention (BCEI) for breast cancer survivors: An interim analysis. Proceedings of the 30<sup>th</sup> Annual Congress of the Oncology Nursing Society, Orlando, FL.
27. McNees, P., Dow, K.H., Ramaswamysanthanam, S., Subramanian, G., & **Loerzel, V.W.** (2005). Improving data integrity: Applying novel tools in a longitudinal breast cancer clinical trial. Proceedings of the 30<sup>th</sup> Annual Congress of the Oncology Nursing Society, Orlando, FL.
28. **Loerzel, V.W.**, Dow, K.H., & Subramanian, G. (2005). Lymphedema: Incidental findings from the BCEI. Proceedings of the 30<sup>th</sup> Annual Congress of the Oncology Nursing Society, Orlando, FL.
29. **Loerzel, V.W.** (2005). Hardiness: A concept analysis. Proceedings of the 19<sup>th</sup> Annual Conference of the Southern Nursing Research Society. Atlanta, GA.
30. Dow, K.H., & **Loerzel, V.W.** (2005). Lymphedema incidence in early stage breast cancer survivors: Secondary analysis of the BCEI. Proceedings of the 19<sup>th</sup> Annual Conference of the Southern Nursing Research Society. Atlanta, GA.
31. Dow, K.H., McNees, P., & **Loerzel, V.W.** (2005). Novel application of CuSum technique to evaluate changes in recruitment strategies on referral and enrollment: Implications for prospective recruitment management. Proceedings of the 8<sup>th</sup> National Conference on Cancer Nursing Research, Fort Lauderdale, FL.
32. Dow, K.H., **Loerzel, V.W.**, Roberts, S., Denton, S., & Nunes, J. (2004). Changing recruitment strategies in longitudinal research. Proceedings of the 18<sup>th</sup> Annual Conference of the Southern Nursing Research Society. Louisville KY.
33. Dow, K.H., **Loerzel, V.W.**, Roberts, S., Denton, S., & Nunes, J. (2004). Using collaboration and innovation to improve subject recruitment and retention in a longitudinal intervention research study. Proceedings of the 29<sup>th</sup> Annual Congress of the Oncology Nursing Society. Anaheim, CA.

**PATIENT EDUCATION:**

34. **Loerzel, V.W.** Primary author or editor of patient education materials developed at M. D. Anderson Cancer Center Orlando.

**2002:**

“Cisplatin” (Chemotherapy)

“Carboplatin” (Chemotherapy)

**2001:**

“What you should know about implanted ports”

“Antioxidants and vitamin supplements”  
 “Managing diarrhea” (Editor)  
 “Anemia”  
 “Alopecia”  
 “Managing nausea and vomiting during cancer treatment”  
 “Dry mouth” (Editor)  
 “Managing a sore mouth and throat” (Editor)  
 “Doxorubicin” (Chemotherapy)  
 “Etoposide” (Chemotherapy)

**2000:**

“Constipation”  
 “Lymphedema” (Editor)  
 “Arm exercises: To minimize the risk of lymphedema” (Editor)  
 “Leg exercises: To minimize the risk of lymphedema” (Editor)  
 “Neutropenia precautions” (Editor)  
 “Cancer information websites: A guide for patients and their families” (Editor)

**1998:**

“An introduction to your blood counts”  
 “Fatigue during cancer treatment”

**VII. PRESENTATIONS**

***REFEREED NATIONAL/INTERNATIONAL:***

- |          |   |
|----------|---|
| Feb 2007 | <u>Poster Presentation.</u> <b>Loerzel, V.W.</b> , Dow, K.H., & McNees, P. (2007). Data Integrity: The value of clinical context in data preparation and entry. Ninth National Conference on Cancer Nursing Research, Hollywood, CA   |
| Oct 2006 | <u>Symposium.</u> <b>Loerzel V.W.</b> , Dow K. H., & McNees P. Tools for managing patient recruitment: Evolving strategies in longitudinal research. 2006 National Congress of the State of the Science in Nursing Research, Washington, D.C.                                     |
| Feb 2006 | <u>Poster Presentation.</u> <b>Loerzel V.W.</b> , Dow K. H., & McNees, P. Why women with breast cancer use or don't use lymphedema prevention and management strategies. American Psychosocial Oncology Society 3 <sup>rd</sup> Annual Conference, Amelia Island.                 |
| Oct 2005 | <u>Poster Presentation.</u> <b>Loerzel, V.W.</b> , Dow, K.H., & McNees, P. Incidental finding related to lymphedema incidence and prevention in quality of life research. 12 <sup>th</sup> Annual Conference of the International Society for Quality of Life. San Francisco, CA. |
| May 2005 | <u>Poster Presentation.</u> <b>Loerzel, V.W.</b> , & Dow, K.H. Lymphedema incidence in early stage breast cancer survivors: Secondary analysis from the BCEI. Oncology Nursing Society 30 <sup>th</sup> Annual Congress. Orlando, FL.   |
| Nov 1998 | <u>Symposium Presentation.</u> Murphy, M., DeJesus, Y., Newman, J., & <b>Wochna, V.</b> From the comprehensive cancer center to the community: Building the bridges of the future. Oncology Nursing Society Fall Institute. Dallas, TX.   |



***REFEREED REGIONAL/STATE/LOCAL:***

- Feb 2007            Symposium, **Loerzel, V.W.**, Dow, K.H., & McNees, P. (2007). Data Integrity: The value of clinical context in data preparation and entry. 21<sup>st</sup> Annual Conference, Southern Nursing Research Society, Galveston, TX.
- Mar 2006            Poster Presentation **Loerzel, V.W.** Theoretical perspectives of quality of life in breast cancer survivors. 2006 Graduate Research Forum. University of Central Florida, Orlando, FL.
- Feb 2006            Doctoral Session Poster Presentation **Loerzel, V.W.** Theoretical perspectives of quality of life in breast cancer survivors. 20<sup>th</sup> Annual conference, Southern Nursing Research Society, Memphis, TN.
- Feb 2006            Symposium, **Loerzel V.W.**, Dow K. H., & McNees P. Tools for managing patient recruitment: Evolving strategies in longitudinal research. 20<sup>th</sup> Annual conference, Southern Nursing Research Society, Memphis, TN.
- Mar 2005            Poster Presentation. **Loerzel, V.W.** “Hardiness: A concept analysis.” 13<sup>th</sup> Annual Research Day. Sigma Theta Tau International Theta Epsilon Chapter, Orlando, FL.
- Mar 2005            Poster Presentation. **Loerzel, V.W.** “Hardiness: A concept analysis.” 2005 Graduate Research Forum. University of Central Florida, Orlando, FL.
- Feb 2005            Poster Presentation. **Loerzel, V.W.**, & Dow, K.H. “Lymphedema incidence in early stage breast cancer survivors: Secondary analysis from the BCEI.” Southern Nursing Research Society 19<sup>th</sup> Annual Meeting. Atlanta, GA.
- Feb 2005            Doctoral Session Poster Presentation. **Loerzel, V.W.** “Hardiness: A concept analysis.” Southern Nursing Research Society Annual Meeting. Atlanta, GA.
- Mar 2004            Paper Presentation. Dow, K. H., & **Loerzel, V.W.** Changing recruitment strategies in longitudinal research. 12<sup>th</sup> Annual Research Day: Spinning the Web: Nursing Theory, Research and Practice. Sigma Theta Tau International, Theta Epsilon chapter. Orlando, FL.

***INVITED (NON-REFEREED) REGIONAL/STATE/LOCAL PAPERS:***

- Nov 2006            Invited Speaker, **Loerzel, V.W.** “Quality of life in older breast cancer survivors: A review of the literature.” Sigma Theta Tau, Theta Epsilon Chapter, Fall General Meeting, Orlando, FL.
- Dec 2005            Invited Speaker, Dow, K.H. & **Loerzel, V.W.** “Quality of life interventions for breast cancer survivors: A collaborative effort. M. D. Anderson Cancer Center Orlando, Oncology Grand Rounds, Orlando, FL.
- Oct 2005            Poster Presentation, **Loerzel, V.W.** & Dow, K.H. “Lymphedema incidence in early stage breast cancer survivors: Secondary analysis from the BCEI.” Research Renewal and Roses, UCF SON Alumni Conference, Orlando, FL.
- 1999-2002            Invited Speaker, “Principles of patient and family education.” Orlando Regional Healthcare System, Oncology/Chemotherapy Symposium. Orlando, FL
- Spring 2001            Invited Speaker, “Current treatment options” First Connection Peer Volunteer Training. Central Florida Chapter of the Leukemia and Lymphoma Society, Orlando, FL.
- 2000-2002            Invited Speaker, “Immediate side effects of chemotherapy.” Orlando Regional Healthcare, Chemotherapy Verification Program. Orlando, FL.
- 2001-2002            Invited Speaker, “Oncologic emergencies.” Orlando Regional Healthcare System. Orlando FL.

- 1998-2001 Invited Speaker, "Learning about cancer: pathophysiology and diagnosis." I Can Cope. American Cancer Society, Orlando, FL.
- Spring 2002 Invited Speaker, "Blood cell transplantation." The University of Central Florida. Medical Technologist Conference, Orlando, FL.
- May 1999 Invited Speaker, "Cancer surgery: An overview." Orlando Regional Healthcare System. Oncology/Chemotherapy Symposium. Orlando, FL.
- Apr 1999 Invited Speaker, "General cancer update." Orlando Regional Healthcare System, 55+ program, St. Cloud Hospital. St. Cloud, FL.
- 1998-1999 Community Presentation, "Cancer prevention and early detection: A focus on breast self exam." Orlando Regional Healthcare System. Orlando, FL.
- Apr 1998 Invited Speaker, "Cancer screening and early detection." Orlando Regional Healthcare System, 55+ program, Orlando. FL.
- March 1998 Invited Speaker, "Immediate side effects of chemotherapy." Chemotherapy Symposium: Beyond the Basics. Orlando Regional Healthcare System and M. D. Anderson Cancer Center Orlando. Orlando, FL.
- Feb 1998 Invited Speaker, "Understanding cancer treatments." I Can Cope. M. D. Anderson Cancer Center Orlando and the American Cancer Society. Orlando, FL.
- Jan 1998 Invited Speaker. "Blood cell transplantation." VNA Home Healthcare. Orlando, FL.
- Nov 1997 Invited Speaker. "Blood cell transplantation." Oncology Nursing Grand Rounds, M. D. Anderson Cancer Center Orlando. Orlando, FL.
- July 1996 Invited Speaker, "Oncologic emergencies." Oncology Nursing Review. Sponsored by the Cleveland Chapter of the Oncology Nursing Society and Cleveland State University. Cleveland, OH.

***ACADEMIC LECTURES AND TEACHING EXPERIENCE:***

- Courses: University of Central Florida, School of Nursing**
- Spring 2007 **Adjunct Instructor**, Nursing Research/Critical Inquiry (NUR-3165 0W61)
- Fall 2006 **Adjunct Instructor**, Principles of Oncology Nursing (NUR-3795 0W91)  
**Adjunct Instructor**, Health Assessment Lab (NUR-3065L-0018)  
**Adjunct Instructor**, Health Assessment Lab (NUR-3065L-0019)
- Sum 2006 **Adjunct Instructor**, Principles of Oncology Nursing, (NUR-3795 0W91).
- Fall 2005 **Adjunct Instructor**, Principles of Oncology Nursing, (NUR-3795 0W91).
- Spring 2005 **Adjunct Instructor**, Principles of Oncology Nursing, (NUR-3795 0W91).
- Sum 2003 **Adjunct Instructor**, Health Assessment Lab (NUR-3065L)

- Lectures: University of Central Florida, School of Nursing**
- Fall 2006 **Invited Speaker**, "Acute care issues in oncology nursing" Lecture for undergraduate students of acute nursing.

Spring 2006	<b>Invited Speaker</b> , “Acute care issues in oncology nursing” Lecture for undergraduate students of acute nursing.
Spring 2005	<b>Invited Speaker</b> , “Acute care issues in oncology nursing” Lecture for undergraduate students of acute nursing.
Nov 2004	<b>Invited Speaker</b> , “Acute care issues in oncology nursing” Lecture for undergraduate students of acute nursing.
2002-2003	<b>Invited Speaker</b> , “Breast health assessment” Lecture for undergraduate students of nursing health assessment.

## VIII. PROFESSIONAL ACTIVITIES & COMMUNITY SERVICE

### *PROFESSIONAL ORGANIZATIONS/ MEMBERSHIP*

<b>Year</b>	<b>Organization</b>
1994 – Present	<b>Oncology Nursing Society</b>
1994-1996	Cleveland Chapter, Oncology Nursing Society
1997 – Present	Central Florida Chapter, Oncology Nursing Society
1993 – Present	<b>Sigma Theta Tau International</b>
2002 – Present	Theta Epsilon Chapter
2002 – Present	<b>Southern Nursing Research Society</b>
1993, 2004 – Present	<b>American Nurses Association and Florida Nurses Association</b>
2006 -- Present	<b>Doctoral Student Nursing Organization</b>

### *PROFESSIONAL SERVICE ACTIVITIES*

#### **Oncology Nursing Society**

	National Service
	Oncology Nursing Certification Corporation
2003 - 2007	<i>Member, OCN® Test Development Committee</i>
2004 - 2007	<i>ONCC Item Writing Mentor</i>
2002	<i>ONCC Item Writing Workshop Participant</i>

	Local/Regional Service
	<i>Oncology Nursing Society</i>
2007	<u>Past-President</u> , Central Florida Chapter
2006	<u>President</u> , Central Florida Chapter

2005 President-Elect, Central Florida Chapter  
 2005 Member- ONS Congress local Planning Committee  
 2004 Director at Large, Central Florida Chapter  
 2003 Nominating Committee Co-chair, Central Florida Chapter  
 2001-2002 Newsletter Chair, Central Florida Chapter  
 1999-2000 Nominating Committee Chair, Central Florida Chapter  
 1996 Secretary, Cleveland Chapter  
 1995-1996 Member, Community Outreach, Cleveland Chapter

***EDITORIAL REVIEW:***

2006- Present Review Board Member, Cancer Nursing (International peer reviewed journal)  
 2004-2006 Review Board Member, Clinical Journal of Oncology Nursing. (National peer reviewed journal).

***COMMUNITY AND INSTITUTIONAL SERVICE:***

2006-2007  
*Community* Member, Patient Services Committee, The Leukemia & Lymphoma Society, Orlando

2005-2006  
*University* Member, Planning Committee, 3<sup>rd</sup> Annual Breast Cancer Update  
*School of Nursing* Elected Student Representative, Doctoral Committee  
*Community* Member, Patient Services Committee, The Leukemia & Lymphoma Society, Orlando.  
Member, Institutional Review Board, M .D. Anderson Cancer Center Orlando.

2004-2005  
*School of Nursing* Elected Student Representative, Doctoral Committee  
*Community* Invited Speaker, “Breast cancer education intervention study: Quality of life in breast cancer survivors.” Summer Undergraduate Research Academy 2004.  
Invited Speaker, “Breast Cancer Awareness.” 4th Annual Breast Health Awareness Day, Sponsored by: Colonial Medical Supplies, Orlando, FL.  
Member, Patient Services Committee, The Leukemia & Lymphoma Society, Orlando.  
 Member, Institutional Review Board, M .D. Anderson Cancer Center Orlando.

2003-2004  
*University* Invited Speaker, “Women’s health/breast cancer.” Open forum on breast cancer for students, faculty and staff, Bluestocking Luncheon Series. The University of Central Florida Women’s Studies Program  
*School of Nursing* Elected Student Representative, Doctoral Committee

*Community* Invited Speaker, “Collaborative partnerships: University and community cancer program relationships to strengthen recruitment and retention of research subjects” The University of Central Florida, School of Nursing, Professional Development Series.

Invited Speaker, “Cancer prevention and early detection” University High School Student Health Awareness Series. Orlando, FL. Quarterly- January, April, June, November.

Member, Patient Services Committee, The Leukemia & Lymphoma Society, Orlando.

Member, Institutional Review Board, M .D. Anderson Cancer Center Orlando.

2002-2003  
*Community* Invited Speaker, “Cancer prevention and early detection” University High School Student Health Awareness Series. Orlando, FL. Quarterly- January, April, June, November.

Member, Patient Services Committee, The Leukemia & Lymphoma Society, Orlando.

Member, Institutional Review Board, M .D. Anderson Cancer Center Orlando.

### **Orlando Regional Healthcare System/ M. D. Anderson Cancer Center Orlando**

<b>Year</b>	<b>Committee</b>
1998-2002	<u>Chair and Co-chair</u> , Oncology Nursing Practice Council- MDACCO
1999-2002	<u>Coordinator</u> , Oncology Nursing Grand Rounds
2001-2002	<u>Member</u> , Institutional Review Board- MDACCO
1999-2002	<u>Member</u> , Process Improvement Committee
2001-2002	<u>Member</u> , Radiation Oncology Conference Planning Committee
2000-2002	<u>Co-coordinator</u> , JCAHO Record Audits
2000-2001	<u>Coordinator</u> , Patient Education Process Improvement Committee
2000-2001	<u>Member</u> , M. D. Anderson Cancer Center Orlando Education Council
	<b>Service</b>
1997-2002	<u>Coordinator</u> , Blood and Marrow Transplant Patient Coordinator and liaison to The University of Texas, M. D. Anderson Cancer Center, Blood and Marrow Transplant Center
1998-2002	<u>Coordinator</u> , Oncology Patient Education
2001-2002	<u>Co-auditor</u> , Concordance Study, M. D. Anderson Cancer Center Orlando and The University of Texas, M. D. Anderson Cancer Center
1998-2001	<u>Coordinator</u> , Wait-Time Study, M. D. Anderson Cancer Center Orlando
2000	<u>Co-Chair</u> , Danskin Triathlon- “Team Survivor” Orlando, FL.
1999-2000	<u>Co-Chair</u> , National Cancer Survivor Day at M. D. Anderson Cancer Center Orlando.
1999-2002	<u>Member</u> , Patient Services Committee, The Leukemia & Lymphoma Society, Orlando.

Updated: June 20, 2007