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Nicole D. Lombardo
The Relationship Between
Complementary Medicine and
Quality of Life Among
Women with Breast Cancer

ABSTRACT

This exploratory study examines the relationship between complementary medicine and quality of life among women with breast cancer. The objective of this study was to better understand why women choose to use these techniques, which techniques they were using, how effective they perceived them to be, and the overall impact on quality of life.

There were twelve women that participated in a semi-structured interview process where they were asked a series of questions about their breast cancer experience. Participant's ages ranged from 32-65 years old, and annual household income varied from less than \$30,000 to greater than \$75,000. Eleven participants identified themselves as Caucasian and one participant was Indian. The diagnoses included Ductal Carcinoma in Situ (DCIS), Invasive Ductal Carcinoma (IDC), and Invasive Lobular Carcinoma (ILC), and staging ranged from 0-IV.

The findings of the research showed that the two most common reasons women gave for using complementary therapies was to control and reduce side effects brought on by conventional treatment and/or the disease itself, and the search for the holistic connection of the mind, body and spirit. Eighty-three percent of participants reported

having a positive or improved quality of life since they began using complementary medicine. Those who have had a reoccurrence and/or have metastatic breast cancer view their quality of life as the most optimal. The study concluded that social workers can help patients by both providing a safe and empathic environment for patients to express their thoughts and feelings and also serving as an educational resource regarding the use of complementary therapies.

THE RELATIONSHIP BETWEEN COMPLEMENTARY MEDICINE
AND QUALITY OF LIFE AMONG WOMEN
WITH BREAST CANCER

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2007

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I especially want to thank my parents for their endless love and patience throughout my academic career, without their support none of my achievements would be possible. To my mother, who is a breast cancer survivor, for letting me be a part of your journey and for inspiring me to pursue this subject.

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CHAPTER I

INTRODUCTION

According to the World Health Organization, more than 1.2 million people will be diagnosed with breast cancer each year worldwide. The American Cancer Society estimates that 178,480 new cases of invasive breast cancer will be diagnosed in 2007. Breast cancer can often be a complex illness that includes several types of diagnoses and staging. Research also shows that breast cancer death rates have steadily decreased since 1990 due to earlier detection and better, more expansive treatment options (Breast Cancer: Statistics, 2007, para 1). One increasingly popular treatment option is the integration of complementary medicine. The National Institutes of Health's National Center for Alternative and Complementary Medicine (NCCAM) stated that Americans spent more than \$27 billion on alternative or complementary therapies in 1997. People diagnosed with cancer represent a large portion of the population that accesses CAM therapies (Richardson, et al., 2000) and women with breast cancer are also said to be high utilizes of these services (Boon, et al., 2007).

Adler (1999) stated that women with breast cancer incorporate complementary medicine into their treatment protocol in the hope that it would increase their chance of survival, because it was in reaction to bad experiences with conventional medicine, to prevent further illness, and/or a belief that they had nothing to lose.

Quality of life is an important component when dealing with a chronic disease such as breast cancer. Research has shown that people who are dealing with a terminal

illness sometimes view their last years as the best years of their life, (Cohen, et al., 1995); and due to the advances in diagnosis and treatment of breast cancer it has led to an increase in survival and therefore a greater emphasis on quality of life, (Pandey, et al., 2002). Quality of life is often measured from four domains: physical well-being, emotional well-being, functional well-being, and social/family well-being, (Friedman, et al., 2006). Breast cancer patients may use conventional medicine to help improve their quality of life, or they may turn to complementary therapies to do the same, but integrating both practices is said to be the optimal strategy (Verhoef, et al., 2005).

The effectiveness and impact of these therapies is still being questioned. There is anecdotal evidence that exists regarding the benefits of using complementary medicine among women with breast cancer, but scientific research is still needed to determine whether these therapies are truly effective and safe.

The purpose of this study is to explore the relationship between complementary therapies and quality of life among women with breast cancer. It is a qualitative study that utilizes a relational, cross-sectional, flexible method. The objective of this study is to investigate the different forms of complementary therapies women are using during the course of their treatment, why women choose to use these techniques, their perceived effectiveness of these therapies, and, most importantly, the impact on quality of life. The results of this research project will help future social workers to provide their patients with better support and education around the relationship between complementary medicine, breast cancer, and quality of life. Because of the large numbers of women that have been or will be diagnosed with breast cancer, this study has high relevance for the field of social work.

CHAPTER II

REVIEW OF THE LITERATURE

Breast cancer patients and their use of complementary medicine is a topic that has received considerable publicity in the past and continues to remain a heavily followed area of interest among health care professionals. This literature review will begin by discussing the increasing rates of breast cancer and reasons why women decide to use complementary therapy in conjunction with conventional medicine. The most commonly used therapies along with a description of who is most likely to utilize these services is also addressed. This section includes a review of the theoretical framework of quality of life, which has been used, in past and present research that pertains to the use of complementary medicine. Racial and ethnic differences are also addressed.

Breast cancer is the most common form of cancer, and is the second leading cause of cancer deaths among women (after lung cancer). In the United States alone, it was estimated that about 40,970 women died from breast cancer in 2006, (Breast Cancer: Statistics, 2007, para 3). It was also estimated that 212,290 new cases of breast cancer were diagnosed in American women in 2006 alone, (The Susan Komen Breast Cancer Foundation, 2006). Breast cancer rates have been steadily increasing over the years and women now have a 1 in 8 chance of developing invasive breast cancer.

Breast cancer is often viewed as a chronic disease rather than an acute illness, which is one reason why women are encouraged to investigate other forms of treatment besides conventional, mainstream medicine, (Lengacher, 2003). Crocetti et al. (1998)

stated that breast cancer patients seek complementary therapies because of the physical distress they experience while going through treatment, and the fear of potential disease reoccurrence. A study by Whitman (2001) concluded that breast cancer patients use complementary therapy to promote wellness, prevent malignant processes, and to control symptoms.

Diagnosis Information

Breast cancer is the growth and spread of abnormal cells because of gene mutations. Malignant tumors are lumps that have the potential to invade and destroy normal tissue, and then travel to other areas of the body. There are several types of breast cancer: Adenocarcinoma, Ductal Carcinoma in Situ (DCIS), Invasive Ductal Carcinoma (IDC), Invasive Lobular Carcinoma (ILC), Inflammatory Carcinoma, In Situ, Lobular Carcinoma in Situ (LCIS), Medullary Carcinoma, Mucinous Carcinoma, Paget's Disease of the Nipple, Phyllodes Tumor and Tubular Carcinoma, (American Cancer Society, 2004). For the purpose of this study the focus will remain on the diagnoses of Ductal Carcinoma in Situ, Invasive Ductal Carcinoma and Invasive Lobular Carcinoma. The term In Situ refers to noninvasive breast cancer that stays inside the milk duct or lobules of the breast, whereas invasive breast cancer breaks through into other parts of the breast and may eventually spread to other parts of the body through the blood or lymphatic system.

Staging is also another important component when receiving a breast cancer diagnosis. Staging is the process of gathering information about the tumor to determine how widespread the cancer is (American Cancer Society, 2004). The stage of the breast cancer is helpful to know when choosing treatment options and determining prognosis.

The most commonly used system to describe the growth and spread of breast cancer is the TNM staging system. T categories describe the tumor's size and spread to the skin or chest wall under the breast. The higher the T numbers the larger the tumor or the more it has spread to the tissues near the breast. N categories indicate whether the cancer has spread to the lymph nodes near the breast and whether the affected nodes are stuck to other structures under the arm. Finally, M categories indicate whether the cancer has spread to distant organs, or to lymph nodes next to the breast. Numbers 0-IV are used in the TNM staging system; zero being the least advanced and aggressive.

Definition of Complementary Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) defines complementary medicine as "...a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine." (<http://nccam.nih.gov/health/whatiscam/>). Complementary therapies are used in conjunction with conventional medicine, whereas alternative therapies are used in place of mainstream practices. The major types of complementary therapies include whole medical systems, mind-body medicine, biologically based practices, manipulative and body-based practices, and energy medicine. Whole medical systems incorporate practices such as homeopathic medicine, naturopathic medicine, traditional Chinese medicine and Ayurveda. Mind-body medicine is designed to enhance the mind's capacity to affect bodily function and symptoms. These therapies include patient support groups, cognitive behavioral therapy, meditation, prayer, mental healing, art, music and dance. Biologically based practices use substances found in nature, such as herbs, food, and vitamins. Manipulative and body-based therapies include

chiropractic, osteopathic manipulation and massage. Energy medicines incorporate the energy fields that surround and penetrate the human body. Examples of energy healing include qi gong, reiki and therapeutic touch.

Studies have shown that when prayer is included in the mind-body definition, these therapies are the most commonly used form of complementary medicine (NCCAM, 2006). Research has shown that patient's subjective impressions of their illness and their ability to cope is directly related to one's survival. Shorter survival in breast cancer patients has been linked to emotional distress and depression and increased psychological distress has been shown to promote disease progression and poorer health (Watson, et al., 1999; Andersen & May, 1991; Cohen & Williamson, 1991). Mind-body interventions aim to improve mood, quality of life, and coping, as well as ameliorate disease-and treatment-related symptoms, such as chemotherapy-induced nausea, vomiting, and pain, (Mundy, et al., 2003).

Targ and Levine (2002) conducted a study that looked at the differences between a standard support group and a mind-body-spirit group for women with breast cancer. Participants in the mind-body-spirit group were taught meditation, affirmation, imagery and ritual. Results showed that both groups were associated with decreased depression and decreased anxiety, but the mind-body-spirit group had better outcomes of spirituality and quality of life. Research states that active participation in mind-body support groups can contribute significantly to the reduction of distress, improve quality of life, reach a deeper sense of meaning and purpose in life, and to the survival rate of women with advanced breast cancer (Spiegel, et al., 1989; Kinney, et al., 2003). In particular, Spiegel et al. (1998) conducted a study that showed women in a mind and body program offered

in conjunction with their conventional cancer treatments lived twice as long as those who did not participate. The program consisted of visualization techniques, meditation, and guided imagery. Carlson, Speca, Patel & Goodey (2003) looked solely at an eight-week stress-reduction meditation program, which included relaxation, meditation and gentle yoga. Results showed significant improvements in overall quality of life, symptoms of stress, and sleep quality. Carlson, Ursuliak, Goodey, Angen & Speca also conducted a study in 2001 that involved a stress-reduction meditation program. The study yielded similar results as the one conducted in 2003. In addition, researchers then introduced a six-month follow-up study to evaluate the long-term effects of such mind-body interventions. Results of the follow-up study showed that less mood disturbance and fewer symptoms of stress were maintained for the full six months after the completion of the initial study.

Manipulative and body-based practices have also been proven to have a beneficial impact on women who are currently undergoing cancer treatment. Billhult, Bergbom, and Stener-Victorin (2007) examined the effect of massage on nausea, anxiety and depression in breast cancer patients receiving chemotherapy. Results showed that massage treatment significantly reduced nausea and vomiting, but was inconclusive on its effects of anxiety and depression.

The Use of CAM Therapies among Breast Cancer Patients

People diagnosed with cancer represent a large portion of the population that accesses CAM therapies. Richardson, Sanders, Palmer, Greisinger, and Singletary (2000) researched CAM use among cancer patients and found that 83% of 453 participants had used at least one CAM therapy as part of their treatment. One possible

limitation to this study was the method of data collection used. A questionnaire does not incorporate a person's story or personal experience and therefore has the potential to leave out valuable information otherwise gained through an interview. Similarly, a study conducted by Dy, Bekele, Hanson, Furth, Mandrekar, Sloan, and Adjei (2004) reported that 88% of 102 cancer patients had used at least one CAM therapy. These studies illustrate the fact that people diagnosed with a chronic illness such as cancer are utilizing complementary medicine as a part of the treatment regimen.

The use of complementary and alternative medicine among women with breast cancer is said to be increasing, but few research studies actually confirm this belief (Boon, et al., 2007). Boon et al. (2007) conducted a study in Ontario Canada that compared overall patterns of CAM use in 1998 versus 2005. Researchers also investigated the specific CAM techniques and therapies that women were utilizing during the course of their treatment. Results showed that in 1998 66.7% of women reported using either a CAM product/therapy or seeing a CAM therapist as compared to 81% in 2005. The most commonly used products and practitioners for treating breast cancer in 2005 were green tea, vitamin E, flaxseed, vitamin C, massage therapists and dietitians/nutritionists.

Research has shown that complementary therapies are used by a number of different people for various reasons. Research has also shown that cancer patients are one of the largest groups that access these services. For the purpose of this research study the focus will remain specifically on breast cancer patients. Shumay et al. (2002) looked specifically at what determined breast cancer patient's use of CAM therapies. One hundred and forty three cancer patients were interviewed at approximately three

years postdiagnosis. Results showed that women with breast cancer, and those experiencing greater symptoms of nausea and vomiting were more likely to turn to complementary medicine for relief.

Adler's (1999) study also examined the varying reasons why women choose to use CAM. Adler audiotaped thirty-six women ages 41-73 that were diagnosed with breast cancer on an average of five years prior to participation. Participants were placed into three focus groups to discuss their perceptions and experiences regarding the use of CAM therapies. Participants were also asked about how they first learned of complementary medicine, and how they continued to obtain further information. Results showed that women chose to participate in CAM therapies in the hope that it would increase their chance of survival, in reaction to bad experiences with conventional medicine, to prevent further illness, and/or a belief that they had nothing to lose. Women reported that they first heard of CAM therapy by word of mouth, the media, practitioners, and/or personal reading. Women continued to investigate these therapies by further reading, and talking with other breast cancer survivors.

Most Commonly Used Form of Complementary Medicine

There are several types of complementary therapies that are available to patients to choose from when undergoing breast cancer treatment. Shen, Andersen, Albert, Wenger, Glaspy and Shekelle (2002) found that of the 73% of women with advanced-stage breast cancer that used CAM, the most common forms were relaxation/meditative techniques and herbal medicine. Balneaves, Kristjanson and Tataryn (1999) also conducted a study to investigate what the most readily used forms of complementary

therapies were among women with breast cancer. The results were similar in nature, but were expanded to include spiritual healing and prayer.

The efficacy of such complementary treatments is at times under question. There is research that supports its beneficial claims as well as research that reject them.

However, research does support the idea that relaxation training helps to reduce the adverse reactions to chemotherapy, (Burish and Lyles, 1981). Hee, Se, Sung, Woo, and Oh (2005) conducted a study in South Korea that assessed the effectiveness of relaxation training and guided imagery in reducing the side effects of nausea and vomiting associated with chemotherapy. They also measured the effects of the training on the patients overall quality of life. Results showed that participants who received relaxation and guided imagery training were significantly less anxious, depressed, and hostile. The researchers also found that these participants were significantly less likely to experience nausea and vomiting both pre and post chemotherapy. Lastly, results indicated that six months after the last chemotherapy treatment participants rated their overall quality of life higher than those that did not receive the training.

Balneaves, Kristjanson, and Tataryn (1999) reported that overall people living with cancer use complementary medicine more frequently, and with breast cancer representing a large proportion of female cancer patients worldwide this may help explain the increase in rates. In addition to investigating gender differences, researchers also questioned what the typical consumer of CAM therapies would look like. Results showed that the typical consumer of complementary therapies is a female, under the age of 65, has a high socioeconomic status, and suffers from a chronic health condition.

Opposing Research

There are studies that show a decline in the use of CAM therapies. For example, Burstein, Gelber, Guadagnoli, and Weeks (1999) surveyed newly diagnosed patients from Boston, MA aged 41-70 years. After surgery, new CAM use was reported to be 28%, whereas 39% of women used these therapies prior to diagnosis. Rosenthal and Dean-Clower (2005) discussed possible risks associated with the use of CAM while using these therapies in conjunction with conventional medicine. There is often a gap in communication between patients and their physicians regarding the use of CAM. Patients often use unsupervised therapies with potentially serious implications. Various herbs and recommended diets may have a negative interaction with the chemotherapy or radiation that the patient is currently receiving. Rosenthal and Dean-Clower (2005) stated that in the United States, CAM has become a multibillion dollar unregulated industry where the consumer absorbs most of the costs. This re-emphasizes the need for further empirical evidence that supports the effectiveness of CAM therapies.

Theoretical Framework

It is important to have a theoretical framework when researching the perceived effectiveness of mind-body therapies in breast cancer outpatients. Society may believe that advanced medical illness and quality of life are contradictory to one another, but research says otherwise (Teno & Stewart, 2006). For example, studies show that people who are dealing with a terminal illness sometimes view their last years as the best years of their life, (Cohen, et al., 1995); and due to the advances in diagnosis and treatment of breast cancer it has led to an increase in survival and therefore a greater emphasis on quality of life, (Pandey, et al., 2002). Quality of life is an important, and relevant

theoretical frame to apply when working with people who have been diagnosed with a disease such as cancer. Research states that people who are diagnosed with cancer use complementary therapy because they feel an urgency to be an active participant in their care in order to survive, they want to improve their quality of life, and lastly because it gives them a sense of hope, (Sollner, et al., 2000).

In recent literature quality of life has been measured from four domains: physical well-being, emotional well-being, functional well-being, and social/family well-being, (Friedman, et al., 2006). Friedman et al. (2006) applied a quality of life framework to investigate the impact that a person's social support, personality, and psychosocial functioning has on women with breast cancer. The four domains used to measure quality of life were chosen because of the reliability, validity, and sensitivity shown in previous studies (Cella, 1997; Webster, et al., 2003). Physical well-being, emotional well-being, functional well-being, and social/family well-being were categories created by patients and expert health care providers. This categorical system used to define 'quality of life' will also be used in the current study.

Several researchers have used the Functional Assessment of Chronic Illness Therapy (FACIT) questionnaire to measure quality of life. The Functional Assessment of Cancer Therapy (FACT) is a more specific scale that is designed to measure multidimensional quality of life in patients with breast cancer. The FACT-B is a 44 item self-report instrument that includes questions from the cancer therapy scale in addition to questions from the breast cancer subscale. The reliability and validity of this scale was tested by Brady et al. (1997).

Quality of life among breast cancer survivors is an area of interest that is being researched worldwide. A Canadian survey of 913 patients with cancer found that 94% experienced one or more of the following psychological and quality of life-related symptoms: fatigue (78%), anxiety (77%), depression (59%), and sleep disturbance (55%), (Ashbury, et al., 1998). A second study conducted by Matthews, Baker, Hann, Denniston and Smith (2002) examined the relationship between health status and quality of life among breast cancer survivors. The results showed that women expressed the greatest dissatisfaction with their sexual ability, physical strength, and bodies in general. Research has shown that quality of life is affected when dealing with illnesses such as breast cancer and patients are actively looking for ways to improve these deficits.

Breast cancer patients may use conventional medicine to help improve their quality of life, or they may turn to complementary therapies to do the same, but using integrative health care can be more beneficial and effective than just using one or the other, (Verhoef, et al., 2005). Integrative Health Care is the synergistic combination of both conventional and complementary medicine. A study conducted by Verhoef et al. (2005) reported that patients who participated in Integrative Health Care experienced improvements in their physical, emotional, and global well-being, along with personal transformation, feelings of connectedness, and cure, (Verhoef, et al., 2005). Complementary therapies are not meant to replace mainstream cancer treatments and are not used to cure disease. Instead, these therapies are aimed at controlling symptoms and improving well-being and quality of life.

Racial and Ethnic Differences

Breast cancer is the most frequently diagnosed cancer among varying racial and ethnic groups, including African American, American Indian, Asian, and Hispanic women, (The Susan Komen Breast Cancer Foundation, 2006). Racial differences do exist among the development and mortality of women with breast cancer. These differences may result from differences of risk factors, biological differences, and differences in screening rates. The overall rate of new cases of breast cancer increased for Asian American, Hispanics and Whites during 1992-2000. In comparison, American Indian and African American rates decreased during this same time period. White women are said to have the highest rate of developing breast cancer among any other racial or ethnic group, (The Susan Komen Breast Cancer Foundation, 2006).

A descriptive, cross-sectional, multi-ethnic study conducted by Alferi, Antoni, Ironson, Kilbourn, and Carver (2001) concluded that of the 231 women questioned 56% of them were undergoing some form of CAM therapy. Of the participants ten percent were African American, twenty-six percent were Hispanic, and sixty-four percent were Caucasian. More specifically, 29% engaged in meditation or imagery, 23% participated in support groups, 22% were in psychotherapy, 21% turned to spiritual healing, and 1% did acupuncture. Racial differences included that African American women used more herbal therapies and spiritual healing than Caucasian and Hispanic women. A limitation to this study was that it used a survey to pole participant's responses, which may have taken away from learning about the personal experiences and perceptions of the various cultural and ethnic affiliations.

The need for further research to investigate the racial and ethnic differences in the utilization of CAM therapies continues. It is also important to be aware of participant's socioeconomic status and acknowledge that such therapies are mostly available to people of a certain class. There is an assumption that those accessing these services have insurance, and since most insurance providers do not cover the cost, participants must then have the financial means to compensate.

Present Research

The literature reviewed here has set the groundwork for this study. It has helped me understand what the strengths and weaknesses are in this field of research, which in turn has been used to develop the current study. Research has proven that people with a chronic illness such as cancer use complementary medicine to enhance their treatment regimen. Research has also suggested that women seek complementary therapies to increase their chance of survival, to assist with conventional medicine, and/or to prevent disease progression, (Adler, 1999). Breast cancer is one of the most common cancers among women and data shows that these women are among the highest users of CAM therapy. Research has also investigated the most commonly used forms of complementary therapy and the reasons women gave for accessing these services. Studies have also been conducted on the importance of a person's quality of life while dealing with a serious illness, and the benefits that complementary medicine has to offer. The present study will focus on breast cancer patients, their use and perceptions of complementary medicine and most importantly the affects on quality of life. Specifically, it will investigate the relationship between complementary medicine and quality of life among women with breast cancer.

CHAPTER III

METHODOLOGY

This study examines the relationship between complementary therapies and quality of life among women with breast cancer. It is a qualitative study that utilizes a relational, cross-sectional, flexible method. A relational design describes patterns in relationships among variables; there is no manipulation of variables. The independent variables in this study are the complementary interventions used, and the dependent variable is the participant's perceived quality of life. The objective of this study was to investigate the different forms of complementary therapies women were using during the course of the treatment, why women choose to use these techniques, their perceived effectiveness of these therapies, and most importantly the impact on quality of life.

Sample

Subjects for this exploratory study were obtained from the Virginia Thurston Healing Garden, located in Harvard Massachusetts. An initial email was sent to the Executive Director of this program informing her about the study, and inquiring about possible participants. A telephone conversation revealed further explanation of the study and its purpose, as well as the Executive Director agreeing to send out a general email to the program's clientele. The email included a brief explanation of the study along with the researcher's contact information. It was important that women did not feel pressured to share their experiences, or participate in the study therefore it was left up to each

woman to contact the researcher for more information. As a result, several women responded via email stating interest in participation. Seven participants were interviewed from the Virginia Thurston Healing Garden and five more referrals came from word of mouth.

Subjects

A snowball sampling of women yielded a total of twelve interviews. Three interviews were conducted in person and nine were done over the telephone. The following information is a summary of what was collected during the demographic section of the interview.

There were a total of twelve women that were interviewed, and of those twelve women, eight participants were married, four were divorced, and of the four that were divorced three of them were currently in another partnered relationship. The ages of participants ranged from 32-65 years old. Eleven participants identified themselves as Caucasian and one participant was Indian. I was not able to obtain a diverse population from the agency I recruited from, which may have impacted my results. Two participants had received a High School diploma, nine participants had obtained a bachelors degree, and one woman had gone on and completed her Masters degree. Participants were then asked to give a range of their annual household income. One participant said that her annual household income was between \$30,000-49,000, three participants made between \$50,000-74,000, and eight participants reported an annual household income of greater than \$75,000 per year. This population did not reflect anyone in a socioeconomic state below 30,000, which may also have an affect on the data.

Additional information was gathered about the family and household dynamics. Participants were asked if they had any children and the ages of the children. Nine women had children and three did not. Of the nine women that had children, four of them had children living in the household while undergoing breast cancer treatment. The children ranged from 5-35 years old.

Participants were also asked about their initial diagnosis, staging, and their current status in the treatment process. Of the twelve participants four were diagnosed with Ductal Carcinoma in Situ (DCIS), four with Invasive Ductal Carcinoma (IDC), and four with Invasive Lobular Carcinoma (ILC). Three participants were diagnosed at Stage 0, four participants were diagnosed at Stage I, two were diagnosed at Stage II, two were diagnosed at Stage III, and one participant was diagnosed at Stage IV. Three participants are currently battling metastatic breast cancer and nine participants are in remission. The first year of diagnosis ranges from 1996-2006, and five out of twelve women have had a reoccurrence in that time frame.

Data Collection

Confidentiality was an important component to this research study; therefore the appropriate and necessary steps were taken to maintain each participant's confidentiality throughout the entire process. Each participant signed a consent form, which stated that information was being gathered for the purpose of research and that only the researcher would have access to the recorded interviews. Participants who choose to complete a telephone interview were mailed two copies of the Informed Consent, one for their records and one copy to sign and mail back to the researcher in the self-addressed, stamped envelope that was provided. The Informed Consent also explained that

participants had the right to withdraw from the study at any time without receiving penalty, or without others being notified of their decision. Confidentiality was upheld by coding tapes, transcripts, and the interview guides to assure that name identification would not appear in the data. The U.S. federal requirements state that researchers must keep all notes, tapes, and transcripts for at least three years after the completion of the study. Data was kept in a locked file cabinet and will remain there until destroyed.

All the procedures and materials used for data collection were submitted to and approved by the Human Subjects Review Committee at Smith College School for Social Work. One data collection instrument was used in this study: a two-page interview guide, which also included demographic questions. The demographic questions included marital status, children, household occupancy, race, age, and annual household income. The other interview questions addressed participant's specific diagnosis, family history, treatment protocol, and their emotional experience throughout their breast cancer journey. Participants were then asked about their use of complementary therapies and the affects that it had on their overall quality of life.

Information was gathered by semi-structured interviews conducted in person and by telephone. Interviews were comprised of twenty-four structured and unstructured narrative questions. Interviews lasted between 30 minutes to 1 and ½ hours. Responses were audio-taped and transcribed.

Data Analysis

Interviews were both transcribed and coded using a note card system where each participant was given a random number. Responses were recorded and categorized by question on separate sheets of paper. The data was then reviewed and analyzed in an

effort to identify similarities and differences in responses. The categorical system was also used to identify any emergent themes across participation.

This study had several limitations. One limitation was that eleven out of twelve participants were Caucasian, and therefore did not include a racially diverse sample. Second, the majority of the participants interviewed reported an annual household income of \$50,000 or greater, which only accounts for those in a middle to upper socioeconomic class. Thirdly, because of the small sample size this study does not allow for generalization of the results to a larger population.

CHAPTER IV

FINDINGS

The purpose of this study was to explore the relationship between complementary therapies and quality of life among women with breast cancer. The following section will address the results of who was most inclined to use complementary therapies; why women choose to use these therapies; the mind, body and spiritual connection of healing, and overall quality of life.

Who Is Inclined to Use Complementary Medicine

Complementary medicine is used by a variety of different people. One major finding of this study was that women diagnosed with Invasive Lobular Carcinoma (ILC) and Invasive Ductal Carcinoma (IDC) were more frequent users of complementary therapy than those who were diagnosed with Ductal Carcinoma in Situ (DCIS). Participants with ILC or IDC reported weekly treatments of at least one form of complementary therapy, whereas those who were diagnosed with DCIS reported biweekly or monthly treatments. Participants with ILC and IDC were also more likely to continue using complementary therapies even after their cancer treatments were completed. Women who were currently undergoing treatment for metastatic breast cancer were the most likely to engage in complementary medicine as opposed to those who were in remission. In this particular sample all twelve participants used some form of complementary medicine at some frequency regardless of their disease type or progression, therefore the results only account for women who have participated in these

therapies. In other words, if a larger, more diverse sample size was obtained these results may differ.

It was also important to research what point in the treatment process participants decided to use complementary therapies. Responses varied, but a total of six women (half of the entire sample) started using complementary therapies about half way through their treatment process. Women with Stage II breast cancer and beyond were more likely to begin using these therapies early on in the treatment process, where as women diagnosed with Stage I breast cancer showed less urgency to use treatments outside of conventional medicine. Participants who had a reoccurrence or disease progression were more apt to either begin using complementary therapies after the cancer came back, or they significantly enhanced their current therapy regimen. For example Ms. J reported,

I had two good years of aromatase inhibitors without any disease progression, but then the cancer began to spread into my soft tissue like my lymph nodes and into my chest wall. This was the point when I really started to pursue complementary medicine.

Another example, Ms. L who had a reoccurrence in 2001 stated,

The first time around I wasn't as into complementary therapies because I didn't know a lot about it and I was really just into sticking with what my doctors told me to do. The second time around I was much more open to different things and was looking for something that would make me feel healthier and better about myself, which was not something I got from conventional medicine.

The Most Commonly Used Complementary Therapies

There were a wide variety of complementary therapies used among participants. The four most frequently reported complementary therapies were acupuncture, reiki, meditation and massage. Participants used more than one complementary therapy during the course of their treatment and they were encouraged to list all of the therapies that they

had engaged in. Acupuncture, reiki, meditation and massage were each used by 58% (7 out of 12 participants) of the total sample size. Results showed that women who used acupuncture used it more often than any other therapy, and reported the most beneficial results in treating side effects. Ms. H reported,

Acupuncture made me feel more balanced and it helped to take away some side effects. It helped me with the metal taste in my mouth from the chemotherapy, it helped keep my blood count stable, it balanced and evened everything out in my body, and it kept my hot flashes under control.

The other forms of complementary medicine included: facials, yoga, nutritionist, homeopathy, support groups, herbal supplements, chi gong, naturopath, holistic chiropractor, visualization, hypnosis, tai chi, emotional freedom technique, energy balance, spiritual/church connection, seeing a social worker, tae kwon do, participating in an adventure camp sponsored by The American Cancer Society, and art therapy.

Why Women Choose to Use Complementary Therapies

There were several interview questions that specifically asked participants why they decided to incorporate complementary therapies into their treatment protocol. The interview question stated, "At what point in the treatment process did you decide to explore complementary therapies? And for what reason(s)?" Women reported a variety of different reasons as to why they turned to complementary therapies, and participants were encouraged to give multiple responses if applicable. The most frequent response to this question (6 out of 12 participants, or 50%) was to control and reduce side effects brought on by conventional treatment and/or the disease itself. For example, Ms. D reported that during her initial biopsy her breast was crushed and damaged to the point that it took two more surgeries for them to remove the cancer due to the build up of scar

tissue. This biopsy left Ms. D with excruciating pain in her left arm. She reported that there was permanent damage done to her breast tissue and nerve endings. Ms. D was left with the feeling that her arm is being plunged into boiling water. She was also experiencing hot flashes and insomnia. Ms. D reported,

The acupuncture and massage allowed me to have mobility in my arm again. I can cook again and the pain is much milder. I also went to a naturopath who helped to decrease my hot flashes and worked on getting me back into a healthier sleeping pattern.

Women who underwent chemotherapy as part of their treatment process were more likely to report using complementary therapies to help reduce side effects than women who did not receive chemotherapy. These women were also more likely to use these therapies on a weekly and biweekly basis. Ms. A, who was 32 years old when first diagnosed with Invasive Ductual Carcinoma, had to undergo chemotherapy and 33 days of radiation.

Ms. A reported,

With the first round of chemotherapy I was so nauseous and could not stop vomiting. They gave me an anti-nausea drug that made me gain weight, and they also gave me a drug to keep my white blood cells up, which I ended up having a bad reaction to. I got a bad mouth infection that went all the way down my throat. I had swollen glands, and the skin on my fingers and toes looked burnt. I eventually lost some feeling in my fingers and toes that lasted for quite a long time. I had a burning sensation that went from my inside out, and I broke out into a rash on various part of my body. During the radiation my skin got so burnt that it bled on several occasions. At one point they had to stop the radiation to give my skin a break. All the while I was also having bouts of insomnia. I think complementary therapies helped me a lot when I was going through all of this. The massages gave me energy boosts and helped with my fatigue. I got several facials which helped with some of my skin issues during radiation and I met with a nutritionist on a regular basis who helped me with my eating habits and to counteract my weight gain.

Another woman, Ms. B, had twelve chemotherapy treatments and as a result suffered from nausea and vomiting. Ms. B stated,

I did acupuncture several times while having chemo because I had heard that acupuncture could help reduce the nausea and vomiting caused by having these treatment. It helped me feel significantly less nauseas, which in turn decreased my vomiting.

Similarly, Ms. I reported,

I suffered several side effects from the chemotherapy and I continue to have some of these symptoms today. I have neuropathy, which causes a lot of pain in my legs, I have difficulty sleeping, and I continue to feel nauseas. At times I still have that metallic taste in my mouth and I have yet to get over the extreme fatigue that sets in during all of these treatments. The acupuncture did help to minimize these side effects. I wasn't feeling as nauseas as I previously was, the pain caused from the neuropathy has decreased, and I always came back with more energy after having an acupuncture treatment.

A second reason why women reported using complementary therapies was to get emotional support, empathy and validation from other woman with breast cancer through support groups, adventure camps, and interactions during other therapy events. Five out of twelve or 42% of participants stated their emotional needs as a reason to explore complementary medicine. The emotional piece of having breast cancer was very important to most women, and was not always able to be fulfilled by family and friends. Ms. G reported having a very long emotional experience during the course of her breast cancer. She explained that people often had a tendency to minimize her experience and her family was in a rush for things to return to normal. Ms. G decided to have a single mastectomy because of her diagnosis and her family history of breast cancer. She found the support she was looking for at the Virginia Thurston Healing Garden located in Harvard Massachusetts. This program serves as a community of support for women with breast cancer. They strive to enable women to find the support they need, to learn about informed choices that contribute to their health, to learn to manage their stress and

improve their quality of life, and to regain control of their health both during and after treatment. Ms. G explained,

The healing garden really helped me deal with what it meant emotionally to lose a breast. I really had to dig deep to find a place like the healing garden because I was so overwhelmed by all the emotions I was having, and all the decisions that needed to be made. The healing garden put me on track, it got me back on my feet again and feeling like a whole person. They really helped me find out what the meaning of the word 'survivor' meant.

Ms. C joined a support that her friend was facilitating,

I started going to this support group even before my first surgery and I got tremendous support from these women. My initial diagnosis was in June of 2000 and I currently have metastatic breast cancer. I now co-facilitate the support group and have for the past couple of years now. These women really provide each other a safe and open environment to share their stories and experiences. I have really gotten the support, empathy and validation that I have not been able to find anywhere else.

Ms. K found that art therapy was an effective practice for her when dealing with her emotions,

I was surprised that art therapy worked for me. I had never tried anything like this before and I wasn't sure how it was really going to help me. Drawing and putting collages together was a way for me to put my emotions on paper. I wasn't even aware that I was feeling the way that I was until I had to draw it. From this point forward I was able to put my cancer in a different perspective and work on moving forward with my life.

Another reason why women choose to use complementary therapies is to help with the reduction of stress. The current study revealed that five out of twelve women (42%) reported using these therapies to reduce stress. Women reported an increase in stress from being sick, from having to make treatment decisions, worrying about a reoccurrence, family obligations, and financial concerns. Ms. E talked about the stress of going through a divorce while trying to battle her breast cancer.

The first time I went through my cancer treatment I was going through a divorce. There were battles over child custody, I lost my home, I lost my job, and I was eating at soup kitchens. I was about to start my radiation treatments while we were fighting over child support and that is when he told me that he was canceling my health insurance. At that point I thought that the man I was married to for 25 years wanted me dead. I had no hope and I thought everything was a done deal. I ended up receiving free care from my local hospital. The stress that I was under while going through all of this told me that I needed something else besides mainstream medicine, that I needed to seek some other ways of healing.

Five out of the twelve women were divorced, and three of them were in the middle of the divorce process when they were initially diagnosed. Each participant who listed stress as a reason why they sought out complementary therapies stated that it might have been the reason, or a contributing factor to why they got breast cancer in the first place.

Other reasons that women gave to explain their use of complementary medicine was to put themselves first, fear of disease progression or disease reoccurrence, the belief in the mind/body/spirit connection, and the need to have something to look forward to.

Ms. A stated,

I choose complementary medicine because I felt like I needed something brighter than the darkness of going to the hospital all the time, and definitely the healing garden was that something for me. It really gave me something to look forward to that I would have not otherwise had.

Although some responses were more common than others, results showed that there were several different reasons why women decided to incorporate complementary therapies into their treatment protocol. Even though the reasoning differed, one commonality across all the responses was that women were looking for something that they could not otherwise receive from conventional medicine, from family and/or from friends, something that they were only able to find in these therapies.

Mind, Body and Spiritual Connection of Healing

There were several benefits that women looked for while using complementary therapies. The previous sections showed that respondents were looking for relief from physical symptoms; they wanted help in dealing with their emotional experience. Six out of twelve, or 50% of participants stated that they were really searching for a mind, body and spiritual way of healing when they choose to use complementary medicine. This was a connection that conventional treatments could not provide, and participants really valued its effectiveness on healing and recovery. Women talked about the importance of having a "fighting spirit" while battling breast cancer. Several participants recognized how difficult it could be to maintain a positive, optimistic spirit when the physical and mental part of one's body is diminished. Ms. C stated,

When I was first diagnosed with breast cancer I think I cried for three days straight and after that I pulled myself up by my bootstraps and told myself that I had to deal with it, and from that point forward I approached the cancer as if I was going to beat it. When I found out that my cancer had spread it was a very down time for me and I felt defeated. I allowed myself to have that down time, but shortly after I felt encouraged again. The mind, body and spiritual connection are a very big part of my healing process.

Ms. J, who has metastatic breast cancer explained,

It is just so crucial to have a fighting spirit while going through all of this. I remember that I didn't feel bad and I wasn't really upset when I was diagnosed. I knew from the start that I had to get over it and that I was going to beat it. I remember when I was first diagnosed with breast cancer I was standing outside and all of a sudden everything seemed clearer and more beautiful to me. It was so important to me to use my mind, body and spirit as a way to reconnect to the universe, and as a way to heal me.

Participants reported that their state of mind was an important part of the healing process.

Women talked about the idea that if one's life is filled with stress and negativity they

believe you are more likely to have disease progression and/or a reoccurrence. Ms E. stated,

I think that part of the reason why the cancer came back was because of all the stress and negativity I was going through with the divorce and the negative thoughts I had about myself. I truly believe that all of that attributed to my reoccurrence.

Ms. J expressed,

I really felt that my cancer came to me as a product of everything that has gone on in my life. It is no coincidence to me that my breast cancer came to me six months after I split up with my ex-husband. All of the bad things and stress that I had in my life for so many years no wonder that my health has gone down hill.

Spirituality was a difficult concept to define and the interview questions used for this study were not designed to investigate participant's specific beliefs about this subject.

Results showed that spirituality meant different things to different women. One aspect that most women shared in common was that when their mind felt connected to their body, and their body to their spirit they felt stronger and healthier.

There were several techniques that participants used to incorporate their spirituality into the healing process. Fifty to 58% of women actively engaged in either yoga or meditation practices during the course of their treatment. Participants spoke of a specific type of breathing called *pranayama*, which means, "deep breathing" in the Hindu tradition. This is a way to unite one's body with the universal energy that is the essence of spirituality. Ms. L reported,

I did yoga and meditation on a weekly, sometimes daily basis. These practices really helped to keep my stress level down which ultimately helped me keep a better mindset about everything that was going on. There is something about the deep breathing that goes along with yoga and meditation that has a healing affect on me. Of course this is nothing that I can prove or measure, but I feel it deep within me that if you breathe deep into the core of your body you are able to release poisoness toxins.

Other women obtain their spiritual connection through religion. Religion and spirituality are often viewed as separate entities in that religion is a bridge to the spiritual but the spiritual lies beyond religion. In this study there was a significant link between religion and spirituality. Ms. F reported,

I really utilized my spiritual connection through my church. I was the chairperson of the Health and Wellness Ministry and through my first diagnosis I maintained that role. It was very helpful to not only be the provider of that group, but a receiver as well.

Lastly, another common response when talking about the need to fulfill one's spiritual connection is the belief in a higher power. Women talked about the importance of having faith during your illness, believing that there is a higher power and a meant to be. This belief has offered women a sense of comfort and allowed them to be more accepting of whatever the future holds. Ms. B states,

It has been a true release for me to know that I am not in total control of my illness. It relinquishes me from some of the responsibility. I believe that there is a being higher than me and higher than anyone else in this world that looks down upon me and takes me under his wing. I trust that this higher power will put me on the path that is meant for me and if that means I will survive this than great, but if that means my time is cut short than I will accept that too. It has taken me a long time to reach this space, but I can truly say and believe that whatever is meant to be will be. For me the connection between my mind, body and spirit is what really makes life worth living.

Ms. I reported,

I had to have faith in God that he would guide me through this journey. I relied on the power of God to give me the strength and courage that I needed to overcome this battle. I didn't leave it all in God's hands, I was determined to fight this battle as much as I could with conventional and complementary medicine, but when times got tough I reminded myself that I was not alone.

Results showed that for most women a true healing process could not occur without the integration of the mind, body and spirit. When these three components were

interconnected women reported less physical aches and pains, and a better outlook on life.

Quality of life

Quality of life was an important piece of this qualitative research study. There were specific interview questions that asked participants to describe their overall quality of life, and the impact (if any) that complementary therapies had on it. Quality of life was broken down into four domains: physical well-being, social well-being, emotional well-being and functional well-being. Ten out of twelve participants (83%) reported having a positive quality of life, and more specifically six out of twelve (50%) women stated that their quality of life had since improved from their initial breast cancer diagnosis. Two out of twelve participants (16%) reported having a negative experience with breast cancer and therefore a decrease in satisfaction with their overall quality of life. Those that reported having an overall positive emotional experience during their breast cancer were more likely to use complementary therapies early on in the treatment process, and were more likely to report a happier and healthier quality of life. Ms. H noted,

Overall my experience with breast cancer was a positive one. I do remember feeling anxious, nervous and having a lot of sleepless nights, but I also remember all of the love and support I received from family and friends. I believe that experience really allowed me to grow as a person and taught me to pay more attention to my body and my own needs. Emotionally I have learned how to limit my negative thoughts, control my mood, and improve my coping strategies. Socially these therapies allowed me to feel well enough to continue spending time with my friends and family. I joined a support group that let me know that other people were going through the same things I was. Physically it helped me with my energy level and kept my side effects under control. Functionally I was still able to compete with my horses and do the things that I love to do.

Participants that had a negative experience throughout their treatment process were less likely to pursue complementary therapies, and more likely to report dissatisfaction with their quality of life. Women who reported having a negative experience and therefore a negative quality of life suffered from sustaining side effects brought on by conventional medicine (chemotherapy, radiation and/or surgical procedures). Both of these women did state that their overall quality of life was beginning to pick up due to the result of continued complementary therapy use. Ms. D reported,

My quality of life has drastically gone downhill ever since I was diagnosed with breast cancer and going through treatments. Luckily it is just starting to pick up because the complementary therapies are decreasing my pain and increasing my mobility. It has been a very isolating experience for me and I didn't have many friends to begin with and I think the whole cancer experience exacerbated that. These experiences are hard to get over because I am left with possible permanent side effects.

Ms. I also reported having a decrease in life satisfaction,

My quality of life is not good, but it is picking up again because of the complementary therapies. The whole year was a write off for me because I wasn't able to do the things that I wanted to do, and I'm still not to that point yet. Mentally I feel like I suffer from chemotherapy (chemo) brain because my short-term memory and concentration have been affected. My energy level is horrible, but it is finally starting to come back. I used to have a very active life before having cancer where I traveled a lot, but every since I got diagnosed my life came to a standstill. I am now trying to pick up the pieces, but I am still left limited.

Disease progression, reoccurrence and staging had a significant impact on how women viewed their quality of life. Participants who had a reoccurrence were more likely to view their quality of life as positive compared to those who had not had a reoccurrence, and those that currently have metastatic breast cancer view their quality of life as the most optimal. Results showed a definite link between severity of disease and quality of life. Ms. J is a 44-year-old woman who was initially diagnosed with Invasive

Lobular Carcinoma breast cancer stage 3 in 2000. She currently has metastatic breast cancer that spread to her lymph nodes and into her chest wall. She reports,

My quality of life is really great. This cancer has done a lot of good in my life. You really learn to live a fuller life when you know it might be cut short. You learn not to sweat the small stuff. I no longer put things off that I want to do. Complementary therapies have helped to give my body a better playing field to fight the cancer, which has given me longevity and helped mainstream medicine work more effectively. These therapies have allowed me to open up my energy lines for healing and enabled me to implement calm, peace and serenity into my daily practice. I want to live my life and not have it be consumed by cancer. The quality of life that these therapies have given me is invaluable and I could never put a price tag on them.

Ms. C is a 63-year-old woman who was also diagnosed with Invasive Lobular Carcinoma in 2000 with stage 1 breast cancer. She had a recurrence in 2004 and currently has metastatic breast cancer that has spread to her bones and liver. Ms. C states,

My quality of life at this point is excellent. I have a great job, good income and a wonderful loving family. I have learned not to put things off. I am going on vacation with my daughter, son-in-law, and grandchild in a month, which we were going to put off but decided not to. Emotionally complementary therapies have helped me handle and cope with my diagnosis and prognosis. Functionally these therapies have allowed me to work full time as a nurse manager on an inpatient psychiatric unit. I didn't want to stop working, stay home and just think about my cancer all day. I am glad I started these therapies early so they got a chance to kick in before my symptoms got bad. I feel that this experience is harder on my family than it is on me. I have learned to remain focused on the present and take one day at a time. Most of the time that is all I can handle anyway.

One of the major findings of this research study is that twelve out of twelve participants reported some positive correlation between the relationship of complementary therapy use and quality of life. Each participant, in varying degrees, believed that complementary therapies have helped to improve their quality of life while fighting breast cancer. Some women reported that these therapies were most helpful in

dealing with the physical ailments, some women found it helpful socially, emotionally, and others found it helpful in terms of functionality. Ms. E reported,

Complementary medicine helped me in a lot of ways and because of these therapies my quality of life has since improved. Socially I am a lot more fun to hang out with than I was six years ago. I feel more connected with people, I'm out doing things, I laugh more, and I have more friends. I would recommend complementary therapies to other women with breast cancer in order to get the mind-body connection that you can't get anywhere else. It has helped me to have a healthy attitude and outlook on life. It has really decreased my stress, which can ultimately lead to disease. If I had the awareness I do now about my health and my body I may not have gotten breast cancer in the first place.

Ms. G stated,

Complementary medicine gave me something to focus on and move forward with. It helped me with my energy level and to feel less stressed. Emotionally these therapies were effective in helping me cope with everything that was going on. Functionally it was sometimes hard to get out of bed from the physical and emotional side effects the cancer gave me and these therapies really helped with that. I know put more time and energy into doing things that I like to do such as playing the flute and I rejoined the orchestra. Prior to my diagnosis I had to cut back on the things I liked to do because of how busy things were with my family, but now I focus on what is important to me and I don't feel guilty about it.

Overall women reported being satisfied with their quality of life and those that were not were experiencing severe side effects from conventional methods. Results showed that it is possible to maintain a positive quality of life while fighting breast cancer.

Other Factors that Affect Quality of Life

One of the most important decisions to be made when diagnosed with breast cancer is the course of treatment. In this study eight women had a lumpectomy, six women had a single mastectomy and two women had a double mastectomy. Of the eight women who had either a single or a double mastectomy all eight of them had some sort of reconstructive surgery to replace the breast(s). Fifty percent of the women who had

breast reconstruction talked about the impact that society had on their decision to replace the breast(s). Ms. B who had a single mastectomy reported,

Because of the number and location of my tumors I really felt that the whole breast tissue needed to be removed, which is why I went with a mastectomy instead of a lumpectomy. When I was asked about my breast reconstruction options I took a few days to think about if I even wanted to replace the breast. I came to the conclusion that because I was 54 and living in the society that we do I had to consider reconstruction because it would not have been acceptable to have no breast.

Women also talked about the influence that society had on their treatment decision to have a single or double mastectomy. Several women talked about the symbolism of a breast in our society, and if there was any chance to keep one breast they would even if a double mastectomy might have been the treatment of choice. Ms. J who also had a single mastectomy stated,

I choose to have a single mastectomy because to have one remaining breast was very important to me. I am 44 years old and I want to still feel like a woman. If I lost both of my breasts that would really take away a lot for me in terms of my sexuality, my femininity, and sensuality.

Society plays an important role in our every day lives and according to this research it also plays a part in our decision making process on how to fight disease.

CHAPTER V

DISCUSSION

The purpose of this study was to explore the relationship between the use of complementary medicine and the impact on overall quality of life. The study was designed to identify how often women were using these therapies, why they chose to use them, what therapies they found most effective, and their current satisfaction with quality of life. The study also examined women's treatment protocols and their emotional experience throughout their breast cancer journey. The main findings of this study confirmed the positive impact that complementary therapies had on quality of life, and the need for further research.

The study was based on interviews with a snowball sample of twelve participants. The focus of the interview was to hear the stories of women who have fought against a possible life-threatening illness and have overcome tremendous obstacles along the way. In addition to hearing women's experiences the focus of the interview was to get a sense of the role that complementary therapies played in their healing process. Why did women turn to such therapies and did they find them effective? And did using complementary therapies help to improve or maintain their quality of life? The respondents were identified through the Virginia Thurston Healing Garden located in Harvard Massachusetts.

The role of complementary medicine among those with possible life threatening illnesses has been an increasing area of interest for researchers and health care

professionals. Although research has been conducted in this field, results are often inconclusive and not scientifically proven. The effectiveness of these therapies is difficult to measure in the human body; therefore people are uncertain about the potential risks and benefits it may cause.

Similar to past research, this study focused on aspects of complementary medicine that could be measured such as frequency of use, most commonly used forms, and timing in the treatment process. Other areas included women's perspective on the effectiveness of these treatments, their emotional experience, and the impact these therapies have had on their overall quality of life.

Who Is Likely To Use CAM

People diagnosed with cancer represent a large portion of the population that accesses complementary therapies. As previously stated, Dy and colleagues (2004) reported that 88% of 102 cancer patients had used at least one form of CAM therapy. More specifically, women with breast cancer are also said to be active participants in the use of these therapies. Boon et al. (2007) conducted a study in Ontario Canada that compared overall patterns of CAM use in 1998 as compared to 2005. In 1998, 66.7% of women reported using some form of complementary medicine compared to the 81% in 2005. In the current study participants were required to have used at least one form of complementary medicine. Those who were diagnosed with late stage breast cancer, those that had experienced a reoccurrence, and women who currently had metastatic breast cancer were the most likely to access these therapies. In this sample each participant had used some form of complementary medicine, therefore if a larger sample size was obtained results may differ. Past and present research has shown that people with serious

illnesses are using complementary therapies as part of their treatment regimens, and therefore demonstrating the need for further research on the safety and efficacy of these services. It is also crucial that health care professionals and patients are educated on the different CAM options and the risks and benefits associated with each therapy.

Most Commonly Used Forms of Complementary Therapies

The results of the present study were similar to past research. Shen et al. (2002) concluded that 73% of women with advanced stage breast cancer were using relaxation/meditative techniques and herbal remedies. Balneaves et al. (1999) conducted a similar study and found the same results, but also included spiritual healing and prayer. The present study found massage, reiki, acupuncture and meditation to be the most commonly used forms of complementary therapies. My research also showed the importance of a mind, body and spiritual way of healing. Studies have shown that when prayer is included in the mind-body definition, these therapies are the most commonly used form of complementary medicine, (NCCAM, 2006). Similarities exist among past and present research.

Why Women Choose to Use CAM?

Adler (1999) reported that women chose to participate in CAM therapies in the hope that it would increase their chance of survival, because it was in reaction to bad experiences with conventional medicine, to prevent further illness, and/or a belief that they had nothing to lose. In addition, Shumay et al. (2002) found that women were more likely to turn to complementary therapies if they were experiencing greater symptoms of nausea and vomiting. Similarly, the present study concluded that the most frequent response to this question was to control and reduce side effects brought on by

conventional treatment and/or the disease itself. A second reason why women reported using complementary therapies was to get emotional support, empathy and validation from other woman with breast cancer through support groups, adventure camps, and interactions during other therapy events. A third reason was to help with the reduction of stress. Other reasons included putting themselves first, fear of disease progression or disease reoccurrence, the belief in the mind/body/spirit connection, and the need to have something to look forward to. Again, there are commonalities and differences in responses across studies, which emphasizes the need for further more expansive research. Although reasoning may have differed, these women continued to use these therapies during treatment and continued to find them effective. It would be beneficial for future research to look further into why CAM use among women with breast cancer is increasing? And to look at the similarities and differences among responses in regards to diagnosis (early stage vs. late stage, remission vs. reoccurrence/metastatic).

Quality of Life

There has been an increasing amount of research conducted on the use of complementary therapies among women with breast cancer. In addition, there is also more attention being paid to quality of life among those with chronic illnesses. The advances that modern medicine has made over the years has allowed people to live longer with serious conditions, which has put a greater emphasis on quality of life, (Pandey et al., 2002). More and more women are becoming breast cancer survivors and therefore there is a real need to follow up with women years after their treatments and surgeries are completed. Arora and colleagues (2006) found that women with breast cancer receive adequate support (informational, emotional, and decision-making support) during the

period closer to diagnosis, but the helpful support and attention drops significantly within the first year. This study emphasizes patients' desire to receive consistent support and attention throughout their cancer journey, which also includes after the completion of their treatments. The current research study expands on this principle to include participants at various stages of their breast cancer experience. The study not only investigates the quality of life of participants at the beginning, middle and end of their illness, but it also serves as a follow up for women that were diagnosed over ten years ago. Two participants were initially diagnosed with breast cancer 12 years ago, three participants were diagnosed 7 years ago, and the rest of the sample was diagnosed 2 years ago or less. The differences in timing of diagnoses have allowed us to gain perspective on the newly diagnosed as well as the long-term breast cancer survivors.

Overall, women were satisfied with their quality of life. Ten out of twelve participants reported having a positive quality of life, while the other two participants had negative reports due to side effects from conventional treatments. One major finding of this study that was consistent with past research was that women who had a reoccurrence and/or currently have metastatic breast cancer view their quality of life as the most optimal. Cohen et al. (1995) concluded that people who are dealing with a terminal illness often times view their last years as the best years of their lives. In the current study women in these circumstances reported that they no longer worry about the little things, they don't put off the things they want to do and accomplish, they spend more time with the people that they love, they don't take life for granted and they feel blessed for each day they are given. Women who were newly diagnosed with breast cancer reported learning these valuable lessons from those who had a reoccurrence. In addition,

women were also taught how important it was to stay positive, and to try and eliminate as many life stressors as possible. They learned the importance of building and maintaining relationships with other women who had breast cancer, and relying on each other throughout the journey. Finally, newly diagnosed women also reported feeling encouraged and hopeful that there are other forms of treatment to turn to if needed, such as CAM.

Quality of life and breast cancer is an extremely important topic to research due to the increasing survival rates among women with breast cancer and the increasing rates of diagnoses.

Racial and Ethnic Differences

Alferi et al. (2001) conducted a descriptive, cross-sectional, multi-ethnic study to investigate the similarities and differences of CAM use across varying racial and ethnic groups. Results showed that Caucasian women were most likely to utilize these therapies; Hispanics second and African American women were the least likely. The present study did not include a racially diverse sample with eleven Caucasian women and one woman who identified as Indian. The need for further research to investigate the racial and ethnic differences in the utilization of CAM therapies continues. Another factor to consider is the socioeconomic status of the participants. Complementary therapies are expensive and often times not covered by insurance. It is important to acknowledge that these therapies may only be available to people of a certain class who have the financial means to partake in such services. The sample obtained for the current study was not racially diverse, and did not include participants from low-income families. Future research should continue to explore similarities and differences in CAM use

among varying racial groups, and research should also investigate whether one's socioeconomic status impacts their use and access to these therapies.

Implications for Social Work Practice

The findings of this study have major implications for social workers that work in hospital settings, in outpatient practices/clinics, and hospice care. The findings showed that women are always seeking supportive, empathic health care professionals to guide them through their journey with breast cancer. Research states that social workers are the most supportive health care professionals outside of nurses and physicians when dealing with complementary therapies (Hann et al., 2004). Women in the current study reported that it was important for the social worker to provide support, create and maintain cohesion among the patient's treatment team, be a good listener, and provide education and informational resources on services that the hospital may or may not provide. Participants expressed feeling more relaxed, confident, and optimistic when they received that kind of care. Efforts need to be made to increase the likelihood of communication between health care professionals and patients regarding complementary therapies. Social workers in any setting should be knowledgeable about what kinds of complementary therapies are available and what other patients have found most effective. Research remains inconclusive of the risks and benefits of using CAM to help treat illnesses, which is why physicians do not always support and encourage participation in such therapies. Social workers should also be aware of this uncertainty and inform patients accordingly. If CAM use is deemed appropriate, social workers should be able to research local healing gardens and facilities that offer these services and provide guidance. Women also found support groups to be very helpful in feeling connected,

being validated, empathized with, and for social interactions. Social workers can contribute by organizing such groups in their local communities.

Quality of life should be one of the main focuses among social workers in the health care profession. Results showed that women who reported having an overall positive emotional experience during their breast cancer were more likely to have a happier and healthier quality of life. Social workers can play an important role in this process. They can contribute to a patient's positive emotional experience by providing them with a safe, empathic, and judgment free environment to express their thoughts and feelings. Social workers can organize support groups in order to provide women with social interactions and validation from other breast cancer patients. Another major finding indicated that women who had a reoccurrence were more likely to view their quality of life better than those who had not had a reoccurrence, and those that currently have metastatic breast cancer view their quality of life as the most optimal. Through support groups and other interactions social workers can bring women together to share their experiences of being sick and of maintaining a good quality of life. This would be a way for women to learn from one another, and to receive hope and encouragement that just because the disease itself has the potential to worsen does not mean quality of life has to.

It is the responsibility of the social worker to provide women with an open and safe place to share their thoughts and feelings without judgment. This current study among others have proven that women's emotional experience while having breast cancer is an important component to their well-being and overall quality of life. Social

workers need to provide women with a place that their family and friends may not be able to give them, a place of validation and empathy.

In order for social workers to be of assistance to breast cancer patients they too need to be given the proper tools and education to do so. Social workers should attend lectures, trainings, and be kept up to date on the latest research regarding complementary therapies. It would be beneficial if these educational opportunities were offered and supported by an individual's workplace, but otherwise the responsibility falls on the social worker to seek out such programs in order to better serve the patient.

A few limitations to this study should be noted. The small sample size did not allow for a generalization of the results to a larger breast cancer population. Additionally, 11 out of 12 participants were Caucasian, therefore this study did not include a racially diverse sample. Women who decided against using complementary therapies were not accounted for and little information was gathered about women's use of complementary therapies prior to their cancer diagnosis.

Recommendations for Future Research

This study serves as an important addition to pre-existing research. Although some scientific evidence exists regarding specific complementary therapies, there are still key questions that need to be answered through scientific clinical trials. Some of these questions include whether or not these therapies are safe, and whether they work for the disease they are aimed to treat. The current study looked at the usefulness of several different forms of complementary therapies on the well-being of breast cancer patients. Future research should continue this search while using a larger sample size in order to inform patients and providers of their use. Research should focus on individual therapies

to get a better sense of what is most effective. Studies should include both women who choose to use complementary therapies as well as those who decided against it.

In addition to researching individual therapies it is important for research to look further at who is accessing these services. Complementary therapies are expensive and usually not covered by insurance, therefore it is important to look at the relationship between people who access these services and their socioeconomic status.

Future studies might examine the impact of the adoption of complementary therapies on breast cancer patients' decision to continue conventional treatment. It is possible that health care professionals may be concerned that by encouraging participation in these therapies may lead to the discontinuation of mainstream care.

Research in the area of complementary medicine continues to grow and expand. Past and present research has shown that women with breast cancer are using complementary therapies. Further research will help to inform both the practitioner and the patient in several areas. First, more information can assist in guiding patients to make responsible, informed treatment decisions. Secondly, providers may find it beneficial to offer patients increased services to help them with the psychological and physical stressors of breast cancer. The social work profession should be an active participant in the growing area of complementary therapies and aim to better serve our patients.

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Appendix A

December 22, 2006

Nicole Lombardo
15 Brewer Drive
Westboro, MA 01581

Dear Nicole,

Your revised materials have been reviewed and you have done a thoughtful and careful job with their revision. You did an excellent job of explaining what you are studying and why, which clarifies the whole project for the reader. Of course you will want to add in your thesis the new news about the reduction of cancer diagnoses in recent years.

All is now in order, although there is one thing we would like you to consider in your questionnaire. Asking about their current relationship status by saying "marital status" is somewhat hetero-centric. Is there a way you can ask about whether they are partnered, that is more inclusive? They may well be living in a committed, unmarried relationship with either a man or a woman and it would be important to know that. It reminds me of the questionnaire I just got regarding my upcoming college reunion (a women's college). It asked if you were married or single and then asked for your husband's name. I'm sure there were a lot of people in my class who felt invisible.

However, we will not hold up approval at this time. Just send Laurie your questionnaire after you revise it. Also, please do not begin recruiting in any organization before you get a written approval (it can be brief) and send copies of those approvals to Laurie.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

We are glad to give final approval to this interesting study and wish you success with it.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Jennifer Perloff, Research Advisor

Appendix B

Informed Consent

Dear Participant:

My name is Nicole Lombardo and I am a second year master's level graduate student at Smith College School for Social Work located in Massachusetts in the U.S. I am conducting a research study about the use of complementary therapies among women with Stage I-IV breast cancer. I will be specifically looking at the relationship between complementary therapy and quality of life. I am especially interested in learning more about why women choose these techniques and how the techniques make them feel.

The National Center for Complementary and Alternative Medicine defines complementary interventions, as is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. These therapies include mind-body interventions, biologically based interventions, manipulative and body-based methods, and energy therapies.

I will be conducting a face-to-face or telephone interview with women ages 30-70 who have been diagnosed with Stage I-IV breast cancer in order to get an accurate picture of each patient's experience with CAM (complementary and alternative medicine) therapies. Participants must currently have breast cancer or have been diagnosed within the past 15 years. Participants must also have participated in convention/mainstream medicine. The interview will take approximately forty-five minutes. The data will be used for my master's level thesis and for publication and presentations on this topic.

Nature of Participation

You are being asked to participate because you are a woman with Stage I-IV breast cancer, who has participated in some form of complementary medicine during the course of your treatment. You will be asked to share your experiences about the use of complementary medicine, your perceived effectiveness of these treatments, and most importantly the impact these therapies have had on your overall quality of life. The interview will be conducted in a way that I will be asking you a series of specific questions in which you can respond however you see fit. I will begin by asking certain demographic questions, then I will proceed to specific questions about the use of complementary medicine, and I will finish with questions pertaining to your overall quality of life.

Your interview will be audiotaped. I will say not say your name while the tape is operating so that you will not be identified by name on this tape.

Risks

The risk of participation can include emotional distress, discomfort, reflection of a painful experience, and the risk of confidentiality being breached by an assumption of participation in an agency. A referral list will be provided for each participant.

Benefits

The social work field will benefit by gaining a better understanding of the relationship between complementary therapy and quality of life, and learn more about why women choose these techniques and how the techniques have an impact on them. Participants will benefit by having the chance to gain a new perspective on complementary treatment, and they will get the opportunity to share and reflect back on their own experiences. Participants will also get the benefit of helping and informing other women who have breast cancer of other treatment possibilities. Compensation will not be provided for participation in this study.

Confidentiality

Maintaining your confidentiality is important to me; however, depending on where the actual interview is conducted may interfere with this. There is a risk of being seen meeting with the researcher. In order to decrease this risk effort will be made to find a meeting place that maintains your confidentiality, while serving as a convenient location for you. Interview content will be held in the strictest confidence and will be carefully protected.

Your name will not be placed on the tape or on any notes that are taken during the interview. An identification code will be assigned to the tape and notes. The list containing names and identification codes will be kept in a separate location. The data will be kept in a locked file cabinet. I must keep all notes, tapes and transcripts for at least three years according to U.S. federal requirements. After this time the data will continue to be kept secured until I physically destroy them.

Confidentiality will not be kept if you share information that indicates that you are at risk of serious harm. I will contact the appropriate authority and put you in contact with appropriate resources at that time.

Informed Consent Procedures

Participation in this study is voluntary and you may withdraw from this study at any time during the interview or immediately after the interview. Participants can withdraw from the study at anytime without receiving a penalty, and without others being notified of your decision. Withdrawal must occur no later than March 1st. You may also choose to refrain from answering specific questions, which is also permitted.

Nicole Lombardo
Smith College
School for Social Work
Northampton, MA 01063
Phone: (508)395-3926
Email: Nicolelt8@aol.com

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THIS STUDY.

Participant's Signature: _____ Date: _____
Researcher's Signature: _____ Date: _____

Please keep a copy of this Informed Consent form for your records.
Thank you very much for participating in this study.

Appendix C

Interview Questions

These questions will be asked in person during a structured interview

Demographic Information

- 1) What is your marital/partner status?
- 2) Do you have any children? Ages?
- 3) Who is currently living in your household?
- 4) What is your race/ethnicity?
- 5) What is your highest level of education?
- 6) How old are you?
- 7) What is your annual household income?

Less than \$34,999

\$35,000 - \$49,999

\$50,000 - \$74,999

More than 75,000

Diagnosis Information

- 1) How many years ago where you first diagnosed with breast cancer?
- 2) Are you currently in remission?
- 3) What type of breast cancer were you diagnosed with?
- 4) What stage where you diagnosed?
- 5) Has anyone else in your family been diagnosed with breast cancer?

Treatment Information

- 1) What were the most important factors to consider when choosing an oncologist and breast surgeon?
- 2) What was your experience like to sit down with your doctor and discuss diagnosis and prognosis? What was your emotional experience during this initial meeting?
- 3) What was your first step in the treatment process? For example: chemotherapy, radiation, surgery, etc.
- 4) At what point in the treatment process did you decide to explore complementary therapies? And for what reason(s)?
- 5) How did you get information about complementary medicine? Practitioners, internet, friends, family?
- 6) What forms of complementary therapy have you used during the course of your treatment? Please be specific.

- 7) How frequently have you /are you using complementary therapy? (number of times per week).
- 8) Had you ever used complementary therapies prior to being diagnosed with breast cancer?
- 9) How effective do you feel these complementary therapies were/are? Please explain in detail.
- 10) Since you have used complementary therapies, has it impacted your overall quality of life? If yes, please explain in what ways it has impacted your quality of life?
- 11) Do you still continue to use these therapies presently? And do you plan to continue using them in the future?

**How has each of these categories been affected by your use of complementary medicine?

Quality of life

Physical Well-Being

Energy level

Pain

Side Effects

Does your physical condition interfere with meeting the needs of your family?

Social Well-Being

Friendships

Emotional support from family?

Family communication about illness

Relationship with significant other/partner

Emotional Well-Being

How are you feeling?

Are you satisfied with how you are coping with the illness?

Are you loosing hope?

Nervous?

Are you worried about dying?

Are you concerned your condition will get worse?

Functional Well-Being

Are you able to work?

Is work fulfilling?

Are you able to enjoy life?

Have you accepted your illness?

Sleeping patterns?

Are you still able to enjoy the things you usually do for fun?

**Are you content with your quality of life at this point?