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Breast cancer is the most prevalent type of cancer for women. The American Cancer Society estimated that approximately 192,000 women were diagnosed with new cases of breast cancer in 2009. Fortunately, the current five-year survival rate for early stage breast cancer is 98% (ACS, 2009). This means many women diagnosed with breast cancer will become survivors. Although transitioning from being a cancer patient to a cancer survivor may be a welcome milestone, it also comes with unpleasant side effects that can negatively impact quality of life (Allen, Savadatti, & Levy, 2009).

The primary purpose of this study was to examine the relationship among mindfulness, quality of life, alexithymia, and self-kindness in breast cancer survivors. A total of 133 Stages 0 to III breast cancer survivors participated in the study. Mindfulness, quality of life, self-kindness, and alexithymia were measured using the Five Facet Mindfulness Questionnaire, the Functional Assessment of Cancer Therapy-Breast, the Self-Compassion Scale, and the Toronto Alexithymia Scale.

A causal path analysis indicated that mindfulness was a significant predictor of quality of life, but self-kindness and alexithymia were not significant mediators. Pearson Product Moment coefficients revealed significant relationships between the four study variables. An ANOVA found that stage of cancer significantly impacted quality of life for Stage 0 and Stage III breast cancer survivors. An ANOVA indicated no significant results for the type of surgery or time since completion of medical treatment on quality of life.

The results suggest that mindfulness, self-kindness, and alexithymia are important factors to consider for quality of life in Stage 0 to III breast cancer survivors. Clinical implications exist for counselors. Further research investigating possible moderating effects of self-kindness and alexithymia is needed.

# MINDFULNESS AND QUALITY OF LIFE AMONG BREAST CANCER SURVIVORS: THE MEDIATING ROLE OF SELF-KINDNESS AND ALEXITHYMIA

by

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#### CHAPTER I

#### INTRODUCTION

In the United States, breast cancer is the most prevalent form of cancer for women with a 12.08% lifetime risk of developing breast cancer (American Cancer Society [ACS], 2009a). In other words, approximately one out of every eight women in the U.S. will develop breast cancer over the course of her lifetime. Further, incidences of breast cancer have been steadily increasing over the past thirty years. An estimated 192,370 women were diagnosed with new cases of breast cancer in 2009, representing an increase of nearly 14,000 new cases from the previous year (ACS, 2008). While the incidence of breast cancer is increasing, fortunately the survival rate also is increasing. The current five-year survival rates for localized breast cancer (i.e., cancer restricted to the breast) and regional breast cancer (i.e., cancer that may have spread to the lymph nodes or exterior breast tissues) is 98% and 84%, respectively (ACS, 2009a). These numbers have improved since 2000, when the five-year survival rates for localized and regional breast cancers were 96% and 77%, respectively (ACS, 2001). Five-year survival rates for women with advanced breast cancer (i.e., cancer that has spread to other parts of the body), however, are still low with 21% in 2000 and 23% in 2009 (ACS, 2001, 2009a). Nonetheless, the trends seem to be toward increased survival rates and, accordingly, it is important to direct research attention to breast cancer survivors. In particular, it seems

vital to further study psychological issues among those diagnosed with an early stage disease as survival rates are particularly high for this group.

Transitioning from being a cancer patient to a cancer survivor may be a welcome milestone, but it also comes with unpleasant side effects that can negatively impact quality of life (Allen, Savadatti, & Levy, 2009). Breast cancer survivors report experiencing a fear of disease recurrence, emotional distress, loss of structure and support that comes with medical appointments and being around other patients, and difficulty returning to life as it was before cancer (Allen et al., 2009). Further, researchers have indicated that more than 50% of post-treatment breast cancer survivors suffer from fatigue and 20% struggle with depression (Broeckel, Jacobsen, Horton, Balducci, & Lyman, 1998; Burgess et al., 2005; Okuyama et al., 2000). Some breast cancer survivors who underwent lymph node removal during their treatment surgeries or received high doses of radiation therapy are at risk of lymphedema, a painful arm, breast, and chest swelling condition that can restrict arm movement, impede physical activity, and affect quality of life (ACA, 2009a). Further, side effects of medical treatments also have been found to cause challenges for breast cancer survivors, including treatment-induced menopause, body image concerns, and weight gain (Helms, O'Hea, & Corso, 2008).

The physical and emotional challenges that arise as a result of transitioning from active treatment to survivorship for women with breast cancer can be conceptualized through Transitions Theory. Transitions Theory is a framework for conceptualizing major life changes such as diagnosis, treatment, and survivorship of breast cancer (Bridges, 1991). Transitions Theory includes three stages (endings, neutral zones, and

beginnings). Further, it holds that people must grieve the ending of one identity or life circumstance in order to resolve and apply meaning to the change as a way of creating and accepting a new identity and life circumstance. This theory is a helpful lens in understanding how women transition from active breast cancer treatment to survivorship, particularly considering that women's experiences with the disease may differ according to the staging of disease and the type of treatment.

The staging of breast cancer (i.e., the size of the original tumor and the spread of the disease), ranging from 0 to IV (0 is a less life threatening diagnosis and IV is the most life threatening diagnosis), appears to be an important distinction for breast cancer survivors and breast cancer researchers. Given that the five year survival rate for stages 0 to IV ranges from 100% (Stages 0 and I) to 86% (Stage II) to 57% (Stage III) to 23% (Stage IV), it is reasonable to categorize Stages 0 to II as early stage disease and stage IV as advanced stage disease (ACA, 2010). Because stage III breast cancer survivors have more in common with those with earlier stages of disease (e.g., higher survival rate and less physical strain) than those with stage IV, many researchers distinguish between stages 0 to III as one group and stage IV as another group (Berger, Lockhart, & Agrawal, 2009; Kim et al., 2008; Lengacher et al., 2009). Further, some researchers have used stage 0 breast cancer survivors as a control group because the surgical treatment is minimally invasive compared to higher stages and these patients are less likely to receive adjuvant therapy (Castellon et al., 2004).

Type of medical treatment also appears to impact the transition of breast cancer patient to breast cancer survivor. It is standard practice for many breast cancer survivors,

particularly those diagnosed with Stage I-IV cancer, to receive some form of adjuvant therapy, including chemotherapy, radiation therapy, and hormone therapy, following surgical treatment. It is important to understand that the side effects of these adjuvant therapies differ. For example, chemotherapy has been found to impact fatigue, menopausal symptoms, and cognitive functioning more than hormone and radiation therapy (Mar Fan et al., 2005). Furthermore, the amount of time since the completion of these treatments is important. In a longitudinal study on the impact of adjuvant therapies on fatigue, menopausal symptoms, and cognitive functioning among breast cancer survivors, the adverse side effects improved over time (Mar Fan et al., 2005). Therefore, it is important to consider the impact of the type of medical treatment received and the time since the completion of treatment when investigating the impact of adjuvant treatment on quality of life of breast cancer survivors.

Quality of life is a multi-dimensional construct that describes the level of one's physical, social, functional, and emotional well-being, as well as one's ability to enjoy life and experience meaning and purpose in life (Brady et al., 1997; Canada, Murphy, Fitchett, Peterman, & Shover, 2008). Even when treatment for breast cancer ends and improvements are made in physical functioning, breast cancer survivors may continue to experience psychological distress (Pinto, Clark, Maruyama, & Feder, 2003). Further, emotional distress may exacerbate fears of the future (Lebel, Rosberger, Edgar, & Devins, 2009). For example, some breast cancer survivors rated fear of dying, fear of cancer recurrence, and fear of future treatment as more distressing than role disruption concerns and physical concerns (Vickberg, 2003). Further, the inability to express this

emotional distress may play a role in overall health outcomes, including the level to which survivors experience threats to their quality of life (Nyklicek, Vingerhoets, & Denollet, 2002). Difficulty identifying, expressing, and distinguishing between feelings or emotional arousal is referred to as *alexithymia* (Porcelli, Tulipani, Maiello, Cilenti, & Todarello, 2007).

The impact of alexithymia on quality of life among breast cancer survivors is unclear at this point. Of the limited studies to date, most researchers have investigated alexithymia as either a diagnostic factor in breast cancer (Servaes, Vingerhoets, Vreugdenhil, Keuning, & Brockhuijsen, 1999) or a contributor to immunity suppression (Todarello, La Pesa, Zaka, Martino, & Lattanzio, 1989). That is, researchers have focused primarily on how alexithymia influences the medical condition. For example, in a study of 86 women with breast cancer, 36.4% revealed traits consistent with alexithymia (Manna et al., 2007). In another study, researchers investigated the relationship between alexithymia and pain experience in a mixed group of cancer diagnoses and found that those who struggled to identify their feelings reported higher levels of pain (Porcelli et al., 2007). Because researchers have focused on the impact of alexithymia on medical conditions and physical symptoms, what is unknown to date is the extent to which alexithymia is related to psychosocial quality of life among survivors. Researchers seem clear that alexithymia is a construct that is prevalent for women with breast cancer and that it appears to be related to medical and physical issues. What is less clear, however, is how alexithymia may be related to post-treatment side-effects and overall quality of life. It is viable that breast cancer survivors who are not able to identify or express their emotions may experience increased difficulties as they move through the developmental transitions of survivorship.

Another construct that appears to be important for survivors is mindfulness. Mindfulness is defined as a nonjudgmental awareness of the present moment (Kabat-Zinn, 1990). Mindfulness means being able to pay attention to and identify bodily present moment experiences (Kieviet-Stijnen, Visser, Garssen, & Hudig, 2008). Recently, mindfulness researchers have begun to establish positive effects on psychological well-being, medical symptoms, and stress symptoms among those with stress-related illnesses, anxiety, cancer, and chronic pain (Baer, 2003; Carmody & Baer, 2008). Among cancer patients, those who completed mindfulness-based stress reduction training reported less stress, higher moods, and better quality of life than those in control groups (Baer, 2003; Kieviet-Stijnen et al., 2008). Similarly, researchers have found that mindfulness training improved overall quality of life, sleep quality, and symptoms of stress among breast and prostate cancer patients (Carlson, Speca, Patel, & Goodey, 2004). Though it has been established that mindfulness can positively affect quality of life in various populations, little is known about the critical factors of mindfulness that contribute to the change. In particular, researchers have not considered the possibility that the relationship between mindfulness and quality of life may be mediated by other factors, including alexithymia and self-kindness (Neff, 2003).

Self-kindness involves extending kindness and gentleness toward oneself and attempting to understand one's self rather than engaging in self-judgment or criticism (Neff, 2003). Though self-kindness has been an important aspect of Buddhist psychology

for over a thousand years, limited empirical research has been conducted (Kornfield, 2009). In fact, to date researchers have only investigated self-kindness as a component of self-compassion, rather than a unique construct (Neff, 2003). Given the emphasis on wellness and positive development within counseling, it seems appropriate to investigate self-kindness. In summary, then, mindfulness, alexithymia, and self-kindness all seem to have some influence on quality of life among cancer survivors. It seems important, therefore, to pursue an understanding of the relationships between these factors within a multivariate framework.

#### **Statement of the Problem**

There is a growing interest in mind-body medicine and alternative approaches to healing for cancer patients (Carlson et al., 2004; Cassileth & Chapman, 1998).

Specifically, mindfulness training holds promise. In fact, Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1990) is one alternative approach that holds promise for cancer patients as well as cancer survivors. For example, MBSR has been found to improve quality of life in early stage breast cancer patients (Carlson et al., 2004; Witek-Janusek et al., 2008). Researchers to date, however, have not investigated the relationship between mindfulness and quality of life among breast cancer survivors who have undergone recent adjuvant therapy that has included chemotherapy and few researchers have included participants who have undergone radiation therapy. For example, Carlson et al. (2004) did not include breast cancer survivors who had completed chemotherapy, radiation, or hormone therapy within the prior three months for their study on mindfulness based stress reduction and quality of life. Similarly, Witek-Janusek et al.

(2008) excluded breast cancer survivors who had undergone systemic chemotherapy. Secondly, researchers who have considered the relationship between mindfulness and quality of life have not focused solely on breast cancer survivors, but rather included mixed cancer diagnoses. Because of this, little is known about the unique attributes of breast cancer survivors. Finally, though there is strong empirical evidence for the positive impact of mindfulness on reducing negative emotions (e.g., anxiety), no studies have investigated the potential for mindfulness to increase positive emotional states such as self-kindness.

Self-kindness is a construct that focuses on being patient and tender with one's self in the context of suffering (Neff, 2003). Theoretically, mindfulness is a related but distinct construct from self-kindness (Neff, 2003). Researchers to date, however, have provided no empirical evidence for this relationship. Furthermore, researchers have not considered self-kindness among a population of breast cancer patients and, more specifically, have not investigated the relationship between self-kindness, mindfulness, and quality of life among breast cancer patients.

As a construct, alexithymia focuses on difficulty identifying and describing emotions (Taylor & Bagby, 2000). Banner (2009) found that alexithymia was a strong predictor of anxiety in women with stages I to III breast cancer. To date, however, no researchers have focused on the relationship between alexithymia and quality of life among breast cancer survivors. Because breast cancer patients have been found to experience powerful emotions as a result of their diagnosis and struggle to experience and express these emotions in a healthy manner (Manna et al., 2007), it is important to

investigate how alexithymia mediates the relationship between mindfulness and quality of life among breast cancer patients (Kabat-Zinn, 1990; Witek-Janusek et al., 2008).

# **Purpose of the Study**

The purpose of this study, then, is to investigate the relationships among mindfulness, self-kindness, alexithymia, and quality of life in stages 0 to III breast cancer survivors. A secondary purpose is to consider how type and time since completion of medical treatment affects quality of life within this group. This study will contribute to the current body of research on breast cancer survivors and the factors that may improve their quality of life during the transition period from patient to survivor. Further, this study will add to the current body of literature on self-kindness and mindfulness. Results from this study will inform counselors, counselor educators, other mental health professionals, and medical professionals who specialize in the biopsychosocial concerns of oncology populations.

## **Research Questions**

The proposed study will investigate the relationships among mindfulness, alexithymia, self-compassion, and quality of life among female breast cancer survivors (stages 0 - III), and examine a hypothesized path model. The following research questions will be addressed:

Research Question 1: What is the effect of time since completion of treatment (in months) on mindfulness, alexithymia, self-kindness, and quality of life for female survivors of breast cancer (Stages 0-III) and the relationship among mindfulness,

alexithymia, self-kindness, and quality of life for female survivors of breast cancer (Stages 0-III)?

<u>Research Question 2:</u> What are the effects of cancer stage (0-III) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

Research Question 3: What are the effects of surgery (i.e., none, lumpectomy, or mastectomy) and adjuvant therapy (i.e., none, hormone therapy, chemotherapy, or radiation) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

Research Question 4: What are the relationships among mindfulness, alexithymia, self-compassion, and quality of life within a path model (see Figure 1) that specifies a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness?

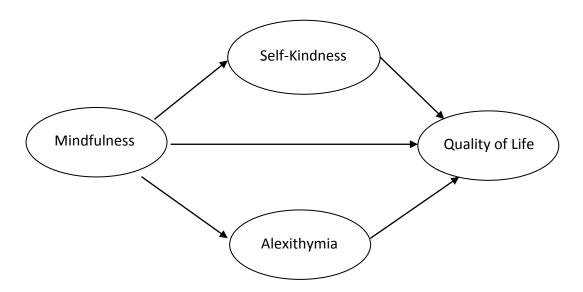


Figure 1. Hypothesized Path Model

# **Need for the Study**

Breast cancer is the most common type of cancer for women in the United States. The American Cancer Society (ACS) estimated that there were 192,370 new cases of breast cancer in women in 2009 (ACS, 2009a). Because of early disease diagnosis and advanced medical treatment, the five-year survival rate for localized stage breast cancer (i.e., stages 0 to II) is 98% and the five-year survival rate for all stages combined (i.e., stages 0 to IV) is 89% (ACS, 2009a). While the survival rate is high, breast cancer patients still face physical and emotional challenges that can affect their quality of life. Regardless of cancer staging, a diagnosis of breast cancer has been found to elicit a high level of distress (National Cancer Institute, 2009). This could explain, at least in part, why breast cancer patients are seeking alternative therapies, including mindfulness training, to cope with the emotional and physical strain of cancer (Cassileth & Chapman, 1998).

Although there is some initial evidence supporting the relationship between mindfulness and quality of life among cancer survivors (Carlson et al., 2004; Witek-Janusek et al., 2008), researchers have not considered that there may be mediating factors that influence the relationship between mindfulness and quality of life. Two possible mediating factors that show promise are alexithymia and self-kindness.

Results of this study could increase counselors' understanding of working with breast cancer survivors, including how to help them improve their quality of life and manage the side effects of medical treatment as they transition into survivorship. Further, results will inform future intervention studies that target mindfulness, self-kindness, and

alexithymia among patients and, in turn, inform counselors in using interventions for breast cancer survivors that target mindfulness, self-kindness, and alexithymia.

Results from this study also will contribute to the current body of literature on breast cancer survivorship and quality of life. Specifically, results of this study will provide researchers and clinicians with a more thorough understanding of the role of mindfulness, self-kindness, and alexithymia in quality of life among breast cancer survivors. Finally, this study may inform future longitudinal studies that could determine developmental stages of transition into survivorship and quality of life for breast cancer patients.

# **Definition of Terms**

Quality of life is defined as a multi-dimensional, holistic "assessment of the combined impact of disease and treatment" on cancer survivors (Cella et al., 1993). Further, quality of life further is defined as optimal physical well-being, social well-being, emotional well-being, and functional well-being during and after medical treatment for cancer (Cella et al., 1993). For the purposes of this study, quality of life will be measured using the Functional Assessment of Cancer Therapy-Breast Quality of Life Instrument (FACT-B; Brady et al., 1997). The FACT-B is a quality of life instrument that has six subscales: physical well-being, social/family well-being, relationship with doctor, emotional well-being, functional well-being, and additional concerns specific to breast cancer.

*Alexithymia* is defined as emotional restriction that involves difficulty identifying and describing feelings, as well as an orientation toward external thinking (Bagby,

Parker, & Taylor, 1994). In this study, alexithymia will be measured using the Toronto Alexithymia Scale (TAS-20; Bagby, Parker, et al., 1994).

Mindfulness is defined as a nonjudgmental awareness of the present moment (Kieviet-Stijnen et al., 2008) and will be measured using the Five Facet Mindfulness Questionnaire (FFMQ; Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006). The FFMQ has five scales that include (a) nonreactivity to inner experience, (b) observing/noticing/attending to sensations/perceptions/thoughts/feelings, (c) acting with awareness, (d) describing/labeling with words, and (e) nonjudging of experience (Baer et al., 2006).

Self-kindness is defined as being open to one's suffering and pain and having a sense of caring and kindness toward oneself, (Neff, 2003) as measured by the Self-Compassion Scale (SCS, Neff, 2003).

Stage 0 breast cancer is a diagnosis of breast cancer where the disease is considered non-invasive and localized to the original affected tissue area of the breast (ACA, 2009a).

Stage I breast cancer is a diagnosis of breast cancer where the disease is invasive and the breast cancer cells are beginning to invade surrounding tissue area. The tumor size for stage 1 breast cancer is up to two centimeters and lymph nodes are disease free (ACA, 2009a).

Stage II breast cancer is a diagnosis of breast cancer where the tumor has either surpassed two centimeters or the disease has spread to the lymph nodes (ACA, 2009a).

Stage III breast cancer is a diagnosis of breast cancer where the tumor has either surpassed five centimeters or spread to the chest wall. The disease may have spread to the lymph nodes as well. Inflammatory breast cancer, a tumor-less breast cancer, is considered stage 3 (ACA, 2009a).

Stage IV breast cancer is a diagnosis of breast cancer where the disease has spread to other areas of the body; usually the bones, brain, liver, or lungs. This is an advanced cancer stage (ACA, 2009a).

Localized breast cancer is defined as breast cancer that is restricted to the breast without evidence of spread to the lymph nodes or surrounding area (ACA, 2009a).

*Regional breast cancer* is defined as cancer that is located within the breast and surrounding lymph nodes (ACA, 2009a).

Advanced breast cancer is defined as cancer that has spread from the original site in the breast to other areas of the body. This includes the spread of disease to lymph nodes, lungs, bones, brain, and liver. When the disease has spread to distant parts of the body, the term *metastatic* breast cancer is used (ACA, 2009a).

Five-year survival rate is defined as the percentage of women with breast cancer who are still living within a five-year period since the original diagnosis. This definition includes breast cancer survivors who die from non-cancer-related causes (ACA, 2009a).

Adjuvant therapy is defined as treatment used in addition to the primary source of treatment. Examples of adjuvant therapies for breast cancer treatment include radiation therapy, chemotherapy, and hormone therapy. The primary source of treatment for breast cancer typically is surgery (ACA, 2009a).

*Radiation therapy* is defined as treatment with high-energy rays (such as x-rays) to kill cancer cells and shrink tumors (ACA, 2010).

*Chemotherapy* is defined as therapy for breast cancer that includes drugs used to weaken and kill cancer cells. Chemotherapy may be administered through intravenous drips or pill form (ACA, 2009a).

Hormone therapy is defined as treatment for breast cancer that includes the use of hormone drugs to alter hormone production. For breast cancer treatment, hormone therapy typically is used to reduce production of estrogen (ACA, 2009a).

Surgery is defined as breast cancer treatment that involves the removal of part or the entire breast. A lumpectomy is a type of surgery that involves removing the tumor and part of the surrounding breast tissue. This surgery is done for early stage breast cancer. A mastectomy is a type of surgery that involves the removal of the breast and part or all of the surrounding tissue, including skin, nipple, areola, and lymph nodes. Mastectomies are performed on a case-by-case basis, though typically for more serious diagnoses, and may even be used as preventive medicine (ACA, 2009a).

## **Brief Overview**

This study will be organized over five chapters. The first chapter includes a brief introduction to breast cancer and a preliminary examination of quality of life, alexithymia, mindfulness, and self-kindness as it pertains to breast cancer survivors. The purpose of the study, statement of the problem, need for the study, definition of key terms, and a brief description of the study also are presented in the first chapter. The second chapter includes a review and critique of the literature relevant to this research

study, including sections on breast cancer survivors, quality of life, transitions theory, alexithymia, mindfulness, and self-kindness. The third chapter contains an overview of the methodology for this study, including a description of the participants, sampling methods, instruments, and data analyses. The fourth chapter will provide a presentation of the results by addressing the five research questions. Chapter five will include a summary of the relevant study results and implications for counselors and counselor educators. Further, recommendations for future research and implications for counseling practice will be delineated.

#### CHAPTER II

#### REVIEW OF RELATED LITERATURE

Cancer is a group of diseases in which abnormal cells in the body mutate and grow out of control (ACS, 2009a). These cells become diseased due to DNA damage caused by genetics, lifestyle choices, and environmental influences (ACS, 2010). Cancer accounts for approximately a quarter of all deaths in the United States, making it the second leading cause of death behind heart disease (ACS, 2008). Because of advances in early detection and treatment, however, 66% of all cancer patients in the United States will live for five years or more (ACS, 2009b). Of particular interest to the current study, the five year survival rate for localized breast cancer is 98% (ACS, 2009a). This translates into over two million breast cancer survivors in the United States (ACS, 2009a).

## The Biology of Breast Cancer

Breast cancer is a disease that originates from the cells of the breast (ACS, 2010). It typically forms in breast ducts, tubes that carry milk to the nipple, or lobules, glands that produce milk (ACS, 2010). Cancer cells develop and spread to form tumors when old cells do not die or when there is an overgrowth of new cells (ACS, 2010). These tumors can be harmless, non-cancerous tumors referred to as benign tumors or diseased, cancerous tumors called malignant tumors (ACS, 2010). When cells from malignant tumors enter the bloodstream or lymphatic system the cancer can spread to other parts of

the body (ACS, 2010). These new areas of cancer growth are referred to as metastases (ACS, 2010). Physicians use the level of metastases and the size of the original tumor to determine the stage of breast cancer (ACS, 2010).

# **Stage of Breast Cancer**

Breast cancer stage refers to the gravity of the breast cancer diagnosis and is used to inform treatment plans (ACS, 2010). Staging is determined in one of two ways: clinical staging and pathologic staging. Clinical staging is used when the stage of the disease is determined based on the results of a physical exam, biopsy, or imaging test (ACS, 2010). Pathologic staging is based on the results of surgery used to assess the breast tumor and surrounding lymph nodes (ACS, 2010. Because pathological staging is considered more accurate, it is the preferred type of staging among medical professionals.

The American Joint Committee on Cancer (AJCC) developed a pathologic staging system referred to as the TNM system (ACS, 2010). TNM staging classifies the level of breast disease based on their T, N, and M stage. T stands for *tumor* (i.e., how big is the tumor), N stands for the spread of disease to lymph *nodes* (i.e., which lymph nodes are affected by the disease), and M stands for *metastasis* (i.e., has the disease spread to other areas of the body) (ACS, 2010). Following the letters T, N, and M appears a number which provides additional information about the tumor, lymph nodes, and metastasis. The number following the T refers to the size of the tumor. These numbers range from 0 to 4 with four indicating a larger tumor size. The number following the N indicates whether the cancer has spread to the lymph nodes. This number ranges from 0 to 3 with 3 indicating advanced spread to the lymph nodes. The number following the M refers to

whether or not the disease has metastasized in the body. The number for this marker is either a 0 (no cancer metastasis) or 1 (positive cancer metastasis) (ACS, 2010).

Once the TNM staging has been completed the cancer diagnosis is then *stage* grouped. Stage grouping is used to inform medical treatment and ranges from I (least advanced) to IV (most advanced) cancer (ACS, 2010). Stage 0 is considered noninvasive and easily treatable (ACS, 2010). Stage 0 is the earliest form of breast cancer and is used when the cancer is limited to the ducts and lobules with not spread to fatty breast tissue (ACS, 2010). Stage IA indicates that the tumor size is 2 cm or less with no spread to the axillary lymph nodes or metastases. Stage IB indicates the tumor is 2 cm or less with minimal metastases in one to three axillary lymph nodes. Two conditions exist to meet criteria for Stage IIA: (a) the tumor is 2 cm or less and cancer larger than 2 mm has spread to 1 to 3 axillary lymph nodes, or (b) the tumor is greater than 2 cm and less than 5 cm with no spread to the axillary lymph nodes. Stage IIB also has two conditions: (a) the tumor is larger than 2 cm but less than 5 cm and has spread to 1 to 3 axillary lymph nodes, or (b) the tumor is larger than 5 cm but has not spread to the axillary lymph nodes or invaded the chest walls. Two conditions apply to Stage IIIA: (a) the tumor is less than 5 cm but has spread to 4 to 9 axillary lymph nodes; or (b) the tumor is greater than 5 cm, has spread to 1 to 9 axillary lymph nodes, but has not grown into the chest wall. Three conditions apply to Stage IIIB. The tumor has grown into the chest wall and one of the following are present: (a) no spread to the axillary lymph, (b) spread to 1 to 3 axillary lymph nodes with trace amount of cancer found in the internal mammary lymph nodes, or (c) spread to 4 to 9 axillary lymph nodes or enlarged mammary lymph nodes.

For Stage IIIC, the tumor can be any size and one of the following conditions is present:

(a) cancer has spread to 10 or more axillary lymph nodes, (b) cancer has spread to lymph nodes under the collar bone, (c) cancer has spread to lymph nodes above the collar bone, or (d) cancer has spread to 4 or more axillary lymph nodes and mammary lymph nodes.

Stage IV is the most advanced breast cancer diagnosis and is used to refer to any breast cancer that has spread to the bone, liver, brain, or lung (ACS, 2010).

All of the staging information is used to determine the type of treatment for breast cancer. The majority of breast cancer cases are diagnosed in the early stages (ACS, 2010), resulting in increased prevalence, treatability, and survivorship.

## **Prevalence of Cancer**

Breast cancer is the most common form of cancer for women (excluding skin cancer, which is not included in general cancer statistics because it is a unique form of cancer) (ACS, 2010). The American Cancer Society reported 192, 370 new cases of breast cancer in 2009 (ACS, 2010). Both men and women can develop breast cancer but it is 100 times more likely to occur in women due to the effects of the female hormones estrogen and progesterone (ACS, 2010). There are many risk factors for breast cancer, some which women cannot change, including gender, age (risk increases with age), heredity, gene mutations, family and personal history of breast cancer, density of breast tissue, early menses (before age 12), and race (Caucasians have the highest risk) (ACS, 2010). Additional lifestyle risk factors include use of oral contraceptives (birth control), hormone replacement therapy, not having children or having children after age 30, not

breast feeding, alcohol use (higher usage increases risk), being overweight, and lack of physical activity (ACS, 2010).

The current five-year survival rate for localized breast cancer (i.e., cancer restricted to the breast) is 98% and 84% for regional breast cancer (i.e., cancer that has spread to the lymph nodes or exterior breast tissues) (ACS, 2009a). The prevalence of breast cancer indicates that many women are impacted by breast cancer and the survival rates indicate that attention must be given to survivorship.

# Survivorship

As of January 1, 2007, an estimated 2.5 million breast cancer survivors were living in the United States (Altekruse et al., 2010). Survivors have unique needs that are beginning to be addressed (ACS, 2010; Morgan, 2009). As a result, the National Cancer Institute (NCI) established the Office of Cancer Survivorship whose primary function is to support research on preventing or reducing the negative effects of cancer on quality of life. Often, women experience difficult transitions beginning at the point of cancer diagnosis and may experience physical and emotional challenges post-surgery, a time period often referred to as the re-entry phase (Allen et al., 2009). Though researchers are beginning to learn more about this transition, further knowledge is needed on breast cancer survivorship, including the impact on quality of life, in order to promote overall well-being. That is, given the high rates of survivorship and the serious emotional and physical sequelae of breast cancer, it is important to increase our understanding of the effects of diagnosis, surgery, and treatment on quality of life.

## **Treatment of Breast Cancer**

There are two broad types of treatment for breast cancer: local therapy and systemic therapy (ACS, 2010). Local therapy, such as surgery and radiation, are limited to one specific area of the body (ACS, 2010). Conversely, systemic therapy such as chemotherapy and hormone therapy are delivered into the bloodstream so that they can treat cancer cells throughout the entire body (ACS, 2010). Often, systemic therapy is used following surgery, given the possibility that cancer cells may have broken off from the breast tumor and traveled through the bloodstream into other areas of the body (ACS, 2010).

# **Surgical Treatment for Breast Cancer**

Most breast cancer survivors have had some type of surgery to remove the breast tumor. Each surgery option has unique benefits and challenges, making surgery selection a personal and, oftentimes, difficult decision (ACS, 2010). The two main categories of surgical treatment for breast cancer are breast-conserving surgeries and mastectomies (ACS, 2010).

**Breast-conserving surgeries.** Breast-conserving surgeries are surgeries that involve removing part of the breast. This includes lumpectomies and partial mastectomies (ACS, 2010). A lumpectomy removes only the breast tumor and marginal healthy breast tissue (ACS, 2010). A partial mastectomy removes more breast tissue than a lumpectomy. Typically, at least one quarter of the breast is removed in partial mastectomies (ACS, 2010).

Side effects for breast-conserving surgeries include temporary pain and swelling, pain, and hard scar tissue development (ACS, 2010). Additionally, a risk for bleeding and infection at the surgery site exists (ACS, 2010). Among women who have lymph nodes removed during their surgeries, lymphedema can develop. Lymphedema occurs when lymph fluid is retained in the arm, causing debilitating swelling and pain (ACS, 2009a).

**Mastectomies.** Mastectomies are surgeries that remove the entire breast (ACS, 2010). There are two primary types of mastectomies, simple mastectomy and radical mastectomy. In a simple mastectomy the entire breast is removed, including the nipple (ACS, 2010). A radical mastectomy is more invasive in that the breast, nipple, underarm lymph nodes, and chest muscle tissues are removed (ACS, 2010). Because this surgery is extensive, it typically is limited to women with large tumors that have grown into the pectoral muscles under the breast (ACS, 2010).

Side-effects for mastectomies include obvious changes to the breast and surgical related pain (ACS, 2010). They also include possible risk of infection, hematoma (buildup of blood in the wound), seroma (buildup of fluid in the wound), numbness in the upper and inner arm, limited arm movement (frozen shoulder), and lymphedema (ACS, 2010).

Regardless of the type of surgery, it is clear that women will experience intense physical effects from surgery for breast cancer. Twenty to 60 percent of women who undergo these surgeries will develop post-mastectomy pain syndrome (this includes women who underwent a lumpectomy) (ACS, 2010). Post-mastectomy pain syndrome

armpit, numbness and shooting pain, and oppressive itching (ACS, 2010). Along with the physical sequelae of breast cancer surgery, women may experience additional concerns that can impact quality of life as a result of post-surgery adjuvant therapy.

# **Adjuvant Therapies for Breast Cancer**

Adjuvant therapies for breast cancer are treatments that occur after the primary treatment (surgery). The most common adjuvant therapies for early-stage breast cancer are radiation, chemotherapy, and hormone therapy (ACS, 2010).

Radiation. Radiation therapy is targeted treatment that utilizes high-energy rays directed at the breast, chest wall, or underarm region following surgery (ACS, 2010). The purpose of radiation is to kill remaining cancer cells that may still be harbored in the body, despite surgical removal of the diseased part of the breast. The amount of radiation prescribed to a woman varies depending on the type of surgery and the spread of the disease (ACS, 2010). A typical radiation prescription is five days per week for six weeks (ASC, 2010). The side-effects of radiation can vary from moderate to severe. Some women will experience swelling and heaviness of the breast, skin burns, and fatigue (ACS, 2010). More severe symptoms include breast reconstruction complications, lymphedema, rib fractures, and, in rare cases, development of new cancer (ACS, 2010). Most of the mild symptoms alleviate after 6 to 12 months, while the more severe symptoms may be permanent (ACS, 2010).

**Chemotherapy.** Chemotherapy is a systemic treatment that introduces cancer killing drugs into the bloodstream (to travel throughout the body) intravenously and

orally (ACS, 2010). The goal of chemotherapy is to attack and destroy leftover cancer cells from surgery. Chemotherapy is typically administered in cycles (e.g., on two weeks, off two weeks) and lasts for several months (ACS, 2010). Though treatment plans vary, chemotherapy usually is most effective when multiple drugs are used simultaneously (ACS, 2010). Because chemotherapy is a powerful adjuvant therapy that works by killing cells that divide and spread into cancer cells, sometimes healthy cells are destroyed in the process. Though each woman's experience is unique, common sideeffects resulting from the destruction of healthy cells exist include hair loss, nausea and vomiting, loss of appetite, mouth sores, risk of infection, easy bruising, and fatigue (ACS, 2010). All of these side-effects subside when treatment ceases. There are additional side-effects, however, that are long lasting or permanent. Younger women who have not entered menopause may experience treatment induced menopause, which causes infertility, hot flashes, and fatigue (ACS, 2010). Other risks include neuropathy (nerve damage) in the hands and feet, heart damage, an increased risk for leukemia, excessive fatigue, and a decrease in cognitive function that affects memory and concentration ("chemo brain") (ACS, 2010).

Hormone therapy. Hormone therapy is a systemic form of adjuvant therapy that is used to prevent the recurrence and spread of breast cancer (ACS, 2010). Because two out of three breast cancers are facilitated by estrogen, the hormone produced from a woman's ovaries, drugs used to block the effects of estrogen or lower the estrogen level in the body are prescribed to prevent the growth or spread of breast cancer (ACS, 2010). Anti-estrogen drugs are prescribed in pill form and taken daily (ACS, 2010). Side-effects

for these drugs include symptoms similar to menopause including hot flashes, vaginal dryness, fatigue, and mood swings (ACS, 2010). Additional, more serious, side-effects include risk of endometrial and uterine cancer, heart attack, stroke, and pulmonary embolism (a blood clot in the lung) (ACS, 2010).

Improvements in treatment for breast cancer have helped to lead to a higher survivor rate. It seems apparent, however, that the diagnosis, surgery, and adjuvant treatment of breast cancer remains a harrowing and life-altering experience.

Accordingly, the transition into survivorship can include difficult quality of life issues.

# **Quality of Life Effects from Breast Cancer**

In order to support and care for breast cancer survivors, it is important to understand relevant quality of life issues. Quality of life is a multi-dimensional construct that includes broad areas related to physical well-being (e.g., level of energy), social well-being (e.g., feeling close to friends and family), emotional well-being (e.g., having hope), functional well-being (e.g., ability to work), and concerns specific to breast cancer (e.g., feelings of femininity and self-consciousness) (Brady et al., 1997).

The most powerful predictor of quality of life is a survivor's perception of control (Ferrell, Dow, & Grant, 1995). Additionally, there are a number of physical issues that impact quality of life, including physical pain and fatigue (Ferrell et al., 1995). Pain and fatigue have been found to be strong predictors of quality of life and are common side-effects of breast cancer treatment (ACS, 2010; Ferrell et al., 1995). Additional physical outcomes of breast cancer survivorship include an altered body image, cardiac damage,

sexual dysfunction, osteoporosis (bone loss), nerve damage, premature menopause, and secondary cancers (Morgan, 2009).

Psychological issues also affect quality of life. For many breast cancer survivors, fear of disease recurrence is an ongoing dilemma (Ferrell et al., 1995). Furthermore, many survivors worry that they may be passing along to their children a genetic predisposition to cancer. Others may suffer from cognitive changes (i.e., memory loss), financial concerns, body image concerns, and altered femininity (Brady et al., 1997; Morgan, 2009). Many of these physical and psychological concerns that affect quality of life are direct effects of the cancer diagnosis, treatment, and transition into survivorship (ACS, 2010).

# **Quality of Life Effects of Diagnosis**

A breast cancer diagnosis can elicit clinically significant levels of traumatic stress symptoms, including symptoms of intrusion and avoidance. In a study of 125 women diagnosed with metastatic breast cancer or a recurrence of cancer, over half scored in the high range on the Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979), indicating significant levels of distress (Butler, Koopman, Classen, & Spiegel, 1999). Similarly, 32.8% of breast cancer patients in a large sample (n = 1249) experienced depression, anxiety, and hostility related to their diagnosis (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Plantadosi, 2001).

### **Quality of Life Effects of Surgery**

Efforts to improve quality of life in breast cancer survivors have led researchers to investigate the impact of surgery on women. More specifically, researchers have begun

to investigate the impact of breast-conserving surgeries versus mastectomies on quality of life (Moyer, 1997). Currently, treatment for early-stage breast cancer is treated with a mastectomy or breast-conserving surgery plus radiation (ACS, 2010; Moyer, 1997). Survival rates for both modes of treatment are equivalent, so the decision to undergo breast-conserving surgery or mastectomy is a personal decision that has possible implications on quality of life (Moyer, 1997).

Physical outcomes. Researchers have found few treatment-related differences in quality of life for breast cancer survivors who have undergone breast-conserving surgery versus mastectomy (Ganz et al., 2004; Janni et al., 2001). The primary differences that have been established include concerns about body image and sexuality (Janni et al., 2001; Janz et al., 2005). Though most researchers have found that breast conserving surgery results in fewer sexual problems and higher body image than mastectomies (Moyer, 1997; Rowland et al., 2000), one group of researchers found that breast-conserving surgery led to lower levels of sexual functioning and sexual enjoyment compared to mastectomy plus breast reconstruction (Janz et al., 2005). Consistent with previous findings, though, Janz et al. (2005) did find that women who had breast-conserving surgery had higher body image, on average, than women who had a mastectomy.

**Emotional outcomes.** In addition to physical quality of life concerns resulting from breast surgery, emotional concerns exist as well. Women awaiting breast surgery have been found to have low emotional well-being, intrusive thoughts, and increased distress (Schnur et al., 2008). In a study of 187 women scheduled for a diagnostic breast

biopsy or a curative lumpectomy (Schnur et al., 2008), a series of surveys measuring distress (Profile of Moods States; Shacham, 1983), emotional well-being (Emotional Well-Being Subscale of the Functional Assessment of Cancer Therapy-General; Webster, Cella, & Yost, 2003), intrusive thoughts (Intrusion Subscale of the Impact of Events Scale; Horowitz et al., 1979), and emotional upset (Visual Analog Scale Emotional Upset; Ahearn, 1997) were completed on the day of participants' scheduled breast surgery. Results indicated that women in both groups reported heightened levels of distress, though the lumpectomy group was significantly higher. Further, women scheduled for a lumpectomy surgery reported significantly higher levels of emotional upset and intrusive thoughts and lower levels of emotional well-being compared to the diagnostic biopsy group. It appears, therefore, that treatment-related surgery causes more anticipatory distress and upset than diagnostic procedures.

Following breast surgery, it appears that women are likely to experience increased depressive symptoms. For example, Karademas, Argyropoulou, and Karvelis (2007) compared women who had undergone mastectomies and were considered disease-free to a healthy control group. A total of 103 breast cancer survivors and 100 matched controls completed a series of questionnaires, including the General Health Questionnaire (Moutzoukis, Adamopoulou, Garyfallos, & Karastergiou, 1990), the Ways of Coping Questionnaire (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), and an illness-related stress measure. Results revealed that women in the mastectomy group reported significantly more depressive symptoms than the matched control group. No group differences were found on other psychological scales (anxiety, somatic symptoms,

social dysfunction). Because women included in the mastectomy group had been disease-free for more than three years and still reported higher levels of depressive symptoms, it seems evident that the emotional impact of breast cancer is lasting.

In addition to experiencing symptoms of depression, breast cancer survivors are at risk for suffering symptoms of post-traumatic stress (Kornblith et al., 2003). In a study on the long- term impact of breast cancer on survivors' quality of life and symptoms of post-traumatic stress, 153 women aged 41 to 87 who had undergone mastectomies and adjuvant therapy within the past 15 to 23 years completed a series of questionnaires in a telephone interview. Participants were asked to answer questions for the following assessments: the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), Posttraumatic Stress Disorder Checklist (the trauma was identified as cancer; Weathers, Litz, Herman, Huska, & Keane, 1993), Conditioned Nausea, Vomiting, and Distress (Cella, Pratt, & Holland, 1986), European Organization for Research Treatment of Cancer Quality of Life (Aaronson et al., 1993), and Life Experience Survey (Sarason, Johnson, & Siegel, 1978), and the MOS Social Support Survey (Sherbourne & Stewart, 1991). Based on the Brief Symptom Inventory, 5% of survivors obtained scores indicative of a psychiatric disorder. Also, it was noted that 15% of the survivors reported experiencing two or more symptoms of posttraumatic stress "extremely often." Furthermore, nearly 5% of survivors met diagnostic criteria for posttraumatic stress disorder. Those with lymphodema and numbness were at an even higher risk for experiencing symptoms of posttraumatic stress (Kornblith et al., 2003).

Decision regret related to the type of surgery chosen also is an emotional outcome related to quality of life for breast cancer survivors (Sheehan, Sherman, Lam, & Boyages, 2008). The period following diagnosis can be especially challenging. Women must cope with the shock of learning they have breast cancer while making difficult and complex decisions related to medical treatment, including the decision on what type of surgery to have (breast-conserving versus mastectomy and reconstruction versus no-reconstruction (Sheehan et al., 2008). In a study on psychosocial and surgical factors on decision regret among breast cancer survivors, decision regret was a relevant outcome related to breast cancer (Sheehan et al., 2008). In their study, Sheehan et al. (2008) assessed 123 women (mean age 52) who had undergone immediate or delayed breast reconstruction following surgery. Decision regret was measured using the Decision Regret Scale (Brehaut et al., 2003), body image was measured using the Body Image Scale (Hopwood, Fletcher, Lee, & Al-Ghazal, 2001), distress was measured using the Impact of Event Scale (Horowitz et al., 1979), social support was measured with the Social Support Questionnaire (Sarason, Sarason, Shearin, & Pierce, 1987), mood was measured with the Positive and Negative Affect Schedule (Watson, Clark, & Tellegen, 1988), and decision influence was determined with a one-item question about the level of decision influence experienced with answer choices ranging from "it was totally my decision" to "it was totally my doctor's decision." Results indicated that 27.6% of breast cancer survivors experienced mild regret and 19.5% experienced moderate to strong regret. Decision regret was related to negative body image and increased psychological distress. Based on their

findings, expectation of surgical outcomes has been hypothesized to alleviate decision regret (Sheehan et al., 2008).

Additionally, fear of disease recurrence is a universal fear for breast cancer survivors that can cause significant distress and impact on quality of life. Although it is known that most cancer survivors experience fear of disease recurrence, less is known about this fear during the transition from active patient to survivor. Allen et al. (2009) qualitatively investigated the transition from breast cancer patient to survivor and the impact on fear of recurrence. Focus group methodology was used for this study, including six groups of approximately 8 women per group. Eligible participants included recent (within the past year) breast cancer survivors of Stage I and II cancer who had undergone adjuvant therapy. Fear of disease recurrence was a powerful fear, with some women thinking about it daily. Furthermore, emotional distress, including depression, was believed to be related to fear of recurrence. Losses associated with the end of treatment (i.e., being monitored by medical staff and daily radiation appointments) were associated with fear. It is understood that heightened fear can compromise quality of life by creating a hyper-vigilance of physical symptoms (Allen et al., 2009).

## **Quality of Life Effects of Adjuvant Therapies**

All adjuvant therapies (radiation, chemotherapy, hormone therapy) have the potential to affect quality of life in some way (ACS, 2010). The areas most impacted by adjuvant treatment include physical health, psychological and emotional well-being, role functioning, social issues, and spousal intimacy (Feigin et al., 2000). Furthermore, the quality of life impact from adjuvant therapies can last for years after treatment has ended

(Schover et al., 1995). In particular, chemotherapy has been found to have a long-term impact on quality of life issues, including psychological distress, poor body image, sexual dysfunction (Schover et al., 1995) and declined mental health (Helgeson, Snyder, & Seltman, 2004) for up to four years after treatment.

It is viable that the physical impact adjuvant therapies have on the body impacts the overall quality of life. Also, higher levels of post-treatment fatigue have been associated with lower quality of life regardless of the intensity of the adjuvant regimen (Berger et al., 2009). Adjuvant therapy, while medically necessary in many cases, further complicates the recovery process. Women who receive adjuvant therapy post-surgery appear to experience more psychological distress and physical impairments than women who have surgery alone (Ganz et al., 2004).

The cumulative side-effects of breast cancer treatment, adjuvant treatments, and unclear expectations of returning to "normal" once treatment has ended make transitioning from patient to survivor difficult. How a woman transitions into survivorship, however, can greatly affect quality of life. In fact, women who enter this "re-entry" phase with heightened distress have been found to have diminished long-term adjustments (Allen et al., 2009; Carver & Antoni, 2004). Clearly, then, it is important to understand the impact of transitioning to survivorship on quality of life.

## Quality of Life Effects during the Transition to Survivorship

Breast cancer survivors experience varying phases of distress from their initial diagnosis to long-term survivor issues. Henselman et al. (2010) identified four distress trajectories for breast cancer survivors including (a) the initial diagnosis, (b) active

treatment, (c) reentry to survivorship, and (d) chronic distress within survivorship.

Though little is known about survivorship for women with breast cancer, researchers are starting to investigate the impact of the "re-entry phase" or, in other words, the transition to survivorship (Morgan, 2009; Rancour, 2008).

Transitioning from patient to survivor comes with a significant amount of uncertainty (Morgan, 2009). Uncertainty related to the meaning of the breast cancer and the comprehensive impact of the disease is a primary concern for survivors once they end active treatment, let go of the routine structure and security of regularly scheduled medical appointments and communication with medical staff, and attempt to return to their daily lives (Morgan, 2009). Because it is unlikely that a person can return to life exactly as it was before cancer, the NCI (2006) recommends survivors find a "new normal." In a sense, a new normal is a new identity, including new perceptions, behaviors, and ways of being in relationships. Creating a new identity can be distressing and grieving the old identity and desire to return to life as it was may be necessary (Rancour, 2008). Additional considerations survivors face that affect quality of life during this transition include decisions about follow-up care, creating wellness plans, managing physical changes, coping with body and intimacy changes, identifying and understanding feelings and emotions, and coping with family and workplace changes (NCI, 2006).

Decisions about follow-up care can be especially upsetting for survivors, given the uncertainty and fear of future outcomes including the possibility of disease recurrence (Allen et al., 2009). Including survivors in the decision-making process for post-

treatment follow-up care has been found to improve overall quality of life (Anderson & Urban, 1999). In a study of 292 breast cancer survivors between the ages of 50 and 85, over half (52%) perceived that they had an active role in their follow-up treatment and 80.4% reported satisfaction with their level of involvement (Anderson & Urban, 1999). Further, having an active role in the decision-making process for follow-up care was found to be a significant predictor of quality of life on six scales including, pain, general health, vitality, physical functioning, emotional functioning, and mental health (Anderson & Urban, 1999). Having a high level of involvement in the treatment-related decision was not a significant predictor, however, of quality of life for active treatment (surgery and adjuvant therapy). This suggests that having a level of control and active involvement may be most important during the transition into survivorship.

It is important to recognize that the end of cancer treatment does not signify the end of the impact of cancer on breast cancer survivors. Many women continue to suffer psychological distress due to the perceived inescapability of a future disease threat and bodily changes (Deimling, Kahana, Bowman, & Schaefer, 2002; Gurevich, Devins, & Rodin, 2002; Sinding & Gray, 2005). For example, in one study of cancer survivors who had completed treatment for breast, prostate, and colorectal cancers, 180 male and female survivors over the age of 60 were interviewed about their level of distress (Deimling et al., 2002). Breast cancer survivors comprised 41% of this study population. Results indicated that 25% of the population met clinical levels for depression, as measured by the CES-D (Radloff, 1977). Additionally, 25% of the population endorsed significant levels of hyper-arousal and 30% endorsed difficult concentrating, as measured by PTSD

Checklist-Civilian (Weathers et al., 1993). Survivors who had undergone chemotherapy, in addition to surgery or other adjuvant therapies, reported significantly higher levels of depression and hostility. Similarly, Sinding and Gray (2005) interviewed 10 breast cancer survivors and highlighted a theme that cancer was ongoing even after the cessation of active treatment. In the context of focus groups, breast cancer survivors spoke of residual anxiety, depression, and reminders of the disease. In reference to the daily reminders of her surgical scars, one survivor lamented, "You can't get up and get dressed without being reminded." In association with increased hyper-arousal and perceived future disease threat, another survivor spoke of "waiting for the other shoe to drop." From these research findings, it seems clear that the impact of cancer continues past the end of treatment. These concerns can be understood within the framework of Transitions Theory (Bridges, 1991).

# **Transitions Theory**

Transitions Theory is a framework for navigating major life change (Bridges, 1991). Transitioning into survivorship is a major life change and can be a challenge for women with breast cancer. Women may experience a disorienting void when they leave their safety net of medical personnel, routine hospital visits, and scheduled treatment plan (Rancour, 2008). Because survivorship is the original goal, women may feel confused when they transition into survivorship and realize they are not the same person as when they started their cancer journey. Many survivors expect for their lives and relationships to return to the way they were and to move forward in life, as if breast cancer was a

benign illness with no aftermath (Rancour, 2008). Bridges' (2004) Transitions Theory is a useful framework for the transition into survivorship.

Transitions Theory breaks down transitions into three distinct stages: endings, neutral zone, and beginnings (Bridges, 2004). The first stage implies that transitions include leaving one way of being or leaving something that is familiar (Bridges, 1991). Even when the *ending* is a positive transition (completing cancer treatment), a sense of loss or grief may be present (Rancour, 2008). Survivors may have unrealistic expectations of how quickly their physical, psychological, relational, and spiritual adjustments will occur once treatment ends (Rancour, 2008). According to Transitions Theory, survivors in this stage may be disengaged, lack connection to their pre-cancer identity, and have a sense of disorientation (Bridges, 1991). It is important to normalize survivors' feelings of grief, sadness, and anger and caution them to assess quality of life improvements on a monthly basis, versus daily or weekly, in order to view changes more realistically (Rancour, 2008).

The second stage of Transitions Theory is *the neutral zone* (Bridges, 1991). This stage is characterized by confusion and anxiety (Bridges, 1991). During the diagnosis and treatment process, many women experience a heightened sense of anxiety and an urgency to act quickly and begin treatment. As a result, little attention is paid to the meaning of the illness. Breast cancer survivors enter the *neutral zone* when they begin to assess how the illness has changed their values, priorities, and identity (Rancour, 2008). At this point, survivors do not identify as cancer patients nor do they feel a sense of normalcy (Rancour, 2008). This is an important period in the transitional process and

rushing through this stage, either independently or at the "encouragement" of others, can cause discomfort, anxiety, and panic (Bridges, 1991). Finding a balance between solitary reflection (through silence, meditation, journaling) and rebuilding social connections can help survivors in this stage. Further, survivors must be reassured that their new identity will emerge over time (Bridges, 1991), that is, that the experience is developmentally normal and will, with work, resolve in time.

The final stage of Transitions Theory is *the new beginning* (Bridges, 1991). A survivor enters *the new beginning* when they have done the work necessary to transition through the first two stages and come to a resolution of how they will move forward (Rancour, 2008). At this point, a new identity may emerge that includes a new life purpose or direction, changes in relationships, and development of new skills (Rancour, 2008).

This theory is relevant to the current study because it promotes three primary skills: attending to feelings (allowing oneself to acknowledge feeling without judgment), befriending feelings (learning to tolerate and accept feelings), and surrendering to the suffering (fostering gentleness toward the self) (Rancour, 2008). Each primary skill promoted through Transitions Theory relates to the individual constructs of the hypothesized path model that the impact of mindfulness on quality of life is mediated by self-kindness and alexithymia. The first primary skill, attending to feelings, is a component of mindfulness, given that mindfulness involves a non-judgmental present orientation toward thoughts and feelings (Kabat-Zinn, 1990). The second primary skill, befriending feelings, requires that one be able to identify, acknowledge, and describe

feelings. People with alexithymia struggle to do this and, therefore, may find it more difficult to transition through difficult times. The final primary skill, surrendering to the suffering, is essentially being kind toward one's self. This skill requires one to nurture self-kindness in times of difficulty. According to Transitions Theory, these skills help people move through transitions into a place of acceptance and peace (Bridges, 1991). Mindfulness, self-kindness, and alexithymia may determine these skills levels and how the stages of transition are experienced. Quality of life is a possible indicator for whether or not these stages of transition are being expressed fully and in a healthy manner.

It is important to recognize the element of time in transitioning from breast cancer patient to breast cancer survivor. Transitions Theory clearly delineates three phases of transition that are time-oriented. One must pass through the ending stage before arriving at the beginning stage. Therefore, it is reasonable to suggest that the further out a breast cancer survivor is from active treatment, the more likely they are to have gone through the three stages of transition.

Helping survivors to understand the stages of Transitions Theory and the skills associated with the theory may impact quality of life. All three of the skills associated with Transitions Theory involve feelings. Some breast cancer survivors struggle with identifying and describing feelings, however, or, in other words, have clinical or subclinical alexithymia (Banner, 2009; Grassi, 2005; Manna et al., 2007).

## Alexithymia

Alexithymia involves restriction of emotions (Bagby, Parker, et al., 1994).

Individuals with alexithymia have difficulty identifying, expressing, and distinguishing

between feelings or emotional arousal (Bagby, Parker, et al., 1994). Alexithymia also is characterized by an external cognitive orientation (Bagby, Parker, et al., 1994). While alexithymia prevalence rates for the general population are estimated to be between 5 and 10% (Mattila et al., 2009), prevalence rates are higher in cancer survivors (26%) and, in particular, breast cancer survivors (36%) (Grassi, 2005; Manna et al., 2007). Alexithymia has been associated with increased severity of fatigue and depression (Bodini et al., 2008), anxiety (Banner, 2009), chronic pain (Lumley, 1997), and lower levels of social support, increased stress, and decreased well-being (Posse, Hallstrom, & Backenroth-Ohsako, 2002). All of these associations have the potential to affect quality of life in breast cancer survivors.

# Alexithymia as Important to Quality of Life

Alexithymia has been found to be associated with lower levels of health-related quality of life in the general population (Mattila et al., 2009), though researchers have not investigated the relationship between alexithymia and quality of life specifically in a sample of breast cancer survivors. It seems, clear, however, that fear of disease recurrence and fear of the future are elements of quality of life for breast cancer survivors. What the survivor does with this fear (for example, experience and express the fear versus deny and suppress the fear) may play a role in quality of life. In fact, fear of the future (e.g., disease recurrence, dying, lack of control) is one of the most stressful issues for breast cancer survivors (Lebel et al., 2009). One implication of this finding is that helping breast cancer survivors learn to cope with their emotional distress may decrease the level of fear they experience. In order to do this it is important to assess

breast cancer survivors for alexithymia to better understand their capacity to understand, experience, and express their emotional experience.

Social support, another important aspect of quality of life for breast cancer survivors (Brady et al., 1997) has been found to be lower in individuals with alexithymia (Posse et al., 2002). One explanation for this involves attachment anxiety, which is that the same mechanisms that lead a person to repress emotions also lead them to isolate socially. Mallinckrodt and Wei (2005) used a bootstrapping model to determine that those with low levels of emotional expression, as measured by an alexithymia scale, found it more difficult to form adult attachments and, therefore, to garner social support. While inhibited emotional expression has been linked to diminished social support, it also has been linked to lower physical well-being in cancer survivors (Porcelli et al., 2007). According to Pennebaker (1997), emotional restriction drains the body of vital energy needed for optimal well-being and taxes the immune system, vascular system, and nervous system. As a result, this can prevent the body from healing and revitalizing necessary systems in the face of a disease threat (Pennebaker, 1997).

## **Alexithymia and Breast Cancer**

Though the traumatic nature of a breast cancer diagnosis may be considered a possible explanation for the high prevalence of alexithymia in breast cancer survivors, alexithymia has been found to be a relatively stable trait in this population (Luminet, Rokbani, Ogez, & Jadoulle, 2007). It is unclear how this might impact the transition from breast cancer patient to survivor. It is known that transitioning to survivorship can be a difficult and uncertain time and emotional expression and social support can lessen

the severity of this (Morgan, 2009). Further, it is known that alexithymia is related to depression, fatigue, increased perceived pain, and lower emotional well-being (Banner, 2009; Bodini et al., 2008; Lumley, 1997; Posse et al., 2002). What is unknown, however, is how alexithymia impacts quality of life for breast cancer survivors during the initial transition period.

### Mindfulness

Mindfulness is a non-judgmental awareness of the present moment that includes a present orientation to thoughts, feelings, and senses (Kabat-Zinn, 1990). Mindfulness can be defined as nonreactivity to inner experiences (noticing senses and thoughts without reacting to them), observing (an awareness of the present moment), acting with awareness (paying attention to the present moment), describing (describing feelings and thoughts), and nonjudging of experience (noticing the present moment without labeling it good or bad) (Baer et al., 2006). Mindfulness also has been defined as a way of being in life, rather than a technique for stress reduction (Smith, Richardson, Hoffman, Pilkington, 2004). Buddha taught that "mindfulness is all helpful" (p. 37). With mindfulness, one is able to direct attention to the inner workings of the mind and body. The seventh principle of Buddhist psychology is that mindful attention can be liberating and bring perspective, balance, and freedom to individuals (Kornfield, 2009). For over a thousand years, Buddhist monks have practiced the art of mindfulness in order to achieve wisdom and "inner illumination" (Kornfield, 2009). Increasingly, though, it seems clear that mindfulness can be taught. Jon Kabat-Zinn developed one of the most popular training programs, an 8-week Mindfulness Based Stress Reduction (MBSR) program, which

involves yoga and meditation, including daily practice of 45 minute long meditation tapes (Kabat-Zinn, 1990). The core practice of MBSR is mindful breathing (focusing on the breath by observing the rise and fall of each breathe) but a strong commitment to practice and an open attitude also are essential components of learning to be mindful (Kabat-Zinn, 1990). This is because mindfulness requires active participation in paying attention to the present moment. One cannot passively be mindful or have mindfulness done to them. Rather, mindfulness is a state of being that comes from within and requires focus and attention (Kabat-Zinn, 1990).

# Mindfulness as Important to Quality of Life

The benefits of practicing mindfulness include improvements in symptoms of stress, mood disturbance, and health-related challenges In a meta-analysis of 20 studies on mindfulness training among samples with various cancer diagnoses, chronic pain, fibromyalgia, coronary heart disease, depression, anxiety, and eating disorders, a significant effect of medium size was found for the impact of mindfulness on mental health (d = 0.54, 95% CI 0.39-0.68, p < .001) and physical health (d = 0.53, 95% CI 0.23-0.81, p = .0004) (Grossman, Niemann, Schmidt, & Walach, 2004). The results of this meta-analysis suggest that MBSR training is a useful intervention for a range of chronic problems. This seems particularly true as the studies included in the Grossman et al. (2004) meta-analysis included various dependent measures, including psychological dimensions of quality of life, depression, anxiety, coping styles, sensory pain, and physical well-being.

MBSR has been found to improve overall quality of life and areas related to quality of life such as emotional well-being (Brotto & Heiman, 2007; Foley, Huxter, Baillie, & Price, 2010; Kuyken et al., 2008; Roemer, Orsillo, Salters-Pedneault, 2008). In a recent study, Foley et al. (2010) investigated the impact of Mindfulness-Based Cognitive Therapy (MBCT) on quality of life and emotional well-being among 115 cancer patients. MBCT is similar to MBSR but also includes an emphasis on mindful awareness of cognitive ruminations. Foley et al. assigned participants to either a treatment group or a wait-list control group. Breast cancer patients comprised 47.3% of the sample, women comprised 77% of the sample, and the mean age of participants was 55.18. The treatment group received an 8-week mindfulness training program that included 2 hour weekly sessions, daily home practice of up to one hour, and 40 minute tape recordings of standard meditations (body scan, walking meditation, and general mindfulness meditation). Each treatment group included 8 to 12 participants. The waitlist group served as the control group and received the mindfulness training upon completion of the study. Outcome measures included depression as measured by the Hamilton Rating Scale for Depression (Williams, 1988), anxiety as measured by the Hamilton Anxiety Rating Scale (Shear et al., 2001), distress as measured by the Depression, Anxiety, Stress Scale (Lovibond & Lovibond, 1995), quality of life as measured by The Functional Assessment of Cancer Therapy-General (Cella et al., 1993), and mindfulness as measured by the Frieburg Mindfulness Inventory (Walach, Buchheld, Buttenmuller, Kleinknecht, & Schmidt, 2006). Data were collected pre and post intervention and the treatment group received a 12-week follow-up assessment postintervention. Initial pre-intervention results indicated that both groups fell within the moderately depressed range, mildly anxious range, and had below average ratings for quality of life. Further, the two groups did not differ significantly at baseline. Post-intervention results revealed that the treatment group had significantly greater improvement for depression (F(1, 166) = 18.78, p < .001), anxiety (F(1, 115) = 10.25, p = .002) and mindfulness (F(1, 115) = 18.51, p < .001). Change in quality of life was not significant at the established alpha level of .01 (F(1, 12) = 6.70, p = .011) but the difference would have been significant had a more liberal alpha level, such as .05, been used. These results provide support for the use of mindfulness interventions to improve overall quality of life and emotional well-being.

Similarly, Kuyken et al. (2008) found mindfulness to have a positive impact on recurrent depression for women In this study, the researchers assigned 123 women (the sample was not breast cancer survivors) between the ages of 21 and 72 to either an intervention group or a standard treatment group for depression relapse prevention. The intervention group involved an 8-week mindfulness training program with an additional focus of helping women taper from their antidepressant medications; the standard care (control group) included continuation of antidepressant medication. Women completed assessments at 3-month intervals for 15 months. Outcome measures were collected for quality of life, depressive symptoms, and possible relapse. Results indicated that over a 15-month period, 47% of the intervention group experienced a relapse of depression compared to 60% of the standard care group. Though there was a trend toward higher quality of life for the intervention group, results were non-significant. These findings

suggest that mindfulness may assist women as they transition from a difficult time (depression) and off of psychotropic medications. This has possible implications for breast cancer survivors who are transitioning off of medications for anxiety or depression.

Mindfulness has been found to improve additional areas of quality of life as well. Recently, researchers investigated the relationship between mindfulness and sexual body image (Fink, Foran, Sweeney, & O'Hea, 2009). Although the study did not target cancer survivors, it is a relevant study nonetheless because many breast cancer survivors have identified body image and sexuality as primary concerns (Schover et al., 1995). In this study, 79 female undergraduate students were asked to complete the Five Factor Mindfulness Questionnaire (FFMQ; Baer et al., 2006) and the Sexual Attractiveness subscale of the Body Esteem Scale (BES; Franzoi & Shields, 1984). Based on a multiple regression analysis, the total score for the FFMQ was significantly predictive of scores for the Sexual Attractiveness subscale of the BES. Further, two subscales of the FFMQ, the Observing subscale and the Describing subscale, were found to be uniquely predictive of the Sexual Attractiveness subscale. This means the ability to pay attention to internal experience (Observing) and label these experiences with words (Describing) was predictive of higher self-perception of sexual attractiveness. Results of this study have limited generalizability, however, as it included a small sample of undergraduate students only. It is unknown the extent to which these findings would generalize to cancer survivors.

### **Mindfulness and Breast Cancer**

Researchers have begun to investigate mindfulness in women with breast cancer. Witek-Janusek et al. (2008) evaluated the effect of mindfulness on immune function, quality of life, and coping in women with breast cancer. Seventy-five women between the ages of 35 to 75 who were post-surgery participated in this study. Women who underwent chemotherapy were excluded from the study. Forty-four women were assigned to an eight week MBSR treatment group and 31 were assigned to a control group. Immune markers, quality of life, coping, and cortisol (a stress hormone) were measured at four points throughout the study: pre-MBSR, four weeks after the start of the MBSR group, upon completion of the MBSR group, and one month after the MBSR. Quality of life was measured by the Quality of Life Index (Ferrans, 1990), coping was measured by the Jalowiec Coping Scale (Jalowiec, Murphy, & Powers, 1984), mindfulness was measured by the Mindfulness Attention Awareness Scale (Carlson & Brown, 2005), immune markers and cortisol were measured by a series of blood samples including peripheral blood mononuclear cells, natural killer cell activity, and cytokines. Immunological assessments revealed that women in the MBSR group experienced a decrease in IL-4 and IL-6 (a positive indication of immunity enhancement) and reestablished a healthy level of natural killer cells and cytokines. Further, the MBSR group experienced a decrease in the stress hormone cortisol. The control group, on the other hand, did not show evidence of immunity enhancement. Women in the MBSR group also reported significant improvement in their overall quality of life when compared to the control group. It is noteworthy that the greatest improvement in quality of life

occurred in the psychological-spiritual and family domains. In terms of coping, the MBSR group demonstrated higher levels of being optimistic (positive thinking) and supportant coping (use of personal, professional, and spiritual resources) compared to the control group.

In a similar study, Carlson et al. (2004) investigated the impact of a MBSR program on breast and prostate cancer outpatients. Patients were eligible to participate in the study if they were over the age of 18, had early stage breast or prostate cancer, were a minimum of three months post-surgery, and were not receiving adjuvant therapies at the time of the study. Forty-three patients participated in the study including 34 women with breast cancer and 9 men with prostate cancer. In a pre-post intervention design, the patients completed an eight week MBSR group. Blood and saliva samples were collected to measure cortisol and hormone levels. Participants also completed a health behavior form (recorded sleep, alcohol consumption, caffeine, smoking), weekly meditation form, quality of life assessment (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Aaronson et al., 1993), and measures of mood (Profile of Mood States, McNair, Lorr, & Droppelman, 1971) and stress (Symptoms of Stress Inventory, Leckie and Thompson, 1979). Only the global scores of the psychological tests were reported. In the sample, pre-post quality of life scores significantly increased (t = -2.23, p < 0.05). There were no changes, however, in mood scores based on the Profile of Moods States. Post-intervention stress scores were significantly lower (t =3.23, p < 0.01) indicating reduced stress levels. Though there were no significant changes in cortisol, it was reported that those with lower levels of afternoon cortisol

reported higher levels of quality of life. In a one year follow-up (Carlson, Speca, Faris, & Patel, 2007), results were similar and positive gains appeared to be maintained. One positive outcome was noted at follow-up that was not detected in the original study as cortisol levels were decreased significantly at follow-up, indicating a reduction in stress.

Finally, in a study on mindfulness and women with breast cancer (Tacon, Caldera, & Ronaghan, 2004), 27 women with breast cancer between the ages of 30 and 75 were recruited to participate in an eight week MBSR program that met weekly for 1.5 hours. At the time of the study, only 3 women were currently undergoing radiation and chemotherapy. The remaining women were taking oral medication. A pre-post design was implemented to assess for anxiety as measured by the State-Trait Anxiety Inventory (Spielberger, 1983), stress as measured by a single 10-point scale question, mental adjustment to cancer as measured by the Mental Adjustment to Cancer (Watson et al., 1988), and health locus of control as measured by the Multidimensional Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978). Results indicated a significant reduction in stress (t(26) = 7.54, p < .001) and anxiety (t(26) = 4.95, p < .001) following the MBSR program. Further, there was a significant reduction in two types of responses to cancer: helplessness-hopelessness (t(26) = 2.66, p < .01) and anxious preoccupation (t(26) = 2.54, p < .01). Scores on the health locus of control reflected an increase in internal locus of control.

Much is known, then, about the importance of mindfulness to psychological and physical well-being. Though it seems clear that mindfulness positively impacts quality of life in breast cancer patients, limited empirical data is available on the impact of

mindfulness on breast cancer survivors who have completed surgery and all adjuvant treatments. Further, less is known about the mediating factors of mindfulness on quality of life in breast cancer survivors.

#### **Self-Kindness**

Self-kindness is defined as extending kindness, understanding, and acceptance toward oneself (Neff, 2003). Self-kindness involves letting go of harsh judgments and self-criticisms in favor of loving and gentle acceptance (Neff, 2003). The origins of the construct self-kindness lay in Buddhist psychology (Kornfield, 2009), strengths-based counseling (Fong, 1990), and Neff's (2003) work on self-compassion.

One of the primary principles of Buddhist psychology is to acknowledge and see the inner nobility and beauty in all people (Kornfield, 2009). This includes having openness to one's own goodness, referred to as one's *Buddha nature* (Kornfield, 2009). Far too often, however, people cling to fears and darker elements of oneself (e.g., feelings of inadequacy, approval seeking) rather than embracing one's strengths and virtues. Robert Johnson (1991) wrote that "it is more disrupting to find that you have a profound nobility of character than to find out you are a bum" (p. 8). *Loving-kindness* meditation is a way to cultivate self-kindness. The Pali (Buddha's language) word for loving kindness, *metta*, means universal, all-embracing love (Germer, 2009). In the fifth century CE, a Buddhist monk Buddhaghosa detailed instructions for metta meditation. An example of one of Buddhaghosa's metta meditations is to repeat the phrases "May I be happy and free from suffering" and "May I keep myself free from enmity, affliction, and anxiety and live happily" (Germer, 2009, p. 137).

Self-kindness also is grounded in counseling's strength-based, developmental, wellness orientation (Fong, 1990; Myers, 1992; Witmer & Sweeney, 1992). Based on this orientation, positive emotions, traits, and resources are identified and expanded upon. This orientation contrasts the medical, illness-oriented model, which is problem-focused and highlights what is wrong with human nature (Myers, 1992). Though it is useful to be able to fully understand people's problems in order to help them, a risk exists of solely focusing on fears, depression, anxiety, and anger while leaving resilient and affirming qualities in the shadow. A developmental, wellness orientation suggests that problems are a part of life and should be viewed as opportunities for personal growth and renewal (Myers, 1992). Furthermore, healthy development and wellness is strived for by means of utilizing the positive forces that presently exist within an individual. It is accepted within counseling that positive thoughts and emotions must be nurtured and fostered for optimal living. Self-kindness is an example of a positive construct that, if nurtured, has the potential to improve quality of life.

Little research has been conducted on self-kindness and, to date, no studies on self-kindness among breast cancer survivors have been published. Kristen Neff is leading the way in research on the similar construct of self-compassion (Neff, 2003). Based on Neff's work, self-kindness is a distinct subscale of the construct of self-compassion. Neff (2009) described self-kindness as being warm toward oneself in the light of suffering, failure, and pain. Further, it involves accepting reality with sympathy and kindness toward oneself. In a study aimed at investigating the construct validity of the Self-Compassion Scale (Neff, 2003), two groups were compared to each other. One

group included practicing Buddhists and the other group included undergraduate university students. Because self-compassion and the components of self-compassion, including self-kindness, are rooted in Buddhist psychology, Neff chose to sample from Buddhists under the assumption that they would have been exposed to teachings of being kind and compassionate to oneself. The research groups were comprised of 43 Buddhist participants and 232 undergraduate student participants. The group with Buddhist participants included 16 men and 27 women. The mean age was 47 years old and the standard deviation was 9.71. The majority of the sample was White (91%). Participants reported practicing Buddhist meditation between 1 and 40 years. All participants in both groups were asked to complete the Self-Compassion Scale and a self-esteem scale. Results revealed a significant between groups difference for the self-kindness subscale (F(1, 27) = 32.00, p < .001). The mean self-kindness score for the group with Buddhist participants was 3.77 with a standard deviation of 0.79. The mean self-kindness score for the group with undergraduate students was 2.99 with a standard deviation of 0.78. What is not clear, however, is whether the difference between groups is a function of Buddhist practice or a function of age. In either case, there is evidence for the discriminant validity of the Self-Compassion Scale, but more research is needed around these constructs. Theoretical and limited empirical evidence suggests self-kindness may be a positive construct that can be taught over time (Neff, 2003, 2009; Neff, Rude, & Kirkpatrick, 2007).

# Self-kindness as Important to Quality of Life

Researchers have yet to investigate the direct impact of self-kindness on quality of life. Similar to the current study, however, Kraus and Sears (2009) hypothesized that self-kindness may be a mediator for mindfulness, which in turn can impact quality of life. They further suggested that though mindfulness often is used to create awareness and observation, it also may serve (through a pathway of self-kindness) to promote increased tolerance to distressing emotions by cultivating positive qualities such as friendliness, joy, and acceptance (Kraus & Sears, 2009). Kraus and Sears (2009) developed the Self-Other Four Immeasurables (SOFI) scale to assess both the positive and negative aspects of the mindfulness experience. Buddhist teachings on the Four Immeasurables, lovingkindness (metta), compassion (karuna), joy (mudita), and equanimity (upekkha), and their opposites (hatred, cruelty, anger, and jealousy) were used to develop the scale. One hundred and twenty-four undergraduate students and 12 experienced meditators participated in the scale development study. Loving-kindness, compassion, and joy were measured, in addition to social desirability, mindfulness, positive and negative affect, and self-compassion. High internal consistency was found for each subscale: Positive Self ( $\alpha$ = 0.86), Negative Self ( $\alpha$  = 0.85), Positive Other ( $\alpha$  = 0.80), Negative Other ( $\alpha$  = 0.82). However, internal consistency for the overall measure was not as strong ( $\alpha = 0.60$ ). Based on factor analyses, the Four Immeasurables did not converge as expected. Instead, the scales loaded based on positive qualities versus negative qualities and self versus other ratings. The SOFI demonstrated strong discriminant, concurrent, and construct validity. This suggests that the SOFI may be used to assess for positive qualities

associated with mindfulness, thus providing a clinical and research tool for assessing positive constructs such as self-kindness.

It seems apparent that developing positive qualities, such as self-kindness, can serve to build personal resources. Fredrickson, Cohn, Coffey, Pek, and Finkel (2008) investigated the impact of a 6-week intervention of loving-kindness instruction on enhancing positive emotions and building personal resources (e.g., the ability to give and receive emotional support and the ability to fight off a common cold). In this study, 139 Compuware Corporation employees participated in a 6-week course on loving-kindness meditation. Sixty-seven participants were randomly assigned to the loving-kindness group and 72 participants were assigned to the waitlist control group. Over half of the participants were female (65.5%) and Caucasian (72.6%). The mean age was 41 years. The training included six weekly one-hour sessions of instruction and practice of meditation directing love and kindness to themselves and others. In a pre-post design, the personal resources measured included mindfulness, agency thinking (belief that one is able to meet goals) and pathway thinking (belief that multiple ways exist to achieve goals), tendency to enjoy pleasant experiences, optimism, ego-resilience, psychological well-being, social support, positive relations to others, illness symptoms, sleep duration, satisfaction with life, and depression. The hypothesized path model suggested that loving-kindness meditation would increase positive emotions, which would increase personal resources, thereby increasing overall life satisfaction. Results indicated that this path was significant for nine resources tested: mindfulness, pathway thinking, tendency to enjoy pleasant experiences, environmental mastery, self-acceptance, purpose in life,

social support, positive relations with others, and illness symptoms. In other words, loving-kindness training significantly increased positive emotions over time, which increased select resources, which, in turn, was associated with significant increases in life satisfaction.

### **Self-kindness and Breast Cancer**

To date, researchers have not studied the impact of self-kindness on breast cancer survivors. Based on the aforementioned theories, however, it is viable that self-kindness has the potential to elicit positive emotions in breast cancer survivors. Also, it seems plausible that these positive emotions could have an impact on emotional and physical quality of life. Self-kindness can be viewed as important to breast cancer survivors based on Buddhist psychology. Buddhist psychology asserts that the human body is highly valued and deemed a priority for self-care (Kornfield, 2009). Regardless of one's age or life circumstance (e.g., surviving breast cancer), it is important to be kind and nurturing to one's body. Kornfield wrote that:

when physical illness arises, it often diminishes our sense of dignity. With this can also come shame and self-hatred. We can take the illness personally, as if it is our fault. But sickness and health are part of every human life. When our hearts open with understanding we will treat this body and mind with kindness no matter what the circumstances. (p. 117)

This kindness has the potential to help create an environment for healing and life enhancement over time. Considering the challenges breast cancer survivors encounter as they recover from the physical and emotional sequelae of the diagnosis, treatment, and transition to survivorship, self-kindness could have a significant impact on their lives.

Germer (2009) wrote that self-kindness is only the beginning of life enhancement. Ultimately, caring and being gentle with oneself leads to deeper more intimate caring of others and, in the Dali Lama's teachings, self-kindness precedes the expression of love and caring to others (Germer, 2009).

## **Summary**

In this chapter, a review of the literature related to the experience of breast cancer and survivorship has been provided. Specifically, research pertaining to quality of life, alexithymia, mindfulness, and self-kindness was presented. Additionally, theory on transition was related to the experience of breast cancer survivorship. In summary, the following highlights were made: (a) treatment for breast cancer results in physical and emotional burdens that impact survivorship for women, (b) alexithymia is prevalent in breast cancer survivors and may exacerbate the negative emotional and physical outcomes of the disease, (c) mindfulness may support women as they transition into survivorship and positively impact quality of life, and (d) self-kindness may induce positive emotions and enhance personal resources that have the potential to impact quality of life. The proposed study seeks to fill the gaps by focusing on breast cancer survivors. More specifically, alexithymia and self-kindness will be explored as possible mediators of the relationship between mindfulness and quality of life in breast cancer survivors.

### **CHAPTER III**

#### **METHODOLOGY**

In Chapters I and II, a study on mindfulness, self-kindness, alexithymia, and quality of life was introduced, a rationale was established, and a review of the relevant literature was provided. The review of the literature in Chapter II supported the need for further study of mindfulness, self-kindness, alexithymia, and quality of life, and offered the possibility that self-kindess and alexithymia may serve to mediate the relationship between mindfulness and quality of life. The current chapter includes a description of the methodology for the current pilot study including hypotheses, participants, instrumentation, data analysis, and procedures.

# **Research Questions and Hypotheses**

Research Question 1: What is the effect of time since completion of treatment (in months) on mindfulness, alexithymia, self-kindness, and quality of life for female survivors of breast cancer (Stages 0-III) and the relationship among mindfulness, alexithymia, self-kindness, and quality of life for female survivors of breast cancer (Stages 0-III)?

Hypothesis 1a: Time since completion of treatment will have an effect on quality of life such that those further out from completion of treatment will report higher quality of life.

<u>Hypothesis 1b:</u> Mindfulness will be significantly positively correlated with self-kindness and quality of life.

<u>Hypothesis 1c:</u> Alexithymia will be significantly negatively correlated with mindfulness, self-kindness, and quality of life.

Research Question 2: What are the effects of cancer stage (0-III) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

<u>Hypothesis 2:</u> Cancer stage will have main effects on all study variables, such that persons with higher stages of cancer will report lower levels of mindfulness, self-kindness, and quality of life, and higher levels of alexithymia.

Research Question 3: What are the effects of surgery (i.e., none, lumpectomy, or mastectomy) and adjuvant therapy (i.e., none, hormone therapy, chemotherapy, or radiation) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

<u>Hypothesis 3a:</u> Type of surgery will have a main effect on all study variables, such that persons who experience more invasive surgery will report lower levels of mindfulness, self-kindness, and quality of life, and a higher level of alexithymia.

<u>Hypothesis 3b:</u> Chemotherapy will have an effect on mean scores of mindfulness, self-kindness, alexithymia, and quality of life, such that persons who receive chemotherapy will report lower levels of mindfulness, self-kindness, and quality of life, and higher levels of alexithymia.

Research Question 4: What are the relationships among mindfulness, alexithymia, self-kindness, and quality of life within a path model that specifies a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness?

<u>Hypothesis 4:</u> The hypothesized path model specifying a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness will account for a statistically significant amount of the variance in quality of life.

## **Participants**

The population for this study is female survivors of Stages 0 to III breast cancer who have completed surgery and adjuvant therapy within the past two years. Participants were recruited from three primary sources. First, women were recruited from Cancer Services, a non-profit agency in the Southeast that provides cancer services and resources to women with cancer. A recruitment mailing was distributed to approximately 1,200 clients from Cancer Services' database of current clients and alumni that included an advertisement for the study. Second, Cancer Services' clients also were recruited at a regional breast cancer conference hosted by Cancer Services. Finally, participants were recruited from a cancer survivor wellness group that was comprised of recent cancer survivors. All group members received medical treatment from a regional cancer center in the Southeast. Group participants received recruitment emails advertising the study.

Using G\*Power 3, an a priori power analysis (Faul, Erdfelder, Lang, & Buchner, 2007), a suggested sample size of 120 is needed for a minimum power of .80 and a moderate effect size of .25. This sample size was determined based on the required analysis for research question three, which required the largest sample size.

### **Procedures**

### Instrumentation

Participants will complete one web-based series of instruments that includes a demographic questionnaire, the Functional Assessment of Cancer Therapy-Breast (Brady et al., 1997), the Twenty-item Toronto Alexithymia Scale (Bagby, Parker, et al., 1994; Bagby, Taylor, & Parker, 1994) the Five Factor Mindfulness Questionnaire (Baer et al., 2006), and the Self-Compassion Scale (Neff, 2003). The demographic questionnaire will always be first in the instrument packet, but the remaining order of the instruments will be randomized to prevent the potential for ordering effects, particularly given that fatigue could be an issue for some participants. The psychometric properties of the four instruments are discussed below. Additionally, permissions from the authors to use all four instruments are included in Appendix B.

Functional Assessment of Cancer Therapy-Breast. Quality of life will be measured using the Functional Assessment of Cancer Therapy-Breast (FACT-B; Brady et al., 1997). The FACT-B is a 44-item self-report instrument with a 5-point Likert-type scale ranging from 0 (not at all) to 4 (very much). The FACT-B has six subscales that include *physical well-being* (e.g., "I have a lack of energy"), *social/family well-being* (e.g., "I get emotional support from my family"), *relationship with doctor* (e.g., "My doctor is available to answer my questions"), *emotional well-being* (e.g., "I feel sad"), *functional well-being* (e.g., "I am able to work"), and *additional concerns* as they relate to breast cancer (e.g., "I feel sexually unattractive"). The FACT-B was normed on two samples of women with breast cancer. Internal consistency for the six subscales ranged

from 0.63 to 0.86 and the alpha coefficient for the overall score for quality of life was 0.90. Acceptable support was provided for one week test-retest reliability (.88 for breast cancer scale and .85 for total score). Construct validity was evidenced through strong, positive correlations with another quality of life measure (r = .86, p < .001) and expected negative correlations for a mood assessment (r = -.70, p < .001; r = -.66, p < .001) (Brady et al., 1997). For the purpose of this study, the unit of analysis will be the global quality of life score.

Toronto Alexithymia Scale-20. The 20-item Toronto Alexithymia Scale (TAS-20; Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994) will be used to measure alexithymia. The TAS-20 is a 20-item instrument with three scales related to alexithymia: (a) difficulty identifying feelings (e.g., "I am often confused about what emotion I am feeling," (b) difficulty describing feelings (e.g., "It is difficult for me to find the right words for my feelings"), and (c) externally oriented thinking (e.g., "I prefer to analyze problems rather than just describe them"). For the current study, the global scale measure of alexithymia will serve as the unit of analysis. All items are measured on a 5-point Likert-type scale ranging from 1 (not at all like me) to 5 (completely like me). Total scores can range from 20 to 100. Higher scores are equated with higher levels of alexithymia (i.e., difficulty expressing emotions). The TAS-20 was normed on samples of male and female university undergraduate students (mean age was 21.1) and male and female psychiatric out-patients (mean age was 36.62) (Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994). Bagby, Parker, et al. (1994) reported a Cronbach's alpha of 0.81 for the total score, indicated acceptable internal consistency. Weaker alphas of 0.78

(subscale 1), 0.75 (subscale 2), and 0.66 (subscale 3) for the three subscales further support use of the global scale. Bagby, Parker, et al. (1994) also reported acceptable three week test-retest reliability (0.77, p < 0.01). Validity was obtained by administering the TAS-20 and four additional assessments of psychological mindedness, need for cognition, psychosomatics, and a personality inventory to undergraduate students and clients from a metropolitan outpatient clinic (Bagby, Taylor, et al., 1994). The TAS-20 had a strong, negative correlation with psychological mindedness, need for cognition, positive emotions, and assertiveness. The TAS-20 also had strong, positive correlations with depression, anxiety, and self-consciousness (Bagby, Taylor, et al., 1994).

Five Facet Mindfulness Questionnaire. The Five Facet Mindfulness

Questionnaire (FFMQ; Baer et al., 2006) will be used to measure mindfulness. The

FFMQ is a 39-item self-report instrument that measures five facets of mindfulness: (a)

observing, (b) describing, (c) acting with awareness, (d) nonjudging, and (e) nonreacting.

Observing is defined as the level at which one notices internal and external sensations

and stimuli (e.g., "When I take a shower or a bath I stay alert to the sensations of water

on my body"). Describing is defined as the level at which one is able to describe their

observations (e.g., "I am good at finding the words to describe my feelings"). Acting

with awareness is defined as the level at which one is in the present moment and paying

attention to one's activity and experiences (e.g., "I find it difficult to stay focused on

what's happening in the present"). Nonjudging is defined as the level at which one

avoids evaluating one's experiences and observations (e.g., "I criticize myself for having

irrational or inappropriate emotions"). Nonreacting is defined as the level at which one is

able to notice internal and external observations without reacting to them (e.g., "I perceive my feelings and emotions without having to react to them"). The FFMQ is measured using a 5-point Likert-type scale ranging from 1 (never or very rarely true) to 5 (very often or always true). The FFMQ provides a global score for mindfulness and individual subscale scores. For the purposes of this study, the unit of analysis will be the global measure of mindfulness.

A sample of male and female undergraduate students was used to norm the FFMQ (Baer et al., 2006). The instrument was found to measure distinct aspects of mindfulness. An exploratory factor analysis indicated that the five-factor model accounted for 33% of the variance and was a good fit. Confirmatory factory analysis further concluded that the model was a good fit. The FFMQ has been reported to have strong internal consistency with Cronbach's alpha of .75 for *nonreactivity*, .83 for *observing*, .87 for *acting with awareness*, .91 for *describing*, .87 for *nonjudging*, and .96 for the full scale score (Baer et al., 2006).

Self-Compassion Scale. The Self-Compassion Scale (SCS; Neff, 2003) will be used to measure self-kindness. The SCS is a 26-item instrument with six subscales: *self-kindness* (e.g., "When I'm going through a very hard time, I give myself the caring and tenderness I need") versus *self-judgment* ("When I see aspects of myself that I don't like, I get down on myself"), *common humanity* ("When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people") versus *isolation* ("When I fail at something that's important to me I tend to feel alone in my failure"), and *mindfulness* ("When something upsets me I try to keep my emotions in balance") versus

over-identification ("When I fail at something important to me I become consumed by feelings of inadequacy"). The SCS was normed on samples of male and female undergraduate students and male and female practicing Buddhists. Acceptable internal consistency has been reported for all subscales, with the *self-kindness* subscale having a reported alpha of .77 (Neff, 2003). Construct validity was obtained through significant correlations with self-criticism (r = -.65, p < .01), social connectedness (r = .41, p < .01), depression (r = -.51, p < .01), and anxiety (r = -.65, p < .01) scales (Neff, 2003). The SCS demonstrated acceptable three week test-retest reliability for the self-kindness subscale (.88). For the purpose of this study, the unit of analysis will be the self-kindness subscale score.

**Demographic questionnaire.** A demographic questionnaire was created by the researcher to collect relevant information including: age, stage of breast cancer, date of last adjuvant treatment, type of adjuvant treatment received, date of last surgical treatment, and type of surgical treatment received. A copy of the demographic questionnaire is included in Appendix B.

### **Data Analysis**

Descriptive statistics will be used to describe the characteristics of the sample based on the data from the demographic questionnaire. Alpha coefficients will be calculated to determine the reliability of each of the measures for this sample, and analyses will be conducted to test each of the research hypotheses.

To test hypothesis 1a (Time since completion of treatment will have an effect on quality of life such that those further out from completion of treatment will report higher

quality of life), an ANOVA will be used to examine the effect of time on quality of life. To test Hypothesis 1b (Mindfulness will be significantly positively related with selfkindness and quality of life) and Hypothesis 1c (alexithymia will be significantly negatively correlated with mindfulness, self-kindness, and quality of life), a Pearson-Product Moment Correlation will be used to examine the relationships among mindfulness, alexithymia, self-kindness, and quality of life. To test Hypothesis 2 (Cancer stage will have main effects on all study variables, such that persons with higher stages of cancer will report lower levels of mindfulness, self-kindness and quality of life, and higher levels of alexithymia), an analysis of variance (ANOVA) will be used to assess for main effects of cancer stage. To test Hypothesis 3a (Type of surgery will have a main effect on all study variables, such that persons who experience more invasive surgery will report lower levels of mindfulness, self-kindness, and quality of life, and a higher level of alexithymia.) and Hypothesis 3b (Chemotherapy will have an effect on mean scores of mindfulness, self-kindness, alexithymia, and quality of life, such that persons who receive chemotherapy will report lower levels of mindfulness, self-kindness, and quality of life, and higher levels of alexithymia), an ANOVA will be used to determine if type of surgery and adjuvant therapy has main effects on mindfulness, alexithymia, selfkindness, and quality of life. To test Hypothesis 4 (The hypothesized path model specifying a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness will account for a statistically significant amount of variance for quality of life), a Causal Steps Analysis with follow-up Bootstrapping will be used. For further details on the hypotheses and analyses, see Table 1.

Table 1

Hypotheses, Variables, and Data Analysis

IV	DV	Analysis
Time (less than 6 months, between 6 months and one year, greater than one year)	Quality of life	ANOVA
	Mindfulness, Self-kindness, Quality of life	Pearson Product- Moment Correlation
	Alexithymia, Mindfulness, Self-kindness, Quality of life	Pearson Product- Moment Correlation
Cancer stage (0-III)	Quality of life, Mindfulness, Alexithymia, Self-kindness	ANOVA
Surgery (none, lumpectomy, mastectomy)	Quality of life, Mindfulness, Alexithymia, Self-kindness	ANOVA
Adjuvant therapy (none, hormone therapy, radiation, and chemotherapy)	Quality of life, Mindfulness, Alexithymia, Self-kindness	ANOVA
Mindfulness (predictor)  Alexithymia (mediator)  Self-kindness (mediator)	Quality of life (criterion)	Causal Steps Analysis with follow-up Bootstrapping Analysis
	Time (less than 6 months, between 6 months and one year, greater than one year)  Cancer stage (0-III)  Surgery (none, lumpectomy, mastectomy)  Adjuvant therapy (none, hormone therapy, radiation, and chemotherapy)  Mindfulness (predictor)  Alexithymia (mediator)	Time (less than 6 months, between 6 months and one year, greater than one year)  Mindfulness, Self-kindness, Quality of life  Alexithymia, Mindfulness, Self-kindness, Quality of life  Cancer stage (0-III)  Cancer stage (0-III)  Quality of life, Mindfulness, Alexithymia, Self-kindness  Surgery (none, lumpectomy, mastectomy)  Quality of life, Mindfulness, Alexithymia, Self-kindness  Quality of life (criterion)

# **Pilot Study**

The primary purpose of the pilot study was to test procedures for feasibility and clarity and to insure research integrity for the larger study. The first research question of the full study was analyzed using pilot study data in order to test data analysis procedures and create and test the database to be used for the full study.

# **Participants**

The pilot study sample included 7 female survivors of Stages 0 to III breast cancer who had completed surgery and adjuvant therapy within the past two years. Over half of the sample had received a lumpectomy and the entire sample received adjuvant therapy that included chemotherapy and radiation. Further, over half of the sample was still receiving hormone therapy when they completed the assessments. The mean age of the sample was 51.3 and all of the women from the sample were recruited from a cancer survivor wellness group. Additional demographic data can be found in Table 1 of Appendix C.

#### Instruments

Participants completed web-based surveys that included a demographic questionnaire, the Functional Assessment of Cancer Therapy-Breast (FACT-B; Brady et al., 1997), the 20-item Toronto Alexithymia Scale (TAS-20; Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994) the Five Facet Mindfulness Questionnaire (FFMQ; Baer et al., 2006), and the Self-Compassion Scale (SCS; Neff, 2003). Additionally, participants were asked to provide open-ended feedback on the procedures, including how long they

spent completing the surveys and what type of general feedback they had about their experience completing the surveys.

Quality of life was measured using the FACT-B. The FACT-B is a 44-item self-report instrument with a 5-point Likert-type scale ranging from 0 (not at all) to 4 (very much). The FACT-B has six subscales that include *physical well-being* (e.g., "I have a lack of energy"), *social/family well-being* (e.g., "I get emotional support from my family"), *relationship with doctor* (e.g., "My doctor is available to answer my questions"), *emotional well-being* (e.g., "I feel sad"), *functional well-being* (e.g., "I am able to work"), and *additional concerns* as they relate to breast cancer (e.g., "I feel sexually unattractive"). The FACT-B was normed on two samples of women with breast cancer. Internal consistency for the six subscales ranged from 0.63 to 0.86 and the alpha coefficient for the overall score for quality of life was 0.90. Acceptable support was provided for three and seven day test-retest reliability (.88 for breast cancer scale and .85 for total score). Construct validity was evidenced through strong, positive correlations with another quality of life measure (r = .86, p < .001) and expected negative correlations for a mood assessment (r = .70, p < .001; r = .66, p < .001) (Brady et al., 1997).

The TAS-20 was used to measure alexithymia. The TAS-20 is a 20-item instrument with three scales related to alexithymia: (a) difficulty identifying feelings (e.g., "I am often confused about what emotion I am feeling"), (b) difficulty describing feelings (e.g., "It is difficult for me to find the right words for my feelings"), and (c) externally oriented thinking (e.g., "I prefer to analyze problems rather than just describe them"). All items are measured on a 5-point Likert-type scale ranging from 1 (not at all

like me) to 5 (completely like me). Total scores can range from 20 to 100. Higher scores are equated with higher levels of alexithymia (i.e., difficulty expressing emotions). The TAS-20 was normed on samples of male and female university undergraduate students (mean age was 21.1) and male and female psychiatric out-patients (mean age was 36.62) (Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994). Bagby, Parker, et al. (1994) reported a Cronbach's alpha of 0.81 for the total score, indicated acceptable internal consistency. Bagby, Taylor, et al. (1994) also reported acceptable three week test-retest reliability (0.77, p < 0.01). Validity was obtained by administering the TAS-20 and four additional assessments of psychological mindedness, need for cognition, psychosomatics, and a personality inventory to undergraduate students and clients from a metropolitan outpatient clinic (Bagby, Taylor, et al., 1994). The TAS-20 had a strong, negative correlation with psychological mindedness, need for cognition, positive emotions, and assertiveness. The TAS-20 also had strong, positive correlations with depression, anxiety, and self-consciousness (Bagby, Taylor, et al., 1994).

The FFMQ was used to measure mindfulness. The FFMQ is a 39-item self-report instrument that measures five facets of mindfulness: (a) observing, (b) describing, (c) acting with awareness, (d) nonjudging, and (e) nonreacting. *Observing* is defined as the level at which one notices internal and external sensations and stimuli (e.g., "When I take a shower or a bath I stay alert to the sensations of water on my body"). *Describing* is defined as the level at which one is able to describe their observations (e.g., "I am good at finding the words to describe my feelings"). *Acting with awareness* is defined as the level at which one is in the present moment and paying attention to one's activity and

experiences (e.g., "I find it difficult to stay focused on what's happening in the present"). Nonjudging is defined as the level at which one avoids evaluating one's experiences and observations (e.g., "I criticize myself for having irrational or inappropriate emotions"). *Nonreacting* is defined as the level at which one is able to notice internal and external observations without reacting to them (e.g., "I perceive my feelings and emotions without having to react to them"). The FFMQ is measured using a 5-point Likert-type scale ranging from 1 (never or very rarely true) to 5 (very often or always true). The FFMQ provides a global score for mindfulness and individual subscale scores. A sample of male and female undergraduate students was used to norm the FFMQ (Baer et al., 2006). The instrument was found to measure distinct aspects of mindfulness. An exploratory factor analysis indicated that the five-factor model accounted for 33% of the variance and was a good fit. Confirmatory factory analysis further concluded that the model was a good fit. The FFMQ has been reported to have strong internal consistency with Cronbach's alpha of .75 for nonreactivity, .83 for observing, .87 for acting with awareness, .91 for describing, .87 for nonjudging, and .96 for the full scale score (Baer et al., 2006).

The self-kindness subscale of the SCS was used to measure self-kindness. The SCS is a 26-item instrument with six subscales: *self-kindness* (e.g., "When I'm going through a very hard time, I give myself the caring and tenderness I need") versus *self-judgment* ("When I see aspects of myself that I don't like, I get down on myself"), *common humanity* ("When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people") versus *isolation* ("When I fail at

something that's important to me I tend to feel alone in my failure"), and *mindfulness* ("When something upsets me I try to keep my emotions in balance") versus *overidentification* ("When I fail at something important to me I become consumed by feelings of inadequacy"). The SCS was normed on samples of male and female undergraduate students and male and female practicing Buddhists. Acceptable internal consistency has been reported for all subscales, with the *self-kindness* subscale having a reported alpha of .77 (Neff, 2003). Construct validity was obtained through significant correlations with self-criticism (r = -.65, p < .01), social connectedness (r = .41, p < .01), depression (r = -.51, p < .01), and anxiety (r = -.65, p < .01) scales (Neff, 2003). The SCS demonstrated acceptable three week test-retest reliability for the self-kindness subscale (.88). For the purpose of this study, the unit of analysis will be the self-kindness subscale score.

A demographic questionnaire was created by the researcher to collect relevant information including: age, stage of breast cancer, date of last adjuvant treatment, type of adjuvant treatment received, date of last surgical treatment, and type of surgical treatment received.

### **Procedures**

An online survey was constructed using Survey Monkey software. Permission to perform the pilot study was requested and approved by the University of North Carolina at Greensboro's Institutional Review Board. After approval was obtained, a recruitment email was sent to members of a cancer survivor wellness group. The members of the cancer survivor wellness group were selected from the same group; however, only ten of the 14 members of the group were selected to receive recruitment emails. Participants

were selected to participate based on the availability of an email address. The recruitment email included a link to the web-based surveys and information about an incentive to participate. The incentive to participate included two \$25 Target gift cards. Informed consent was provided and obtained by requesting participants to click a button to agree to participate in the study in order to proceed to the pilot study. Participants who wished to be included in the incentive drawing were asked to provide their mailing address. The surveys took 18 to 30 minutes to complete. Data were uploaded from Survey Monkey into an Excel spreadsheet and then uploaded again into an SPSS (SPSS, 2010) database. Although the pilot study sample size was inadequate for meaningful analyses and conclusion, the results of the first question are reported in Appendix C. Research questions 2, 3, and 4 were not analyzed due to small sample size.

Although it is not possible to draw any conclusions from these findings because it is based on a sample of only 7 participants, there were a number of interesting findings that bear further exploration in the full study. First of all, the field testing of procedures and processes was quite successful. Participants seem to have no trouble navigating the online survey and indicated that the format and questions were clear. One participant did indicate that it was possible to have both a lumpectomy and a mastectomy. Accordingly, the Demographic Questionnaire was changed to add a response of "Both" to the question, "What type of surgery did you have?" Because one potential participant began the survey process but did not complete the surveys, it is possible that burnout or fatigue may be a consideration for the full study.

Of particular interest in the results was the strong correlation between Mindfulness and Quality of Life (r = .75). Although it is impossible to generalize from such a small sample, this does provide some preliminary evidence that the primary predictor and criterion variables in this study do indeed have a substantive relationship. Of the two potential mediating variables (Alexithymia and Self-kindness), Self-kindness in particular bears further attention as it correlates moderately with the predictor variable (Mindfulness; r = .55) and strongly with the outcome variable (Quality of Life; r = .92). Thus, although more data is needed to afford the luxury of generalizations with any confidence, it appears that Self-Kindness, as hypothesized, may serve to mediate the relationship between Mindfulness and Quality of Life. Whether this mediating path is more substantive than the direct path (i.e., how Mindfulness impacts Quality of Life directly) will be an interesting question for the full study.

### **Revisions to Full Study Based on Pilot Study**

Overall, the field-testing process was highly successful and there is only one change to the instrumentation that was made for the full study. On the Demographic Questionnaire, the question, "What type of surgery did you have," will now have an additional answer choice as "Both" will be added for participants who had both a lumpectomy and a mastectomy.

#### **CHAPTER IV**

#### RESULTS

The purpose of this study was to investigate the relationships among mindfulness, self-kindness, alexithymia, and quality of life in stages 0 to III breast cancer survivors. A secondary purpose was to consider how type of medical treatment and time since completion of medical treatment affected quality of life within this group. In this chapter, the results are presented. Results include demographic data describing the sample, descriptive statistics, and reliability coefficients of the measures used. Results of the analyses used to test each hypothesis also are presented.

# **Description of Sample**

Participants were recruited from three primary sources. The first source included Cancer Services, a nonprofit agency that provides free wellness services to cancer patients and survivors. The second source included past and present members of a cancer survivor psycho-educational wellness group, Finding Your New Normal (FYNN), which is sponsored by a regional cancer center in the Southeast. Twelve hundred breast cancer survivors who utilized services from Cancer Services received a mailing that included a recruitment advertisement for the web-based survey packet constructed using Survey Monkey. Further, approximately 85 breast cancer survivors who attended a breast cancer survivor conference sponsored by Cancer Services received survey packets that included administrator instructions, consent forms, and self-addressed stamped envelopes. Finally,

60 breast cancer survivors who attended FYNN also received survey packets that included administrator instructions, consent forms, and self-addressed stamped envelopes. Six participants reported having Stage 4 breast cancer and were removed from the dataset. This left a total of 133 participants. A power analysis suggested a sample size of 120 was necessary for a minimum power of .80 and a moderate effect size of .25 (Faul et al., 2007). This sample size was determined based on the required analysis for research question four, which required the largest sample size.

Prior to beginning data analyses, missing values were replaced with average scores for individual participants on the given subscale. In accordance to scale developer's instructions, certain items for the FACT-B, TAS-20, FFMQ, and SCS were reverse coded before total scale values were computed.

In addition to data collection from the four instruments used in the study (FACT-B, TAS-20, FFMQ, and SCS), demographic data were collected, including age, ethnicity, cancer stage, and medical treatment. Medical treatment demographics included the type of surgery (none, lumpectomy, or mastectomy), type of adjuvant therapy (none, radiation, chemotherapy, both), and use of hormone therapy. Also, participants were asked if they had any mindfulness training and if they maintained a mindfulness practice.

Demographics were calculated for the entire sample and is summarized in Table 2.

All 133 participants were female breast cancer survivors, given that the study was designed to investigate this population. The average age of participants was 59.66 (SD = 9.45). The majority of the participants identified as White (n = 116, 87.2%).

Variable	M	SD	n	%
Age	59.66	9.45	126	94.7
Ethnicity				
American Indian			1	0.8
Asian			0	0.0
Black, African-American			13	9.8
Native Hawaiian			0	0.0
White			116	87.2
Hispanic, Latina			0	0.0
Multiracial			1	0.8
Stage				
0			13	9.8
I			58	43.6
II			38	28.6
III			15	11.3
Unsure/Missing			9	6.8
Surgery				
None			0	0.0
Lumpectomy			62	46.6
Mastectomy			70	52.6
Adjuvant Tx				
None			28	21.1
Radiation			29	21.8
Chemotherapy			17	12.8
Both			56	42.1
Hormone Tx				
Yes			60	45.1
No			70	52.6
Fime since Completion of Tx				
Ongoing			21	15.8
< 6 months			27	20.3
6 months to 1 year			10	7.5
> 1 year			69	51.9
Mindfulness Training				
Yes			31	23.3
No			99	74.4
Actively Practice Mindfulness				
Yes			17	12.8
No			90	67.7

Smaller percentages identified as Black, African-American (n = 13, 9.8%), American Indian (n = 1, .8%), and Multiracial (n = 1, .8%). Stages 0 to III breast cancer were included in the study, although the majority of participants indicated that they were diagnosed with either Stage I (n = 58, 43.6%) or Stage II (n = 38, 28.6%) breast cancer. Thirteen participants reported a Stage 0 diagnosis (9.8%), 15 reported Stage III (11.3), and 9 were unclear about their diagnosis or missing data (6.8%). All participants had either a lumpectomy (n = 62, 44.6%) or a mastectomy (n = 70, 52.6%) for surgical treatment of their breast cancer. Not all participants, however, received adjuvant therapies. Twenty-eight participants (21.1%) received no adjuvant therapy. Nearly half (n = 56, 42.1%) of all participants received both radiation and chemotherapy treatments. Twenty-nine (21.8%) received only radiation treatment and 17 participants (12.8%) received only chemotherapy treatment. Hormone therapy was split relatively evenly with 60 participants (45.1%) receiving hormone therapy and 70 (n = 52.6%) not receiving therapy. Although the majority of the sample completed their treatment over a year ago (n = 69, 51.9%), 21 (15.8%) were still undergoing hormone therapy, 27 (20.3%) finished treatment less than six month ago, and 10 (7.5%) finished between six months and one year ago. The majority of participants had no training in mindfulness (n = 99, 74.4%) or current practice (n = 90, 67.7%).

## **Descriptive Statistics for Instrumentation**

Means and standard deviations for the total scales of the FACT-B, TAS-20, and FFMQ and the self-kindness subscale of the SCS were calculated for the total sample to assess how much variance existed for participant responses. Norms for the FACT-B

were taken from a study of nearly 400 breast cancer patients (Brady et al., 1997). Current study results revealed participants had lower means scores of quality of life compared to the population norm. Norms for the TAS-20 were developed using two comparison samples of undergraduate students and psychiatric patients (Bagby, Parker, et al., 1994). Results of the current study revealed that the current sample had a similar mean (M = 54.86, SD = 11.33) to the psychiatric population (M = 54.45, SD = 13.48) more so than the undergraduate student population (M = 47.48, SD = 10.96). Nearly one third of the current sample (28%) scored in the high alexithymia range, over one third (33%) scored in the moderate alexithymia range, and 64% scored in the cumulative moderate to high alexithymia range.

Norms for the FFMQ were formed on four samples, including student, community, highly educated, and meditation populations, however norms for the total scale were not published by the original authors (Baer et al., 2008). The FFMQ scores for the current sample (M = 135.35, SD = 19.62) were substantially higher, however, than the scores found by Banner (2009) for a similar sample of breast cancer survivors (M = 113.43, SD = 17.75). Norms for the self-kindness subscale of the SCS were developed on an undergraduate student population (Neff, 2003). Interestingly, results of the current study revealed a similar although slightly higher mean (M = 3.46, SD = .86) than found among the student population (M = 3.05). It is not possible from this data to tease out the disease versus age effects on self-kindness, but the difference in scores is interesting. See

Table 3
Sample Score Ranges, Means, Standard Deviations, and Norms (N = 133)

Instrument	Possible Range	Sample Range	Scale Mean	Scale SD	Norm Mean	Norm SD
Functional Assessment of Cancer Therapy- Breast Total Scale	0-144	40-139	110.94	19.92	112.8	20.9
Toronto Alexithymia Scale-20 Total Scale	20-100	20-86	54.86	11.33	47.48- 54.45	10.96- 13.48
Five Facet Mindfulness Questionnaire Total Scale	39-195	94-186	135.37	19.62	113.43	17.75
Self-Compassion Scale Self-Kindness Subscale	1-5	1-5	3.46	.86	3.05	.75

Cronbach's alphas were computed as a measure of internal consistency for the total scales of the FACT-B, TAS-20, and FFMQ and the self-kindness subscale of the SCS. Table 4 compares the alpha coefficients of the current study with published studies. All alpha coefficients reached or exceeded acceptable reliability levels.

# **Research Questions and Hypotheses**

The goal of the study was to examine the relationships among mindfulness, self-kindness, alexithymia, and quality of life in female survivors of Stages 0 to III breast cancer. Therefore, four research questions and seven hypotheses were developed.

Table 4

Instrument Scale Reliabilities

Instrument	# of items	α in previous studies	α in current study
Functional Assessment of Cancer Therapy-Breast <b>Total Scale</b>	36	.90	.90
Toronto Alexithymia Scale <b>Total Scale</b>	20	.7886	.82
Five Facet Mindfulness Questionnaire Total Scale	39	.92	.91
Self-Compassion Scale Self-Kindness Subscale	5	.78	.86

# Research Question 1/Hypotheses 1a-c

Research Question 1 explored the effect of time since completion of treatment on mindfulness, alexithymia, self-kindness, and quality of life in the full study sample. Hypothesis 1a suggested that a time since completion of treatment would have a significant effect on quality of life, with quality of life being higher for those with greater time since completion of treatment. Based on a one-way ANOVA, however, there was no significant effect of time since completion of treatment on quality of life (F(3, 126) = 2.55, p > .05). Hypothesis 1a was not supported (see Table 5).

A Pearson product-moment correlation was used to analyze whether mindfulness was positively related to self-kindness and quality of life (Hypothesis 1b). As hypothesized, mindfulness was significantly related to self-kindness (r = .65) and quality of life (r = .47) at p < .01. Similarly, a Pearson product-moment correlation was used to

test whether alexithymia would be negatively related to mindfulness and self-kindness, and quality of life (Hypothesis 1c). All three correlations were significant at p < .01. As indicated in Table 6, alexithymia was negatively correlated with mindfulness (r = -.56), self-kindness (r = -40), quality of life (r = -.44).

Table 5

One-way ANOVA for Time since Completion of Treatment

	Time Since Completion of Treatment	Group Means	df	Mean Square	F	Sig
	Ongoing	113.55	3	996.95	2.55	.059
EACT D	< 6 mo	101.71	123	391.77		
FACT-B	6 mo – 1 yr	117.36	126			
	> 1 yr	112.39				
	Ongoing	52.33	3	320.81	2.55	.059
TAG 20	< 6 mo	56.73	122	125.91		
TAS-20	6 mo – 1 yr	62.60	125			
	> 1 yr	53.43				
	Ongoing	139.86	3	547.577	1.44	.235
EEMO	< 6 mo	137.11	117	380.970		
FFMQ	6 mo − 1 yr	124.60	120			
	> 1 yr	135.88				
SCS:	Ongoing	3.74	3	1.29	1.83	.146
self-	< 6 mo	3.50	117	.70		
kindness	6 mo – 1 yr	2.96	120			
subscale	> 1 yr	3.45				

Similarly, a Pearson product-moment correlation was used to test whether alexithymia would be negatively related to mindfulness and self-kindness, and quality of life (Hypothesis 1c). All three correlations were significant at p < .01. As indicated in Table 6, alexithymia was negatively correlated with mindfulness (r = -.56), self-kindness (r = -.44).

Table 6

Pearson Product-Moment Correlations

Variable	QOL	Alexithymia	Mindfulness
QOL Alexithymia Mindfulness SK	44** .47** .37**	56** 40**	.65**

<sup>\*</sup>significant at the p < 0.01 level SK = self-kindness QOL = quality of life

## **Research Question 2/Hypothesis 2**

Research Question 2 examined the effect of cancer stage on quality of life, mindfulness, alexithymia, and self-kindness. Table 7 presents the results of a one-way ANOVA used to test the hypothesis that cancer stage would have a main effect on mindfulness, self-kindness, alexithymia, and quality of life. No significant results were found for mindfulness, self-kindness, and alexithymia. There was, however, a significant effect of cancer stage on quality of life (F(4, 132) = 2.76, p < .05). Post hoc comparisons

with Scheffe statistic revealed that significant mean differences existed between Stage O (M = 121.95) and Stage 3 (M = 98.42) breast cancer and quality of life.

Table 7

One-way ANOVA for Cancer Stage

	Stage of	Group		Mean		
	Cancer	Means	df	Square	F	Sig
FACT-B	0	121.95	4	1038.49	2.76	.03
	I	112.23	128	376.59		
	II	109.53	132			
	III	98.42				
TAS-20	0	53.08	4	100.74	.78	.54
	I	53.33	127	129.31		
	II	56.12	131			
	III	57.22				
FFMQ	0	141.15	4	503.06	.22	.93
	I	137.42	122	381.16		
	II	135.08	126			
	III	129.00				
SCS: self-	0	3.51	4	.16	.23	.93
kindness	I	3.45	121	.76		
subscale	II	3.56	125			
	III	3.38				

# Research Question 3/Hypotheses 3a-b

Research Question 3 explored the mean differences of surgery and adjuvant therapy on quality of life, mindfulness, alexithymia, and self-kindness. Two one-way ANOVAS were used to test whether breast cancer survivors who had mastectomies would report lower levels of mindfulness, self-kindness, and quality of life and higher levels of alexithymia (Hypothesis 3a) and whether breast cancer survivors who underwent chemotherapy would report mean differences in study variables (Hypothesis 3b). No significant results were found for surgery (see Table 8).

Table 8

One-way ANOVA for Surgery

	Type of	Group Means	df	Mean	F	Ç:a
	Surgery		ui	Square	_	Sig
FACT-B	Lumpectomy	111.34	1	26.70	.07	.80
	Mastectomy	110.44	130	401.76		
			131			
TAS-20	Lumpectomy	54.15	1	62.44	.48	.49
	Mastectomy	55.53	129	129.88		
			130			
FFMQ	Lumpectomy	138.02	1	847.53	2.22	.14
	Mastectomy	132.82	124	382.67		
			125			
SCS:	Lumpectomy	3.46	1	.02	.02	.88
self-	Mastectomy	3.44	123	.73		
kindness			124			
subscale						

The omnibus ANOVA indicated a significant effect of adjuvant therapy on quality of life (F(1, 131) = .07, p < .05). Post-hoc comparisons using Scheffe's statistic did not indicate any significant differences in FACT-B scores based on type of adjuvant therapy. See Table 9 for results.

## Research Question 4/Hypothesis 4

Research Question 4 asked about the relationships among mindfulness, quality of life, self-kindness, and alexithymia within a model that specified a relationship between mindfulness and quality of life mediated by self-kindness and alexithymia. The model hypothesized that mindfulness would not be a significant direct predictor of quality of life when self-kindness and alexithymia were entered into the model as mediators.

Table 9

One-way ANOVA for Adjuvant Treatment

	Type of Adjuvant Treatment	Group Means	df	Mean Square	F	Sig
FACT-B	None	117.70	3	1149.28	3.02	.03
	Radiation Only	114.80	126	381.12		
	Chemotherapy	103.12	129			
	Only	107.39				
	Both					
TAS-20	None	52.47	3	81.66	.62	.61
	Radiation Only	54.78	125	132.25		
	Chemotherapy	56.56	128			
	Only	55.65				
	Both					
FFMQ	None	137.35	3	203.12	.51	.67
	Radiation Only	137.96	120	395.33		
	Chemotherapy	131.35	123			
	Only	134.33				
	Both					
SCS: self-	None	3.43	3	.09	.12	.95
kindness	Radiation Only	3.46	119	.75		
subscale	Chemotherapy	3.35	122			
	Only	3.49				
	Both					

To test hypothesis 4, a causal step path analysis (Barron & Kenny, 1986) with follow-up bootstrapping (Preacher & Hayes, 2008) was conducted. See Figure 2 for the results of the path analysis and Table 10 for the results of the bootstrapping.

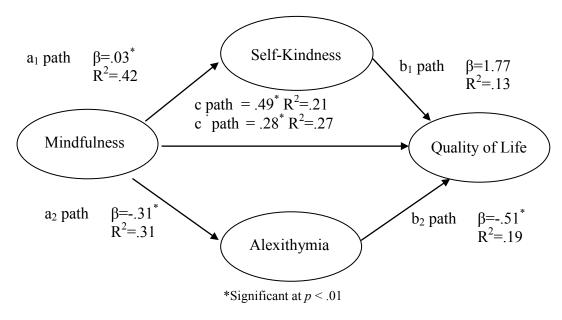


Figure 2. Path Analysis

Table 10

Path Analysis of Mediating Role of Self-Kindness and Alexthymia (N = 133)

Variable	$Adj R^2$	β	se	t	p
Mindfulness to Mediators (a paths)					
Self-Kindness	.42	.03	.00	9.54	.00*
Alexithymia	.31	31	.04	-7.10	.00*
Direct Effect of Mediators (b paths)					
Self-Kindness	.13	1.77	2.41	.74	.46
Alexithymia	.19	51	.17	-3.06	.00*
Total Effect of Mindfulness on QOL (c path)					
Mindfulness	.21	.49	.08	5.89	.00*
Direct Effect of Mindfulness on QOL (c' path)	.27	.28	.11	2.41	.02*
*p > .01 QOL = quality of life					
Causal Steps ab Path	Bootstrapping Bias Corrected 95% Confidence Interval		<u>l</u>		
Variable			Point Estin	mates	
		ower	Upper	r	Mediation
Self-Kindness .05	•	11	.18		no
Alexithymia .04		04	.31		yes

The overall model accounted for 27% of the variance in quality of life. The results indicated that mindfulness was found to be a significant predictor of quality of life based on the non-mediated direct path between mindfulness and quality of life (c path,  $\beta$  = .49), in and of itself accounting for 21% of the variance in quality of life. Using the causal steps method, mindfulness also was found to be a significant predictor of quality of life (c' path,  $\beta$  = .28). Further, mindfulness predicted self-kindness (a<sub>1</sub> path,  $\beta$  = .03,  $R^2$  = .42) and alexithymia (a<sub>2</sub> path,  $\beta$  = -.31,  $R^2$  = .31). Self-kindness, in and of itself, did not predict a significant amount of the variance in quality of life (b<sub>1</sub> path,  $\beta$  = 1.77,  $R^2$  = .13). Alexithymia, however, was a significant predictor of quality of life (b<sub>2</sub> path,  $\beta$  = -.31,  $R^2$  = .19).

The causal steps analysis demonstrated evidence of a mediating relationship between mindfulness and quality of life, given that the direct relationship (c path, t = 5.89, p = .00) between mindfulness and quality of life dropped when self-kindness and alexithymia were added to the model (c' path, t = 2.41, p = .02). Based on Preacher and Hayes (2008) follow-up bootstrapping method, the ab path for alexithymia was significant. Because the c' path for the direct impact of mindfulness on quality of life also was found significant, alexithymia is considered a partial mediator in the model.

### **Summary**

Results of the study were provided in this chapter. Descriptions of the sample, procedures, descriptive statistics, and reliability coefficients for each instrument also were provided. All instruments were found reliable and acceptable for the study sample. The data analysis for each hypothesis was presented and results were discussed.

Mindfulness was positively related to self-kindness and quality of life and negatively related to alexithymia. Alexithymia was negatively related to self-kindness and quality of life. A significant difference was found for Stage 0 and Stage III breast cancer survivor's quality of life. Types of surgery and adjuvant therapy were found to have non-significant effects on quality of life. Alexithymia was a significant mediator for mindfulness as a predictor of quality of life, though self-kindness was not. In Chapter V, the results for each hypothesis are discussed, limitations are provided, and implications for counselors and future research are presented.

#### **CHAPTER V**

#### **DISCUSSION**

In Chapter IV, the results of the study investigating mindfulness, quality of life, alexithymia, and self-kindness in Stages 0 to III breast cancer survivors were presented. In this chapter, a discussion of the results is provided, limitations of the study are outlined, and implications for counselors and areas of future research are discussed.

# **Overview of the Study**

One in eight women in the United States will develop breast cancer over the course of her lifetime (ACS, 2009a). Though incidences of breast cancer are increasing, so too is the survival rate (ACS, 2009a). The current survival rate for early stage breast cancer ranges from 84% to 98% (ACS, 2009a). Though survivorship is celebrated, painful emotional and physical outcomes can arise once treatment for cancer has ended (Allen et al., 2009; Broeckel et al., 1998; Burgess et al., 2005; Okuyama et al., 2000). These outcomes have the potential to affect breast cancer survivor's quality of life (Allen et al., 2009).

The stage of breast cancer, type of surgery and adjuvant treatment, and time since completion of treatment have been found to be important factors for breast cancer survivors (ACS, 2009a). Further, the variation of these factors has the potential to lower quality of life. Mindfulness may be a relevant construct for improving quality of life, as it has been positively associated with increased psychological well-being, decreased

medical symptoms, and fewer stress symptoms among those with stress-related illnesses, anxiety, cancer, and chronic pain (Baer, 2003; Carmody & Baer, 2008).

Further, researchers have reported high prevalence rates for alexithymia in women with breast cancer (Manna et al., 2007). Alexithymia has been found to be associated with lower levels of health-related quality of life in the general population (Mattila et al., 2009) as well as increased severity of fatigue and depression (Bodini et al., 2008), anxiety (Banner, 2009), chronic pain (Lumley, 1997), and lower levels of social support, increased stress, and decreased well-being (Posse et al., 2002). Therefore, assessing for alexithymia in a breast cancer survivor population may be an important aspect of improving quality of life.

Self-kindness is a positive construct that involves being gentle and kind toward one's self (Neff, 2003). Because counseling is rooted in a strength-based, developmental, wellness orientation (Fong, 1990; Myers, 1992; Witmer & Sweeney, 1992), it is accepted that positive thoughts and emotions should be nurtured for optimal well-being. No previous researchers have examined self-kindness in breast cancer survivors, but it seems theoretically conceivable that self-kindness could increase quality of life among this group.

Accordingly, this study was developed to explore the impact among mindfulness, quality of life, self-kindness, and alexithymia on survivors of Stages 0 to III breast cancer. Also, it was the intent of this study to explore how stage of cancer, time since completion of medical treatment, and type of surgery and adjuvant treatment impact mindfulness, quality of life, self-kindness, and alexithymia. Breast cancer survivors from

a cancer services organization in the Southeast and a cancer survivor psycho-education group completed instruments to measure the four study variables: mindfulness, quality of life, alexithymia, and self-kindness. Mindfulness was measured using the Five Factor Mindfulness Questionnaire (Baer et al., 2006), quality of life was measured using the Functional Assessment of Cancer Therapy-Breast (Brady et al., 1997), alexithymia was measured using the Twenty-Item Toronto Alexithymia Scale (Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994), and self-kindness was measured using the self-kindness subscale of the Self-Compassion Scale (Neff, 2003). One hundred and thirty-three participants completed the instruments and a demographic questionnaire.

Overall, results of the statistical analyses revealed the expected relationships among mindfulness, quality of life, alexithymia, and self-kindness. However, time since completion of treatment had no effect on the study variables. Cancer stage had a significant effect on quality of life but no other study variables. Type of surgery and adjuvant therapy had no effect on study variables. The analyses provided support for the hypothesized path model that mindfulness is a predictor of quality of life, and alexithymia was found to be a partial mediator of the relationship between mindfulness and quality of life. The results of each hypothesis are discussed below.

### **Discussion of Results**

## **Hypotheses 1a-c**

Hypothesis 1a suggested that time since completion of treatment would have an effect on quality of life. The results did not support hypothesis 1a, as time since completion of treatment had no significant impact on quality of life (F(3, 126) = 2.55, p > 0

.05). There are several ways to interpret this finding. First, 15.8% of the sampled reported they were receiving ongoing hormone therapy. For the purposes of this study, participants still taking hormone therapy were considered done with active treatment because many women with early stage breast cancer are prescribed to take hormone therapy following the completion of treatment to prevent new cancer cells from forming (National Cancer Institute [NCI], 2010). For example, Tamoxifen is a common antiestrogen drug prescribed to women with ductal carcinoma in situ (abnormal cell growth in the breast ducts) (NCI, 2010). Generally, Tamoxifen is prescribed for 2 to 3 years and up to five years. Tamoxifen has serious possible side effects that include stroke, blood clots, and uterine cancer, although more typical side effects include vaginal discharge, hot flashes, fatigue, nausea/vomiting, headaches, vaginal dryness, and irritation of the skin around the vagina (NCI, 2010). The possible side effects of taking hormone therapy could have impacted the effect of time since completion of treatment on quality of life in such a way that the expected improvement in quality of life for survivors a year or more out from active treatment was confounded. Another possible explanation for this result is that the developmental stage for emotional and physical transition into survivorship extends past the one year mark for completion of treatment. Allen et al. (2009) investigated the transition from breast cancer patient to survivor in women who had completed treatment in the prior 12 months and found that women reported significant levels of emotional and physical distress. Though time since completion of treatment had no significant effect on quality of life in this study it is possible that the categories of time since completion of treatment were too close together (i.e., under 6

months, 6 months to a year, and over a year). Perhaps, time since completion of treatment would have had a more powerful effect on quality of life if the categories had been extended to specific time intervals past 12 months. For example, would there be a significant effect of time since completion of treatment on quality of life for women who completed treatment in the past 6 months compared to 2.5 years out?

Hypothesis 1b suggested that mindfulness would be positively related to quality of life and self-kindness. The results supported this hypothesis, in that mindfulness had a significant positive relationship with quality of life (r = .47, p < .01) and self-kindness (r = .47, p < .01)= .65, p < .01). Previous studies have found similar results for the relationship between mindfulness and quality of life in active breast cancer patients and newly diagnosed breast cancer patients (Carlson et al., 2004; Witek-Janusek et al., 2008). This study confirms that mindfulness is an important factor for quality of life in breast cancer survivors. One possible explanation for this finding is that breast cancer survivors who have an increased awareness of their own suffering may be more likely to pay attention to the suffering of others. Rancour (2008) wrote that this heightened awareness for other's suffering may increase positive emotions such as gratitude and understanding. Not surprisingly, mindfulness also was positively related to self-kindness in breast cancer survivors, a positive construct. A possible explanation for the positive relationship between mindfulness and self-kindness in breast cancer survivors is that women who have higher levels of mindfulness find it easier to be gentle and kind to themselves during difficult emotional and physical transitions. As women transition away from the security of weekly medical appointments and lose the assurance that their health is being

monitored closely by capable medical staff, women mindful of their fears and grievances may experience a sense of universality with other breast cancer survivors going through similar transitions. This connection with other survivors may elicit emotional space to be self-kind and self-soothing.

Self-kindness also was found to be significantly positively related to quality of life (r = .37, p < .01). It may be that developing positive qualities, such as self-kindness, can serve to build personal resources and reduce intrusive negative thoughts and avoidant coping. In a study of breast cancer survivors at 3, 6, 9, and 12 months post-mastectomy surgery, women who used avoidance at the initial baseline reported lower levels of quality of life 12 months post-surgery (van de Wiel, Geerts, & Hoekstra-Weebers, 2008). It may be that avoiding distressing thoughts and emotions contributes to lower quality of life. Self-kindness involves letting go of harsh judgments and self-criticisms in favor of loving and gentle acceptance (Neff, 2003). It's possible that self-kindness could help breast cancer survivors embrace post-treatment thoughts and emotions. Because limited research has been conducted on self-kindness, further research is needed to investigate further the relationship between self-kindness and quality of life.

Hypothesis 1c suggested that alexithymia would be negatively related to mindfulness, quality of life, and self-kindness. The results supported this hypothesis. Alexithymia was significantly negatively related to mindfulness (r = -.56, p < .01), quality of life (r = -.44, p < .01), and self-kindness (r = -.40, p < .01). These results suggest that being able to identify, describe, and process emotions may be related to an easier transition into survivorship, though it is important to reiterate that these findings

are correlational and causation cannot be inferred. Fear of disease recurrence and heightened emotional distress are common for breast cancer survivors transitioning into survivorship (Allen et al., 2009). It is possible that being able to acknowledge these difficult emotions may have positive outcomes related to quality of life, mindfulness, and self-kindness. Previously, researchers have shown that alexithymia is associated with lower levels of health-related quality of life in the general population (Mattila et al., 2009, 2010). This study confirms this negative relationship between alexithymia and quality of life. Further, previous findings suggested breast cancer survivors have a higher prevalence rate of alexithymia (36%; Manna et al., 2007) than the general population (5-10%; Mattila et al., 2009); the rate of cumulative moderate to high levels of alexithymia for the current study was 64%.

## **Hypothesis 2**

Hypothesis 2 suggested that cancer stage would have an effect on mindfulness, quality of life, alexithymia, and self-kindness. Results partially supported this hypothesis. There were no significant effects of cancer stage on mindfulness, alexithymia, and self-kindness, but a significant effect did occur for quality of life. Post hoc comparisons revealed that significant mean differences existed between Stage O (M = 121.95, SD = 10.06) and Stage III (M = 98.42, SD = 21.34) breast cancer and quality of life. Stage 0 breast cancer has a 5 year survival rate of 100% compared to 67% for Stage III breast cancer (ACA, 2009b). Therefore, it is possible that survivors of Stage III breast cancer face increased existential concerns compared to women diagnosed with Stage 0 breast cancer. More specifically, a possible existential concern could relate to fear of

disease recurrence. In one study, 56% of women who received curative surgical treatment for breast cancer reported moderate to high levels of fear of disease recurrence (van den Beuken-van Everdingen, Peters, Rijke, Schouten, van Kleef, & Patijn, 2008). Furthermore, in that study fear of disease recurrence was negatively correlated to quality of life. In another study of breast cancer survivors who were on average 47 months posttreatment, nearly one quarter (23.6%) of women reported to have moderate to high fear of disease progression (Mehnert, Berg, Henrich, & Herschback, 2009). Similar to the previous study, fear of disease progression was significantly negatively correlated with quality of life. Stage of breast cancer was found to have no effect on fear of disease progression, however, participants with Stage 0 were not included in this study, rather only Stages 1 to 1V were included. Further research is needed to understand the internal process and existential concerns that may arise for breast cancer survivors, including how quality of life might be impacted. Results for the impact of cancer stage on quality of life should be interpreted with caution, given that four analyses were run at the same time. Future studies replicating the results are warranted.

## Hypotheses 3a-b

Hypothesis 3a suggested that women who had more invasive surgery (mastectomy) would report lower levels of mindfulness, self-kindness, and quality of life and higher levels of alexithymia. This hypothesis was not supported. A possible explanation for this finding is that surgery in general, regardless of the type, impacts quality of life, mindfulness, self-kindness, and alexithymia. Data were not available to test whether having surgery versus no surgery would impact the four study variables, as

all 133 participants had surgery. It is feasible to hypothesize that any breast disfigurement is traumatic and has the potential to impact the study variables. Still, this was a surprising finding based on the current literature. Skrzypulec, Tobor, Drosdzol, and Nowosielski (2009) found that women who experienced more invasive surgery (i.e., total mastectomy versus partial mastectomy) reported that the intensity of post-traumatic stress after the operation had a stronger impact on anxiety and depression for women with a total mastectomy versus a partial mastectomy. A logical extrapolation from this would be that women who underwent a mastectomy versus a lumpectomy would experience a greater impact on the variables in the current study, but such was not the case. It may be, however, that the type of surgery is less important. Wronska, Stepien, and Kulik (2003) compared women who had mastectomies to a healthy control group and found that overall quality of life difference between groups was insignificant. However, there were significant differences between groups related to the physical well-being and emotional well-being subscales of the FACT-B. It is possible that role functioning and social functioning are less impacted by surgery, thereby affecting the overall findings related to quality of life.

Hypothesis 3b suggested that chemotherapy would have more of a deleterious impact on mindfulness, quality of life, self-kindness, and alexithymia than radiation. Results indicated that the type of adjuvant therapy had a significant impact on quality of life, but the differences were not distinguishable in post hoc analyses. One possible explanation for this is that small differences occurred across groups that provided power to the analysis but not enough to be distinguished in post hoc analyses. There were no

significant results for mindfulness, self-kindness, and alexithymia. Further research is needed to distinguish the impact of adjuvant therapy on quality of life. Chemotherapy has many late onset side-effects such as neuropathy, early-onset menopause, fatigue, and memory problems ("chemo brain") that have the potential to impact quality of life (ACA, 2009a). Because results were significant for the impact of adjuvant therapy on quality of life, future studies are warranted to flush out exactly what type of adjuvant therapy impacts quality of life.

## **Hypothesis 4**

Hypothesis 4 suggested a model specifying a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness would account for a statistically significant amount of variance for quality of life. Results indicated that the model was significant, accounting for 27% of the variance in quality of life. Consistent with the findings of previous researchers (Carlson et al., 2004; Witek-Janusek et al., 2008), mindfulness was a strong predictor of quality of life, in and of itself accounting for 21% of the variance. Although this information is correlational and causation cannot be inferred, the strength of this relationship is striking. Additionally, alexithymia was a significant mediator. Although the results indicated alexithymia was a significant mediator, it is more accurate to consider alexithymia a partial mediator, given that the direct relationship between mindfulness and quality of life was still significant when alexithymia was entered into the model. In order for alexithymia to be considered a full mediator, the direct relationship between mindfulness and quality of life must be non-significant. Because alexithymia was a partial mediator for mindfulness and quality of

life and had a significant direct correlation to quality of life, alexithymia may be an important construct for breast cancer survivors and warrant additional attention both clinically and in research. As was found in this study, previous researchers have found alexithymia to be related to a decreased quality of life (Mattila et al., 2009, 2010). It is important to understand that alexithymia might have potential to further lower the direct impact of mindfulness on quality of life. If mindfulness is thought of as an enhancer of quality of life and alexithymia is thought of as detraction from quality of life then alexithymic breast cancer survivors may be at risk for losing the positive impact of mindfulness on quality of life. Accordingly, alexithymia seems to be an important attribute related to quality of life, but additional research is warranted to further tease out the role of alexithymia among breast cancer survivors.

### Limitations

The results of the current study provide valuable information regarding the importance of mindfulness and quality of life for breast cancer survivors. Also, this study provided insight into the mediating qualities of self-kindness and alexithymia. Finally, the current study provided information about the importance of stage of cancer and type of surgery and adjuvant treatment for breast cancer survivors. As with all research studies, however, limitation exist that contextualize the findings.

The study used web-based survey methodology, which has clear limitations. Surveys rely on participant self-report, which requires participants to have a sense of self-awareness and report accurately. Clearly, this is not always the case. In using surveys, there is a risk that participants report limited awareness and accuracy, thereby increasing

the possibility for a stronger negative or positive bias than truly exists. Further, web-based survey methods limit the generalizability of the results, given the inherent lack of accurate sample description. It is not possible to know for certain who participated in the study, as recruitment advertisements may have been forwarded to unknown participants. Also, it is not possible to know how non-respondents differ from respondents, limiting the external validity of the findings.

Another limitation of the study included measuring mindfulness and alexithymia. Levels of mindfulness and alexithymia could have impacted reporting. People with higher levels of mindfulness may have heightened self-awareness compared to those with lower levels of mindfulness, which could possibly have affected how participants assessed their quality of life, self-kindness, and alexithymia. The same could be said for alexithymia. Participants who struggle to identity feelings and emotions may have underreported emotional outcomes related to quality of life.

This study investigated outcomes for only female breast cancer survivors.

Though less than one percent of breast cancer survivors are male (ACA, 2009a), it is important to consider how the male experience of breast cancer may be different from the female experience. This is especially relevant to self-kindness given the generalization that breast cancer is a feminine disease.

Another limitation involved the sampling methods. The majority of the sample came from three sources, a cancer services organization in the Southeast called Cancer Services, a regional breast cancer survivor conference sponsored by Cancer Services, and a breast cancer survivor wellness group. It is unclear how generalizable the results are to

other breast cancer survivors. Further, many women from Cancer Services chose not to participate. A recruitment brochure was mailed to 1200 breast cancer survivors and the total sample included 133 participants, which equated to a return rate of 11%. It is unclear why possible participants chose to not complete the surveys. One explanation could be that those who chose not to participate in the study were too fatigued or were experiencing more negative symptoms than those who chose to participate. This explanation might indicate a possible positive bias in the results such that this sample may have over-reported higher quality of life.

A final limitation to the study included how the data were collected for the variable time since completion of treatment. Participants were asked when they completed their final treatment in an open-ended question. As a result, some participants reported the year they finished rather than the month and year. This provided a challenge for data analysis. A better way to collect this information in the future would be to have multiple choice options listed in months since completion of treatment.

### **Implications for Counselors**

The current study provides some empirical support for the usefulness of mindfulness as a quality of life intervention for breast cancer survivors. The results provide evidence that breast cancer survivors with higher levels of mindfulness generally report higher levels of quality of life. Although causation cannot be inferred from the correlational data in this study, the strength of the relationship between mindfulness and quality of life suggest that it may be important for counselors who work with breast cancer survivors to assess mindfulness and incorporate mindfulness training into their

counseling. This could be done formally or informally. Formal assessment of mindfulness for breast cancer survivors would include using a mindfulness assessment such as the Five Facet Mindfulness Questionnaire (FFMQ; Baer et al., 2006). It is possible, however, to informally assess for mindfulness as well. Informal assessment of mindfulness would include observing how breast cancer survivors attribute judgment to their experience with breast cancer. For example, do they blame themselves for their diagnosis? Do they berate themselves for not being able to jump back into a lifestyle that included working full-time and managing a household? Also, an informal assessment would include how attached clients are to their former pre-cancer self. Do they accept that their body is different now? Do they accept that their perspective on life may be different now? Do they strive to return to exactly who they were and how things in life were for them before cancer? Further informal assessment of mindfulness would include assessing their level of self-care. Do they feel a sense of hurry and time pressure? Do they avoid self-care opportunities (exercising, meditating, eating well) because they do not believe they have time for these activities? These are just some of the ways to informally assess mindfulness in breast cancer survivors. Once the level of mindfulness has been determined, it is recommended that counselors integrate mindfulness training into the counseling process to increase quality of life among cancer survivors.

The results of this study also demonstrated a positive relationship between mindfulness and self-kindness. A possible implication for counselors includes using mindfulness interventions (e.g., mindfulness training, yoga, meditation) to increase self-kindness in breast cancer survivors. Mindfulness and self-kindness have been found to

be important components related to understanding, appreciating, and being touched by one's suffering (Neff, 2003). It is feasible that increased mindfulness and self-kindness may be important factors in helping breast cancer survivors fully experience and accept their journey with cancer.

Another implication to the study involves the relationship between self-kindness and quality of life. Until this point, self-kindness was theoretically associated with happiness, peace, and life enhancement (Germer, 2009). Results from this study support a significant positive bivariate relationship between self-kindness and quality of life. Therefore, it is recommended that counselors work to foster and encourage self-kindness in breast cancer survivors as a way to increase their quality of life and support them through the difficult transition from patient to survivor. Interventions might include (a) helping survivors give themselves permission to still not feel well, although treatment has ended, (b) helping survivors to elicit support from loved ones who expect them to be *back to normal*, (c) helping survivors to accept the parts of themselves that they do not like, and (d) helping survivors to identify parts of themselves they enjoy and appreciate.

Results from this study implied that alexithymia plays a key role via an inverse relationship to quality of life, mindfulness, and self-kindness among breast cancer survivors. Because alexithymia is a form of emotional restriction, these findings further imply that it is important to be able to identify emotions, describe and express emotions, and accept contact with emotions for breast cancer survivors. Though it is important to remember that the results are correlational, not causal, struggling with emotional

expression is related to decreased quality of life. This implies that is may be important for counselors to help breast cancer survivors increase emotional expression skills.

Improving emotional expression skills may involve elements of mindfulness. Having a nonjudgmental awareness of the present moment may help breast cancer survivors begin to learn how to identify their emotions and gain contact with their emotions. Similarly, observing, noticing, and attending to sensations also may help survivors notice and connect with their emotions. Therefore, it is recommended that counselors use mindfulness training with breast cancer survivors who struggle with emotional expression. This could be done in either individual or group settings.

Similar to mindfulness, self-kindness also may improve emotional expression skills in breast cancer survivors. Breast cancer survivors who lean toward emotional restriction may find it easier to express themselves if they are open to their own suffering, which is an essential aspect of self-kindness. Further, releasing harsh judgments and viewing one's self with a sense of gentleness and love may facilitate openness to experiencing unwanted emotions. Therefore, it is recommended that counselors use interventions to enhance self-kindness in order to help breast cancer survivors improve emotional expression.

### **Recommendations for Future Research**

As with any study, the current study raises certain questions that warrant additional research attention. One, in particular, is the finding that mindfulness is strongly related to quality of life. Researchers have begun to examine the impact of mindfulness training on cancer survivors (Lengacher et al., 2009). Additional research is

warranted to further tease out the efficacy of such programs and the mechanisms by which this change occurs.

Further, the current study examined a mediating analysis for mindfulness, quality of life, self-kindness, and alexithymia. Because the model was found to be significant but alexithymia was a partial mediator and self-kindness was not a significant mediator, a future study examining self-kindness and alexithymia as possible moderators may be warranted. Because mindfulness significant impacted self-kindness and alexithymia, and alexithymia significantly impacted quality of life in the path analysis, it is clear they are important constructs to investigate related to quality of life. The fact that self-kindness and alexithymia did not fully mediate the path between mindfulness and quality of life does not mean that these variables are unimportant in understanding quality of life among breast cancer survivors. More research attention is warranted.

Results of the casual path analysis indicated that alexithymia, in particular, shows promise as an important factor in a multivariate consideration of breast cancer survivor quality of life. The initial causal steps analysis suggested that alexithymia served a partial mediating function but failed to account for full mediation of mindfulness and quality of life.

An additional limitation of the current study is that the sample size precluded examination of the individual facets of mindfulness, which have been previously demonstrated to be related to, but distinct from, one another (Baer et al., 2006). Follow-up research with a larger sample is warranted to investigate the facets of mindfulness that are most important for breast cancer survivors.

An additional area of research that warrants attention is the role of time since completion of treatment. Results from the current study were not significant; however, methodological limitations, including the categories of time since completion that were used and the lack of participants who were more further removed temporally from their treatment could have contributed to this finding. Little empirical research has examined the developmental process from initial diagnosis, active treatment, transition into survivorship, and long-term survivorship. It is reasonable to hypothesize that developmental transitions occur but additional empirical work is needed in this area. Future longitudinal studies could begin to investigate possible developmental models of the entire cancer experience, with a focus on survivorship stages. As well, future short-term research is needed to understand how survivors transition initially and long-term.

### Conclusion

This study examined mindfulness, quality of life, self-kindness, and alexithymia in survivors of stages 0 to III breast cancer. Stage of cancer, time since completions of treatment, and type of surgery and adjuvant therapy also were considered. One hundred and thirty-three breast cancer survivors participated in this study. Data were analyzed using correlations, ANOVAs, and causal path analysis with follow-up bootstrapping. Results supported the hypotheses that a positive relationship would exist among mindfulness, self-kindness, and quality of life and a negative relationship would exist among alexithymia and the three other study variables. Further, results supported the impact of mindfulness on quality of life and suggested self-kindness and alexithymia are important factors to consider for breast cancer survivors.

Implications for counselors included (a) conducting mindfulness assessments and interventions to improve quality of life in breast cancer survivors, (b) helping to foster self-kindness in breast cancer survivors, and (c) helping breast cancer survivors process their emotional experience of cancer and transition into survivorship. Additionally, it was recommended that counselors help improve emotional expression skills for those who struggle with emotional restriction.

The current study supports further research into the moderating affects of self-kindness and alexithymia on mindfulness, the subscales of mindfulness that are most relevant to breast cancer survivors, longitudinal studies on survivorship, and short-term studies on the initial transition into survivorship. Using improved sampling methods and research designs would enhance understanding about mindfulness, quality of life, self-kindness, and alexithymia for women who transition into breast cancer survivorship.

There are still unknowns related to mindfulness, quality of life, self-kindness, and alexithymia in survivors of Stage 0 to III breast cancer. Still, it seems clear that mindfulness, self-kindness, and alexithymia are important areas to explore further as work is done to gain knowledge about and improve the quality of life of breast cancer survivors navigating through a challenging transitional process.

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# APPENDIX A

# INFORMED CONSENT

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## **Long Consent Form (Pilot Study)**

#### UNIVERSITY OF NORTH CAROLINA AT GREENSBORO

### CONSENT TO ACT AS A HUMAN PARTICIPANT: LONG FORM FOR PROCEDURE TESTING

Project Title: Mindfulness and Quality of Life Among Breast Cancer Survivors: The Mediating Role of Self-Kindness and Alexithymia

Project Director: <u>Dr. Craig Cashwell, Ph.D.</u>	
Participant's Name:	

#### What is the study about?

This is a research project. Quality of life for breast cancer survivors is an important consideration. Therefore, counselors strive to create more effective interventions. The goal of this study is to gain an increased understanding of the mediating characteristics of how mindfulness impacts quality of life in breast cancer survivors in order to inform clinical interventions.

#### Why are you asking me?

We invite you to participate in this study to help us provide information to counselors and counselor educators regarding the mediating affects of self-kindness and alexithymia on mindfulness and quality of life. You have been selected for this survey based on your experience surviving breast cancer. All participants in this study must be women over the age of 18 who have completed treatment for breast cancer in the last two years.

### What will you ask me to do if I agree to be in the study?

This survey will take approximately 20-25 minutes to complete. You can decide to not participate at any time. If you feel discomfort at any time, feel free to stop taking the survey.

### What are the dangers to me?

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. However, there is a possibility that answering some of the questions could cause an emotional reaction. If you have any emotional concerns related to filling out the questions you may contact Alli Forti at 617-504-2498 to schedule a counseling appointment. Questions regarding your rights as a participant in this project can be answered by calling Mr. Eric Allen at (336) 256-1482. Questions regarding the research itself can be answered by Dr. Craig Cashwell by calling (336) 334-3427.

## Are there any benefits to me for taking part in this research study?

Participants may benefit from the personal satisfaction of contributing to the field of psycho-oncology and counselor education as this study will lead to increased information for the educational community of counselors and counselor educators.

## Will I get paid for being in the study? Will it cost me anything?

There are no costs to you for participating in this study. If you choose to complete the study and provide a mailing address, you will be entered into a drawing for a \$20 gift card to Target.

## How will you keep my information confidential?

All information obtained in this study is strictly confidential unless disclosure is required by law. Data will be stored on a password protected laptop and external hard drive. Data will not be identifiable to individual participants. Data collection procedures are anonymous.

Absolute confidentiality of data provided through the Internet cannot be guaranteed due to the limited protections of Internet access. Please be sure to close your browser when you finished so no one will be able to see what you have been doing.

#### What if I want to leave the study?

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way.

### What about new information/changes in the study?

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

#### **Voluntary Consent by Participant:**

By clicking on the "I Agree" button you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. You are agreeing that you are 18 years of age or older.

# APPENDIX B

# **INSTRUMENTS**

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## **Demographic Questionnaire**

What is your age?

What is your race/ethnicity?

What is your sex?

When were you diagnosed with breast cancer?

What breast cancer stage were you diagnosed with?

Did you have surgery to treat the breast cancer?

What type of surgery did you have?

Did you have radiation to treat your breast cancer?

Did you have chemotherapy to treat your breast cancer?

Did you receive hormone therapy to treat your breast cancer?

When was your last treatment for breast cancer?

# **Cancer Services Questions**

Circle the number that corresponds with how much you agree or disagree with the following statements. Give only once answer for each statement.

Circle 0 if you STRONGLY DISAGREE Circle 1 if you MODERATELY DISAGREE Circle 2 if you NEITHER AGREE NOR DISAGREE Circle 3 if you MODERATELY AGREE Circle 4 if you STRONGLY AGREE								
I'm concerned about accessing the medical care I need:								
0	1	2	3	4				
I worry about the effect of stress on my diagnosis:								
0	1	2	3	4				
I worry about the change in my appearance as a result of my treatment:								
0	1	2	3	4				
I'm concerned about how I'm coping with my diagnosis:								
0	1	2	3	4				
I'm worried about how to effectively communicate with friends and family about my diagnosis:								
0	1	2	3	4				
I'm bothered by side effects of treatment:								
0	1	2	3	4				
I understand my diagnosis:								
0	1	2	3	4				
Answer YES or NO for the following questions.								

Cancer Services was able to meet my needs. YES or NO

If Cancer Services had not been available to me, I know of other resources that would've been able to help me. YES or NO

#### **FACT-B**

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

0=Not at all

1=A little bit

2=Somewhat

3=Quite a bit

4=Very much

## **PHYSICAL WELL-BEING**

1. I have a lack of energy	0	1	2	3	4
2. I have nausea	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4. I have pain	0	1	2	3	4
5. I am bothered by side effects of treatment	0	1	2	3	4
6. I feel ill	0	1	2	3	4
7. I am forced to spend time in bed	0	1	2	3	4
SOCIAL/FAMILY WELL-BEING					
8. I feel close to my friends	0	1	2	3	4
9. I get emotional support from my family	0	1	2	3	4
10. I get support from my friends	0	1	2	3	4
11. My family has accepted my illness	0	1	2	3	4
12. I am satisfied with family communication about my illness	0	1	2	3	4
13. I feel close to my partner (or the person who is my main support)	0	1	2	3	4

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next section.					
14. I am satisfied with my sex life	0	1	2	3	4
EMOTIONAL WELL-BEING					
15. I feel sad	0	1	2	3	4
16. I am satisfied with how I am coping with my illness	0	1	2	3	4
17. I am losing hope in the fight against my illness	0	1	2	3	4
18. I feel nervous	0	1	2	3	4
19. I worry about dying	0	1	2	3	4
20. I worry that my condition will get worse	0	1	2	3	4
FUNCTIONAL WELL-BEING					
21. I am able to work (include work at home)	0	1	2	3	4
22. My work (include work at home) is fulfilling	0	1	2	3	4
23. I am able to enjoy life	0	1	2	3	4
24. I have accepted my illness	0	1	2	3	4
25. I am sleeping well	0	1	2	3	4
26. I am enjoying the things I usually do for fun	0	1	2	3	4
27. I am content with the quality of my life right now	0	1	2	3	4
ADDITIONAL CONCERNS					
28. I have been short of breath	0	1	2	3	4
29. I am self-conscious about the way I dress	0	1	2	3	4
30. One or both of my arms are swollen or tender	0	1	2	3	4

31. I feel sexually attractive	0	1	2	3	4
32. I am bothered by hair loss	0	1	2	3	4
33. I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
34. I worry about the effect of stress on my illness	0	1	2	3	4
35. I am bothered by a change in weight	0	1	2	3	4
36. I am able to feel like a woman	0	1	2	3	4
37. I have certain parts of my body where I experience pain	0	1	2	3	4

### T A S - 20

Using the scale provided as a guide, indicate how much you agree or disagree with each of the following statements by circling the corresponding number. Give only one answer for each statement.

Circle 1 if you STRONGLY DISAGREE
Circle 2 if you MODERATELY DISAGREE
Circle 3 if you NEITHER DISAGREE NOR AGREE
Circle 4 if you MODERATELY AGREE
Circle 5 if you STRONGLY AGREE

1.	I am often confused about what emotion I am feeling.	1	2	3	4	5
2.	It is difficult for me to find the right words for my feelings.	1	2	3	4	5
3.	I have physical sensations that even doctors don't understand.	1	2	3	4	5
4.	I am able to describe my feelings easily.	1	2	3	4	5
5.	I prefer to analyze problems rather than just describe them.	1	2	3	4	5
6.	When I am upset, I don't know if I sad, frightened, or angry.	1	2	3	4	5
7.	I am often puzzled by sensations in my body.	1	2	3	4	5
8.	I prefer to just let things happen rather than to understand why they turned out that way.	1	2	3	4	5
9.	I have feelings that I can't quite identify.	1	2	3	4	5

10.	Being in touch with emotions is essential.	1	2	3	4	5
11.	I find it hard to describe how I feel about people.	1	2	3	4	5
12.	People tell me to describe my feelings more.	1	2	3	4	5
13.	I don't know what's going on inside me.	1	2	3	4	5
14.	I often don't know why I am angry.	1	2	3	4	5
15.	I prefer talking to people about their daily activities rather than their feelings.	1	2	3	4	5
16.	I prefer to watch "light" entertainment shows rather than psychological dramas.	1	2	3	4	5
17.	It is difficult for me to reveal my innermost feelings, even to close friends.	1	2	3	4	5
18.	I can feel close to someone, even in moments of silence.	1	2	3	4	5
19.	I find examination of my feelings useful in solving personal problems.	1	2	3	4	5
20.	Looking for hidden meanings in movies or plays distracts from their enjoyment.	1	2	3	4	5

# **Five Facet Mindfulness Questionnaire**

Subject number_						
				Date		
	_	tatements using t cribes <u>your own c</u>	-			
1	2	3	4	5		
never or very rarely true	rarely true	sometimes true	often true	very often or always true		
1. When I'	'm walking. I delil	perately notice the	sensations of m	v bodv moving.		
	<u> </u>	s to describe my fe		y 00 <b>4</b> y 1110 (111 <b>g</b> .		
	٥	ng irrational or ina	Ü	ions.		
	•	d emotions without				
		nd wanders off and	_			
		oath, I stay alert to	_			
boo	dy.					
7. I can ea	sily put my beliefs	s, opinions, and ex	pectations into v	words.		
8. I don't p	pay attention to wl	nat I'm doing beca	use I'm daydrea	ming, worrying, or		
oth	nerwise distracted.					
9. I watch	my feelings withou	out getting lost in th	nem.			
10. I tell m	nyself I shouldn't	be feeling the way	I'm feeling.			
11. I notice	e how foods and d	rinks affect my the	oughts, bodily so	ensations, and		
em	otions.					
12. It's har	rd for me to find the	he words to describ	e what I'm thin	king.		
13. I am ea	asily distracted.					
14. I believ	ve some of my tho	oughts are abnorma	al or bad and I sl	nouldn't think that		
wa	y.					
15. I pay a	ttention to sensati	ons, such as the wi	nd in my hair o	r sun on my face.		
16. I have	16. I have trouble thinking of the right words to express how I feel about things					

17.	I make judgments about whether my thoughts are good or bad.
18.	I find it difficult to stay focused on what's happening in the present.
19.	When I have distressing thoughts or images, I "step back" and am aware of
	the thought or image without getting taken over by it.
20.	I pay attention to sounds, such as clocks ticking, birds chirping, or cars
	passing.
21.	In difficult situations, I can pause without immediately reacting.
22.	When I have a sensation in my body, it's difficult for me to describe it
	because I can't find the right words.
23.	It seems I am "running on automatic" without much awareness of what I'm
	doing.
24.	When I have distressing thoughts or images, I feel calm soon after.
25.	I tell myself that I shouldn't be thinking the way I'm thinking.
26.	I notice the smells and aromas of things.
27.	Even when I'm feeling terribly upset, I can find a way to put it into words.
28.	I rush through activities without being really attentive to them.
29.	When I have distressing thoughts or images I am able just to notice them
	without reacting.
30.	I think some of my emotions are bad or inappropriate and I shouldn't feel
	them.
31.	I notice visual elements in art or nature, such as colors, shapes, textures, or
	patterns of light and shadow.
32.	My natural tendency is to put my experiences into words.
33.	When I have distressing thoughts or images, I just notice them and let them
	go.
34.	I do jobs or tasks automatically without being aware of what I'm doing.
35.	When I have distressing thoughts or images, I judge myself as good or bad,
	depending what the thought/image is about.
36.	I pay attention to how my emotions affect my thoughts and behavior.
37.	I can usually describe how I feel at the moment in considerable detail.
38.	I find myself doing things without paying attention.
39.	I disapprove of myself when I have irrational ideas.

## **Self-Compassion Scale**

### HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost	İ			Almost
never 1	2	3	4	always 5
•	_		•	
1.	I'm disapp	oroving and	l judgmen	ntal about my own flaws and inadequacies.
2.	When I'm	feeling do	wn I tend	to obsess and fixate on everything that's wrong.
3.	When thin	gs are goir	ng badly fo	for me, I see the difficulties as part of life that
	everyone g	goes throug	gh.	
4.	When I thi	nk about n	ny inadeq	uacies, it tends to make me feel more separate
	and cut of	f from the	rest of the	e world.
5.	I try to be	loving tow	ards myse	elf when I'm feeling emotional pain.
6.	When I fai	l at someth	ning impo	ortant to me I become consumed by feelings of
	inadequac	y.		
7.	When I'm	down and	out, I rem	aind myself that there are lots of other people in
	the world	feeling like	e I am.	
8.	When time	es are reall	y difficult	t, I tend to be tough on myself.
9.	When som	nething ups	sets me I t	try to keep my emotions in balance.
10	. When I fe	el inadequa	ate in som	ne way, I try to remind myself that feelings of
	inadequac	y are share	ed by most	et people.
11	. I'm intole	rant and in	npatient to	owards those aspects of my personality I don't
	like.			
12	. When I'm	going thro	ough a ver	ry hard time, I give myself the caring and
	tenderness	I need.		
13	. When I'm	feeling do	wn, I tend	d to feel like most other people are probably
	happier th	an I am.		

14. When something painful happens I try to take a balanced view of the situation
15.I try to see my failings as part of the human condition.
16. When I see aspects of myself that I don't like, I get down on myself.
17. When I fail at something important to me I try to keep things in perspective.
18. When I'm really struggling, I tend to feel like other people must be having an
easier time of it.
19. I'm kind to myself when I'm experiencing suffering.
20. When something upsets me I get carried away with my feelings.
21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
22. When I'm feeling down I try to approach my feelings with curiosity and
openness.
23. I'm tolerant of my own flaws and inadequacies.
24. When something painful happens I tend to blow the incident out of proportion
25. When I fail at something that's important to me, I tend to feel alone in my
failure.
26. I try to be understanding and patient towards those aspects of my personality
don't like.

## APPENDIX C

## PILOT STUDY METHODS AND RESULTS

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### **Pilot Study**

The primary purpose of the pilot study was to test procedures for feasibility and clarity and to insure research integrity for the larger study. The first research question of the full study was analyzed using pilot study data in order to test data analysis procedures and create and test the database to be used for the full study.

## **Participants**

The pilot study sample included 7 female survivors of Stages 0 to III breast cancer who had completed surgery and adjuvant therapy within the past two years. Over half of the sample had received a lumpectomy and the entire sample received adjuvant therapy that included chemotherapy and radiation. Further, over half of the sample was still receiving hormone therapy when they completed the assessments. The mean age of the sample was 51.3 and all of the women from the sample were recruited from a cancer survivor wellness group. Additional demographic data can be found in Table 1.

#### Instrumentation

Participants completed web-based surveys that included a demographic questionnaire, the Functional Assessment of Cancer Therapy-Breast (FACT-B; Brady et al., 1997), the Twenty-Item Toronto Alexithymia Scale (TAS-20; Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994) the Five Facet Mindfulness Questionnaire (FFMQ; Baer et al., 2006), and the Self-Compassion Scale (SCS; Neff, 2003). Additionally, participants were asked to provide open-ended feedback on the procedures, including how long they spent completing the surveys and what type of general feedback they had about their experience completing the surveys.

Quality of life was measured using the FACT-B. The FACT-B is a 44-item self-report instrument with a 5-point Likert-type scale ranging from 0 (not at all) to 4 (very much). The FACT-B has six subscales that include *physical well-being* (e.g., "I have a lack of energy"), *social/family well-being* (e.g., "I get emotional support from my family"), *relationship with doctor* (e.g., "My doctor is available to answer my questions"), *emotional well-being* (e.g., "I feel sad"), *functional well-being* (e.g., "I am able to work"), and *additional concerns* as they relate to breast cancer (e.g., "I feel sexually unattractive"). The FACT-B was normed on two samples of women with breast cancer. Internal consistency for the six subscales ranged from 0.63 to 0.86 and the alpha coefficient for the overall score for quality of life was 0.90. Acceptable support was provided for three and seven day test-retest reliability (.88 for breast cancer scale and .85 for total score). Construct validity was evidenced through strong, positive correlations with another quality of life measure (r = .86, p < .001) and expected negative correlations for a mood assessment (r = .70, p < .001; r = -.66, p < .001) (Brady et al., 1997).

The TAS-20 was used to measure alexithymia. The TAS-20 is a 20-item instrument with three scales related to alexithymia: (a) difficulty identifying feelings (e.g., "I am often confused about what emotion I am feeling"), (b) difficulty describing feelings (e.g., "It is difficult for me to find the right words for my feelings"), and (c) externally oriented thinking (e.g., "I prefer to analyze problems rather than just describe them"). All items are measured on a 5-point Likert-type scale ranging from 1 (not at all like me) to 5 (completely like me). Total scores can range from 20 to 100. Higher scores are equated with higher levels of alexithymia (i.e., difficulty expressing emotions). The

TAS-20 was normed on samples of male and female university undergraduate students (mean age was 21.1) and male and female psychiatric out-patients (mean age was 36.62) (Bagby, Parker, et al., 1994; Bagby, Taylor, et al., 1994). Bagby, Parker, et al. (1994) reported a Cronbach's alpha of 0.81 for the total score, indicated acceptable internal consistency. Bagby, Parker, et al. (1994) also reported acceptable three week test-retest reliability (0.77, p < 0.01). Validity was obtained by administering the TAS-20 and four additional assessments of psychological mindedness, need for cognition, psychosomatics, and a personality inventory to undergraduate students and clients from a metropolitan outpatient clinic (Bagby, Taylor, et al., 1994). The TAS-20 had a strong, negative correlation with psychological mindedness, need for cognition, positive emotions, and assertiveness. The TAS-20 also had strong, positive correlations with depression, anxiety, and self-consciousness (Bagby, Taylor, et al., 1994).

The FFMQ was used to measure mindfulness. The FFMQ is a 39-item self-report instrument that measures five facets of mindfulness: (a) observing, (b) describing, (c) acting with awareness, (d) nonjudging, and (e) nonreacting. *Observing* is defined as the level at which one notices internal and external sensations and stimuli (e.g., "When I take a shower or a bath I stay alert to the sensations of water on my body"). *Describing* is defined as the level at which one is able to describe their observations (e.g., "I am good at finding the words to describe my feelings"). *Acting with awareness* is defined as the level at which one is in the present moment and paying attention to one's activity and experiences (e.g., "I find it difficult to stay focused on what's happening in the present"). *Nonjudging* is defined as the level at which one avoids evaluating one's experiences and

observations (e.g., "I criticize myself for having irrational or inappropriate emotions"). *Nonreacting* is defined as the level at which one is able to notice internal and external observations without reacting to them (e.g., "I perceive my feelings and emotions without having to react to them"). The FFMQ is measured using a 5-point Likert-type scale ranging from 1 (never or very rarely true) to 5 (very often or always true). The FFMQ provides a global score for mindfulness and individual subscale scores. A sample of male and female undergraduate students was used to norm the FFMQ (Baer et al., 2006). The instrument was found to measure distinct aspects of mindfulness. An exploratory factor analysis indicated that the five-factor model accounted for 33% of the variance and was a good fit. Confirmatory factory analysis further concluded that the model was a good fit. The FFMQ has been reported to have strong internal consistency with Cronbach's alpha of .75 for *nonreactivity*, .83 for *observing*, .87 for *acting with awareness*, .91 for *describing*, .87 for *nonjudging*, and .96 for the full scale score (Baer et al., 2006).

The self-kindness subscale of the SCS was used to measure self-kindness. The SCS is a 26-item instrument with six subscales: *self-kindness* (e.g., "When I'm going through a very hard time, I give myself the caring and tenderness I need") versus *self-judgment* ("When I see aspects of myself that I don't like, I get down on myself"), *common humanity* ("When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people") versus *isolation* ("When I fail at something that's important to me I tend to feel alone in my failure"), and *mindfulness* ("When something upsets me I try to keep my emotions in balance") versus *over-*

identification ("When I fail at something important to me I become consumed by feelings of inadequacy"). The SCS was normed on samples of male and female undergraduate students and male and female practicing Buddhists. Acceptable internal consistency has been reported for all subscales, with the *self-kindness* subscale having a reported alpha of .77 (Neff, 2003). Construct validity was obtained through significant correlations with self-criticism (r = -.65, p < .01), social connectedness (r = .41, p < .01), depression (r = .51, p < .01), and anxiety (r = -.65, p < .01) scales (Neff, 2003). The SCS demonstrated acceptable three week test-retest reliability for the self-kindness subscale (.88). For the purpose of this study, the unit of analysis will be the self-kindness subscale score.

A demographic questionnaire was created by the researcher to collect relevant information including: age, stage of breast cancer, date of last adjuvant treatment, type of adjuvant treatment received, date of last surgical treatment, and type of surgical treatment received.

#### **Procedures**

An online survey was constructed using Survey Monkey software. Permission to perform the pilot study was requested and approved by the University of North Carolina at Greensboro's Institutional Review Board. After approval was obtained, a recruitment email was sent to members of a cancer survivor wellness group. The members of the cancer survivor wellness group were selected from the same group; however, only ten of the 14 members of the group were selected to receive recruitment emails. Participants were selected to participate based on the availability of an email address. The recruitment email included a link to the web-based surveys and information about an

incentive to participate. The incentive to participate included two \$25 Target gift cards. Informed consent was provided and obtained by requesting participants to click a button to agree to participate in the study in order to proceed to the pilot study. Participants who wished to be included in the incentive drawing were asked to provide their mailing address. The surveys took 18 to 30 minutes to complete. Data were uploaded from Survey Monkey into an Excel spreadsheet and then uploaded again into a SPSS (SPSS, 2010) database.

## **Data Analysis and Overview of Results**

Although the pilot study sample size was inadequate for meaningful analyses and conclusion, the results of the first question are reported below. Research questions 2, 3, and 4 were not analyzed due to small sample size.

<u>Research Question 1:</u> What are the relationships among time since completion of treatment (in months), mindfulness, alexithymia, self-kindness, and quality of life for female survivors of breast cancer (Stages 0-III)?

<u>Hypothesis 1a:</u> Time since completion of treatment will be significantly positively correlated with quality of life.

<u>Hypothesis 1b:</u> Mindfulness will be significantly positively related with self-kindness and quality of life.

<u>Hypothesis 1c:</u> Alexithymia will be significantly negatively correlated with mindfulness, self-kindness, and quality of life.

Research Question 2: What are the effects of cancer stage (0-III) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

<u>Hypothesis 2:</u> Cancer stage will have main effects on all study variables, such that persons with higher stages of cancer will report lower levels of mindfulness, self-kindness, and quality of life, and higher levels of alexithymia.

Research Question 3: What are the effects of surgery (i.e., none, lumpectomy, or mastectomy) and adjuvant therapy (i.e., none, hormone therapy, chemotherapy, or radiation) on mean scores of mindfulness, alexithymia, self-kindness, and quality of life among female survivors of breast cancer?

<u>Hypothesis 3a:</u> Type of surgery will have a main effect on all study variables, such that persons who experience more invasive surgery will report lower levels of mindfulness, self-kindness, and quality of life, and a higher level of alexithymia.

<u>Hypothesis 3b:</u> Chemotherapy will have an effect on mean scores of mindfulness, self-kindness, alexithymia, and quality of life, such that persons who receive chemotherapy will report lower levels of mindfulness, self-kindness, and quality of life, and higher levels of alexithymia.

Research Question 4: What are the relationships among mindfulness, alexithymia, self-kindness, and quality of life within a path model that specifies a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness?

<u>Hypothesis 4:</u> The hypothesized path model specifying a relationship between mindfulness and quality of life mediated by alexithymia and self-kindness will account for a statistically significant amount of the variance in quality of life.

Frequencies were computed for the demographic questions. At the time of data collection, two participants were receiving ongoing hormone therapy and over half (57.1%) had received hormone therapy as part of their adjuvant therapy. Further, nearly half (42.9%) of the participants had undergone a mastectomy as part of their surgical treatment. More descriptive results are reported in Table 1.

Table 1

Demographic Description of the Pilot Study

Variable		Mean (Range)	n	%
Age		51.3 (41-56)		
Stage of breast	Stage 0		0	0.0
cancer	Stage I		2	28.6
	Stage II		3	42.9
	Stage III		2	28.6
Time since	Ongoing (Hormone Tx)		2	28.6
completion of	< 6 months		2	28.6
treatment	6 months to one year		1	14.3
	> one year		2	28.6
Type of surgical	None		0	0.0
treatment	Lumpectomy		4	57.1
	Mastectomy		3	42.9
	Both		0	0.0
Type of adjuvant	None		0	0.0
therapy	Radiation only		0	0.0
1.7	Chemotherapy only		0	0.0
	Both		7	100.0
Hormone therapy	Yes		4	57.1
1 7	No		3	42.9

Additionally, descriptive statistics and Chronbach alphas were calculated for each of the study instruments. Albeit based on a sample size too small to make generalizations, results support the reliability of these instruments with the target population. This information is provided in Table 2.

Table 2

Pilot Study Instrument Descriptive Statistics

Instrument	M	SD	α	# of items
Functional Assessment	106.6	18	.93	37
of Cancer Therapy-				
Breast				
Twenty-Item Toronto	50.9	12.7	.87	20
Alexithymia Scale				
Five Facet Mindfulness	3.3	.49	.93	39
Questionnaire				
Self-Compassion Scale:	3.3	.65	.73	26
Self-Kindness Subscale				

<sup>\*</sup>inadequate sample size

**Hypothesis 1.** A Pearson Product-Moment Correlation Coefficient was used to test hypothesis 1 regarding the relationship between time since completion of treatment, quality of life, alexithymia, mindfulness, and self-kindness. Self-kindness was found to be significantly positively correlated with quality of life (r = .92, p < .05). Although this finding is inconclusive because of the small sample size, it bears attention in the full study. Because these findings are based on a very small sample, the model was maintained for the full study. It is possible, though, that self-kindness serves as a primary

predictor of quality of life rather than as a mediating variable. No other correlations were significant.

Table 3

Pilot Study Pearson Product-Moment Correlations

Variable	Time	QOL	Alexithymia	Mindfulness
Time	_	_	_	
QOL	01	_	_	_
Alexithymia	22	25	_	_
Mindfulness	.67	.75	65	_
SK	.05	.92*	.07	.55

<sup>\*</sup>significant at the p < 0.05

**Hypotheses 2-4.** Because of the limited sample size, Hypotheses 2, 3a, 3b, and 4 were not tested.

#### **Discussion**

Although it is not possible to draw any conclusions from these findings because it is based on a sample of only 7 participants, there were a number of interesting findings that bear further exploration in the full study. First of all, the field testing of procedures and processes was quite successful. Participants seem to have no trouble navigating the online survey and indicated that the format and questions were clear. One participant did indicate that it was possible to have both a lumpectomy and a mastectomy. Accordingly,

the Demographic Questionnaire was changed to add a response of "Both" to the question, "What type of surgery did you have?"

Of particular interest in the results was the strong correlation between Mindfulness and Quality of Life (r = .75). Although it is impossible to generalize from such a small sample, this does provide some preliminary evidence that the primary predictor and criterion variables in this study do indeed have a substantive relationship. Of the two potential mediating variables (Alexithymia and Self-kindness), Self-kindness in particular bears further attention as it correlates moderately with the predictor variable (Mindfulness; r = .55) and strongly with the outcome variable (Quality of Life; r = .92). Thus, although more data is needed to afford the luxury of generalizations with any confidence, it appears that self-kindness, as hypothesized, may serve to mediate the relationship between Mindfulness and Quality of Life. Whether this mediating path is more substantive than the direct path (i.e., how Mindfulness impacts Quality of Life directly) will be an interesting question for the full study.