EXAMINING THE RELATIONSHIP BETWEEN INNER STRENGTH AND SYMPTOM BURDEN IN OLDER WOMEN WITH LYMPHOMA

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DEDICATION

For my two daughters Annie and Elizabeth,

two women of great inner strength.

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ABSTRACT

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Adults age 65 and older are the fastest growing population in the United States diagnosed with cancer; however, due to age and gender disparities older women are largely ignored in clinical trials. The purpose of this study was to examine the relationship between inner strength and symptom burden in older women with lymphoma. The secondary objective was to examine how age and time since diagnosis correlate with inner strength, symptom burden, and quality of life. Eighty women were recruited from an inpatient oncology unit at a large comprehensive cancer hospital.

Statistical analysis revealed that women who scored high in inner strength experienced significantly less symptom burden. Older age was also a significant predictor of quality of life. The older the woman, the greater her inner strength, and the lower her symptom burden. The inner strength scales of engagement and movement were the strongest elements in reducing symptom burden. This study contributes to the body of nursing research relevant to older women and affirms the theory of inner strength. Measurable nursing interventions are needed to support the lives of older women with and without cancer.

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CHAPTER I

INTRODUCTION

The United States is currently undergoing two unprecedented demographic shifts that have potential catastrophic health care, social, and financial repercussions. The first major demographic shift is the rapidly increasing population of adults born between 1946 and 1964, commonly called the baby boomer generation, as a result of access to improved medical technology and increased life expectancy. The second major demographic shift is the increasing numbers of people over the age of 65 developing cancer and/or living with side effects of cancer treatment. "These demographic shifts in our society are expected to exert substantial stressors on the nation's health care system, and highlight the need to address the shortcomings in cancer clinical trials and disparities in cancer care" (Smith, Smith, Hurria, Hortobagyi, & Bucholz, 2009, p. 2758).

Currently, 46% of all cancer survivors are 70 years of age or older. It has been projected that approximately 70% of all cancers will be diagnosed in older adults by 2030 (American Cancer Society, 2015). The United States Census Bureau estimated that the adult population age 65 and older was approximately 43.1 million in 2012. This population is expected to reach 83.7 million by the year 2050 (Ortman, Velkoff, & Hogan, 2014). The lack of clinical trials and age-specific interventions for cancer care in older adults has marginalized this population. This remains a serious dilemma because

"the most significant risk factor for the development of cancer is ageing" (Lichtman, Hurria, & Jacobson, 2014, p. 2521).

In the past decade, government and private sector agencies have begun to address age and gender disparities that predominate in cancer and survivorship care. The National Cancer Institute (NCI) and the National Comprehensive Cancer Network (NCCN) created senior adult guidelines for the management of cancer in older adults. The American Society of Clinical Oncologists (ASCO) has issued recommendations to improve evidence-based care in this population that promote research designs including adults aged 65 years and older (Hurria et al., 2015). The Institute of Medicine (IOM) acknowledges the importance of gender-specific research, recognizing that women and men have different health care needs and experience different symptoms and responses to treatment modalities (2010). Symptom burden is experienced differently in older men and woman and requires gender-related intervention to support this population from diagnosis through late survivorship. This study examined the relationship between inner strength and symptom burden in women 65 years and older with cancer. "Although the concept of enhancement of inner strength is not limited to ethnicity or gender, current theory development has focused on the gender-specific needs of women" (Dingley & Roux, 2013, p. 33).

The side effects of a cancer diagnosis and its subsequent treatment with chemotherapy, radiation, and or immunotherapy can affect an older woman's quality of

life (QOL). A majority of studies examining QOL in female cancer patients over the age of 65 have been conducted with breast cancer patients. Few research studies have examined QOL in older women with Lymphoma. A recent dedicated clinical trial that looked at disease characteristics, treatment, and survival in males and females aged 80 and older called for additional studies to "characterize the impact of treatment of diffuse large cell lymphoma on QOL among patients in this age group" (Williams et al., 2015, p. 1).

Oncology nursing has long recognized the enormous complexity of nursing care for the older adult. In 2006, Deborah Boyle chronicled the evolution of nursing focus and research in the care of older adults with cancer from 1975 to the present. Boyle highlighted eras of bias, advocacy, and action that have driven nursing science with respect to care of the older adult. "The concept of enhancement of inner strength is not limited to ethnicity or gender, current theory development has focused on the gender-specific needs of women" (Dingley & Roux, 2013, p. 33). This study examined the relationship between inner strength and symptom burden in women 65 aged years and older with cancer. Quality of life in this population was examined as a secondary variable.

Problem of Study/Statement of Purpose

Cancer is considered a chronic disease "that can negatively affect the biopsychosocial balance in cancer survivors and impede their progress along the cancer

trajectory" (Petty & Lester, 2014, p. 107). Although literature supports various interventions to help manage symptom burden, little has been written about how to identify, strengthen, support, and mobilize the inner strengths of female cancer survivors. The IOM (2011) report "Clinical Preventative Services for Women: Closing the Gap" recognized that "many factors shape the health and well-being of women outside the realms of clinical services. These factors include changes in women's concept of self-efficacy to promote health, and changes in women's self-empowerment to address their own health and wellness" (p. 21).

The purpose of this study was to examine the relationship between inner strength and symptom burden in older women living with a lymphoma diagnosis. Knowledge regarding the nexus of inner strength and symptom burden will inform the formulation and testing of nursing interventions to support improved well-being of older women with cancer.

Rationale for Study

Older cancer patients are living longer because of advances in treatment and cancer care, but are not necessarily living better. Clinical trials have under-represented older women with cancer, excluding this population from the benefits of evidence-based research. The 2008 IOM report entitled "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" recognized the importance of patient-centered care.

A cancer diagnosis is devastating and can cause worry and fear of sickness and death. These feelings can produce posttraumatic transformations (PTTs) of either

positive or negative stress (Kahana, Deimling, Sterns, & VanGunten, 2011), which can result in negative or positive coping styles during the cancer survivorship journey. According to the theory of inner strength, inner strength is precipitated by a challenging life event such as cancer. The plan of care for cancer patients should include interventions and resources to enhance cognitive, emotional, and physical outcomes. By developing inner strength, older women can achieve adaptive coping and positive adjustment to a cancer diagnosis and treatment, eventually creating for themselves a "new normal" way of life. "The new normal is characterized by a deep personal satisfaction experienced as a result of helping and supporting others, which in turn serves as a source of inner strength" (Dingley & Roux, 2013, p. 33).

Psychosocial care in oncology is emerging as a vital part of cancer care. "In addition to improving emotional well-being and mental health, provision of psychosocial care has been shown to yield better management of common diseases-related symptoms and adverse effects of treatment such as pain, and fatigue" (Jacobson, Holland, & Steensma, 2012, p. 1151). Coping studies among adult cancer survivors age 60 and older found that the most prominent coping strategies were planning and acceptance (Deimling et al., 2006). Breast cancer patients age 70 or older were who coped through optimism, mastery, spirituality, and social support had better outcomes with respect to life satisfaction, depression, and general health (Perkins et al., 2007). A study conducted by the Duke University Center for the Study of Aging and Human Development looked at coping strategies in response to stress in a sample of healthy adults ages 55 to 80.

Findings showed that older adults most effectively used passive strategies that modify perceptions of stress or the effective consequences of stress. "The findings support the importance of palliative coping strategies for personal well-being" (George & Siegler, 1982, p. 154).

A cancer diagnosis is life changing. Patients can use inner strength acquired through life's joys, stressful events, losses, and successes to improve their sense of well-being, strengthen coping strategies, and develop a sense of self-management and empowerment. Health and cancer research must consider the biological, psychosocial, psychological, demographic, and cultural differences that are inherent to women.

Theoretical Framework

The middle range Theory of Inner Strength will guide this study (Roux et al., 2001). The initial theory was developed inductively through a synthesis of narratives from five qualitative studies of women including: 1 - women with breast cancer (Roux, 1993); 2 - Stories of inner strength in a racially-mixed population of women (Moloney, 1995); 3 - coronary artery disease (Dingley, 1997); 4 - women with multiple sclerosis (Koob & Roux, 1999); and 5- psychological health of healthy women (Rose, 1990). A life-changing experience such as cancer, chronic illness, loss, adversity, or oppression becomes a radical stimulus for initiation of change to assure well-being. Lewis and Roux (2011) describe the inner strength theory as a process by which:

> (a) Anguish and searching encompasses the transition from the point of fear and shock experienced with a challenging life event to a point of acceptance; (b) connectedness describes the nurturing of supportive life's possibilities; (c) engagement describes self-determination and engaging in life's possibilities and

(d) movement describes the dimension of movement, rest, and balance of mind and body (p. 154).

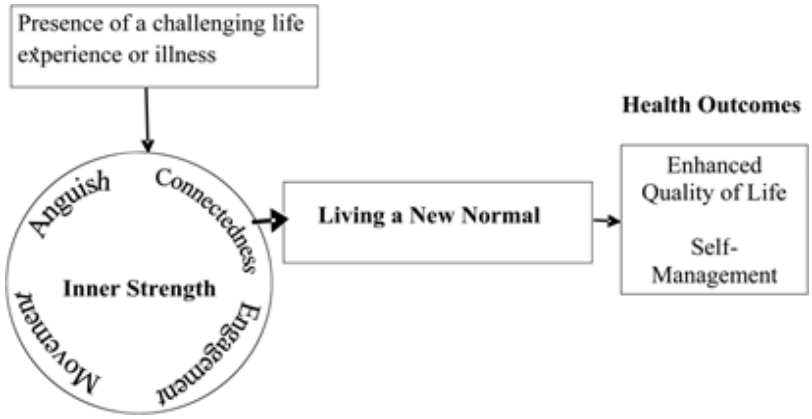

Figure 1: The theory of inner strength is a process of adjustment to a life challenge.

Development of inner strength can help women with cancer find new meaning and acquire a sense of mastery and self-determination as they adjust to their new normal. "Inner strength can be a positive healing force. Using the theory of inner strength, the enhancement of physical, emotional, spiritual, and social strengths assists a person to live as fully as possible" (Roux, Dingley, Lewis, & Grubs, 2004, p. 33). The theory of inner strength is projected to improve quality of life and foster self-management of life and health care while learning to live within a new normal (Roux, Dingley, & Bush, 2002).

Assumptions

The theory of inner strength (Dingley, 2008) assumes that:

1. Humans have the potential and the capacity to build inner strength.
2. A challenging life event or chronic health condition may act as a catalyst for the expansion and expression of inner strength.
3. Inner strength is a developmental process of growth and restoration of wholeness.

4. Inner strength is a central human resource that promotes well-being and healing.
5. Womens' experiences of inner strength are unique and gender specific.

Research Questions

The following research questions were proposed:

1. What is the relationship between the four subscales of inner strength—anguish, connectedness, engagement, and movement—as measured by the Inner Strength Questionnaire (ISQ), and the two subscale scores of the MD Anderson Symptom Inventory (MDASI) core items—symptom severity and symptom interference—in older female lymphoma survivors?
2. How do age and time since diagnosis correlate with the four ISQ subscale scores and the MDASI core items?
3. What is the relationship between the four self-reported ISQ subscale scores and quality of life (QOL) as measured by the Numeric Single Scale Assessment (NSSA)?

Definition of Terms

Inner Strength

Conceptual definition. "Inner strength is defined as having the capacity to build the self through a developmental process that positively moves the individual through the challenging events commonly experienced while living with a chronic illness" (Lewis & Roux, 2011, p. 154). It is the deeper and at times less apparent capacity or potential for effective action, durability, and endurance that is the essential part of the innermost being.

Operational definition. Women's inner strength will be measured using the ISQ in four domains: anguish, connectedness, engagement, and movement.

Symptom Burden

Conceptual definition. "Symptom burden: is defined as, "the subjective, quantifiable prevalence, frequency, and severity of symptoms that place a physiologic burden on patients and may produce multiple negative physical, psychological, and emotional patient responses" (Gapstur, 2007, p. 677).

Operational definition. Symptom burden will be measured using the MDASI core items scale. The MDASI has 19 items that comprise two parts: symptom severity and symptom interference.

Quality of Life

Conceptual definition. "Quality of life is a measure of an individual's ability to function physically, emotionally and socially within his/her environment at a level consistent with his/her own expectations" (Church, 2004, p. 8).

Operational definition. Quality of life will be measured by a single item scale called the NSSA. Each item in the NSSA has been independently validated and can be used independently. The NSSA items ask patients to describe their overall QOL for the past week and various aspects of well-being on a 0–10 scale, with 0 being "as bad as it can be" and 10 being "as good as it can be." The item, "How would you describe your overall quality of life?" can be used as a global QOL measure and should take less than one minute to complete (Sloan, Aaronson, Cappelleri, Fairclough, & Varricchio, 2002).

Limitations

The study population will consist of women over the age of 65 who are being treated for lymphoma at a national comprehensive cancer center in Houston, Texas. Although this heterogeneous population sample will reflect the relationship of inner strength and symptom burden experienced by patients from this institution, the information cannot be generalized to the national public, which may be more diverse than this sample.

Summary

Women aged 65 years and older have been marginalized as a group because of gender and age. The result of this disparity is limited clinical research and evidence-based care to support their survivorship. Leveraging inner strength in this unique patient population has the potential to dramatically impact their disease experience. The aim of this study was to examine the relationship between inner strength and symptom burden in older women with lymphoma to inform future interventional research.

CHAPTER II

REVIEW OF LITERATURE

Search Methods

Databases searched for relevant literature were CINAHL Complete, SocIndex with Full Text, Medline with Full Text, Academic Search Complete, Psychology & Behavioral Science Collection, Woman's Studies International Collection, and Google Scholar. Various combinations of the following keywords were used in the search: *inner strength*, *cancer*, *older women*, *hematologic cancer*, *symptom burden*, and *survivorship*. Articles were included if they were peer-reviewed and involved women over the age of 65. The initial search for articles was limited to those published between 2005 and 2015 using the keywords *inner strength*, *older women*, *symptom burden*, *cancer*, and *survivorshi*p. There were no articles that included all the key words in various forms, so the timeline was expanded to 1990 to 2015 and the keywords *women* and *older women with cancer* were added. The new search identified six qualitative studies that included the keywords *women* and *inner strength* and three quantitative research studies that examined the role of *inner strength* in quality of life among *older women with cancer*. There are gaps in the literature pertaining to the relationship between *inner strength* and *cancer symptom burden* in the literature search.

Inner Strength

Inner strength was first documented in nursing research literature in an article by Rose (1990) entitled, "Psychological Health of Women: A Phenomenological Study of Women's Inner Strength." Nine themes were generated from this study that supported psychological health in healthy women, including: quintessencing, centering, quiescence, apprehending intrication, introspecting, using humor, interrelating, having capacity, and embracing vulnerability. "For nursing to substantiate and accomplish a health and wellness orientation, there is a need for nursing research to focus on healthy functioning of individuals rather than on investigations in mental health that typically converge on illness" (Rose, 1990, p. 56).

The benefits of developing inner strength when faced with a life-changing event such as cancer are well documented in the literature. Development of inner strength showed efficacy in a diverse population of women with a variety of disease conditions, including: coronary artery disease (Dingley, Bush, & Roux, 2001), HIV (Haile, Landrum, Kotarba, & Trimble, 2002), multiple sclerosis (Koob, Roux, & Bush, 2002), older Hispanic women with chronic disease (Dingley & Roux, 2003), women from El Salvador during and after a civil war (Rutherford & Parker, 2003), myocardial infarction (Mendes & Roux, 2010), cancer patients (Dingley & Roux, 2013), and chronic health problems (Lewis & Roux, 2011). These studies identified common themes and characteristics experienced by women when faced with a life-changing situation. Dingley, Roux, and Bush (2000) described the defining attributes of inner strength as:

> A process of growth and transition, a point of confronting a life experience or event, a deepening of self- knowledge, a cognition of one's needs and sources to meet those needs, connectedness with others, and a focused and balanced interaction with the environment (p. 32).

Early nursing research used qualitative inquiry to characterize women's subjective experiences with cancer. Women experienced health within the context of breast cancer as an illness, and faced a shift in their life perspective (Moch, 1990). Women with stage IV breast cancer described inner strength as increasing self-worth, receiving help, reaching out, finding a purpose in life (Coward, 1990), and a process of reconstructing and integrating one's self (Kinny, Rodgers, Nash, & Bray, 2003). With the turn of the century, nursing research in women with cancer continued to further define the unifying concepts of inner strength. The realization of possessing inner strength is a process of development that can be used when faced with a devastating, life-threatening event such as a cancer diagnosis. Women begin to create a new normal—acknowledging fear; developing a new self; staying active; realizing harmony in their environment; connecting to family, friends, and a higher being (Roux, Bush, & Dingley, 2001); and "accepting the challenge to go on living, working actively on the healing process, finding new meaning in life, and introducing radical change in life" (Jensen, Back-Pettersson, & Segesten, 2000, p. 11). Women who lived with both intimate partner abuse and a cancer diagnosis reported having discovered their inner strength when diagnosed with cancer. Their focus became their own health, and with increased social support they made changes or left the abusive relationship (Speakman, Paris, Gioiella, & Hathaway, 2014).

The increasing population of older women surviving cancer has brought new focus to research on aging. Older women in rural Appalachia diagnosed with gynecologic cancers "acknowledged an inner strength that transcended how they viewed their prognosis for the future" (Allen & Roberto, 2013, p. 7). Another study showed that some older women were able to "move beyond the physical and emotional trauma of having breast cancer and adopted a state of positive adaptations as viewing their cancer as a bump in the road" (Loerzel & Aroian, 2013, p. 69).

More recent studies have been conducted by a Swedish group using a different theoretical/conceptual construct to explore inner strength in older men and women. In these studies, inner strength was measured using the Inner Strength Scale (ISS) theorized by Dr. B. Lundman, who examined inner strength within the context of connectedness, firmness, flexibility, and creativity. Inner strength was revealed as a source that promoted well-being in social relationships and improved functional status in people ages 85 years and older (Lundman et al., 2012). People aged 60-72 and critically ill found the presence of a family member as significant in finding inner strength (Alpers, Helseth, & Bergbom, 2012). A larger study in Sweden and Finland involving 6119 adults older than 65 years found that those with a disease had lower self-reported quality of life and a lower degree of measured inner strength. Conversely, those with a higher reported quality of life during illness had a higher measure of inner strength (Viglund, Jonsen, Strandberg, Lundman, & Nygren, 2014). The oldest men and women, ages 80 to 100 years, were found to have a higher measure of inner strength that correlated with higher

levels of independence, integrity, and enjoying life (Moe, Hellzen, Ekker, & Enmarker, 2013). A qualitative study used focus groups of elderly women to explore how inner strength increased coping capacities in frail older adults (Boman, Lundman, & Fischer, 2015). A study by Boman, Gustafson, Haggblom, Santamaki, & Nygren (2015) found that high levels of measured inner strength correlated with less depression in a group of older women living by the Baltic Sea. Three mixed-methods studies used qualitative and quantitative methods to explore how older women's narratives described their efforts to make the best of challenging situations and associated a strong sense of inner strength with better mental health. This study also reported a lower measure of inner strength in participants with mental illness. Most importantly, the study identified the constructs of inner strength in the older women (Boman, 2016).

According to Dingley and Roux (2013), "Quantitative testing to examine the relationships among the concepts of the Theory of Inner Strength and other potential variables is needed to support its application as a foundation for theoretically based assessments and interventions" (p. 32). This would enable clinicians to identify patients' needs and assist them in developing positive coping mechanisms to achieve the outcomes as described in the theory of inner strength: living a new normal, finding new meaning in life, a sense of well-being, self-determination and mastery, enhanced quality of life, and self-management. A quantitative study examined the role of inner strength in the quality of life and self-management of 107 older women. The study showed "that women who experience inner strength have enhanced quality of life and self-management abilities.

Understanding ways to facilitate inner strength may be valuable for women as they move through the recovery process and survivorship" (Dingley & Roux, 2014, p. 41). Community-based interventions can help cancer survivors and their families overcome adversity and fear of recurrence by incorporating family-centered interventions that build the inner strength of the individual and family (Roux, Solari-Twadell, & Ackers, 2015).

Symptom Burden

Patients with cancer experience multiple symptoms that can cause them psychological, emotional, and physical distress. These symptoms can either occur from the disease itself or from the treatment of their cancer. "The impact of these multiple symptoms upon the patient can be described as 'symptom burden', a concept that encompasses both the severity of the symptoms and the patient's perception of the impact of the symptoms" (Cleeland, 2007, p. 16). "Patients define 'symptom burden' as a loss of functional abilities along with psychological suffering, both of which are affected by the impact of specific severe symptoms" (Gill, Chakraborty, & Selby, 2012, p. 88). In elderly cancer survivors, comorbidities were associated with greater symptom burden and intensity (Beck, Gail, Caserta, Lindau, & Dudley, 2009).

Patients with lymphoma have considerable physical and psychological symptom burden that affects all phases of the illness and survivorship (Manitta, Zordan, Cole-Sinclair, Nandurkar, & Philip, 2011). Lymphoma is a hematological cancer for which important treatment discoveries have resulted in longer remissions and improved quality of life, resulting in a large population of short- and long-term survivors. Most of these

advances in treatment have been realized in younger patients, however the incidence of lymphoma increases with age. Given that the fastest growing population diagnosed with cancer are aged 65 years and older, it is important that older patients with hematologic cancers become a focal point of clinical trials (Marr, Jones, Jackson, & Osborne, 2011).

Survivorship in Older Women

The National Coalition for Cancer Survivorship (NCCS) states that, "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life" (Stovall, 2005, p. 1). This definition is also accepted by the National Cancer Institute (NCI) and the National Comprehensive Cancer Network (NCCN). The older adult diagnosed with cancer and undergoing treatment will experience side effects that impact their physical, psychological, emotional, and spiritual life. Survivorship can be very challenging in adults aged 65 and older because this population may have already experienced senescence and comorbidities associated with aging that compound the side effects of chemotherapy. "Even in the absence of disease, aging is accompanied by overall physiological declines. In 1975, the Duke longitudinal studies demonstrated declines in physical functioning, EEG abnormalities, impaired cerebral blood flow, and sleep disturbances" (George, Palmore, & Cohen, 2014, p. 61).

A gender gap exists even though females compromise the largest segment of the survivor population and the most common cancer is female breast cancer (Rao & Denmark-Wahnefried, 2006). Surviving cancer treatment can leave the older woman with a sense of distress and diminished physical function (Hurria et al., 2009), poor

psychosocial well-being (Robb et al., 2007), depression (Dingley & Roux, 2013), and decreased quality of life (Roiland & Heidrich, 2011). The NCCN recently issued new guidelines for cancer survivorship that add a new focus and include subtopics and recommendations for exercise, cognitive function, sleep disorders, anxiety and depression, immunization, and sexual function. But the one gap that remains, guidelines for the care of the older cancer survivor, instead are incorporated into the overall recommended survivorship guidelines therefore the unique needs of the older cancer survivor are not recognized in these guidelines.

The hematologic cancer survivorship clinic at MD Anderson Cancer Center manages patients who are at least five years out from diagnosis. The late effects of chemotherapy and side effects from radiation are monitored. Long-term surveillance monitors for late effects, psychosocial functioning, and nutrition, providing a passport plan for health to improve communication with the patient's primary care physician.

Quality of Life

Most studies of QOL among older women were conducted in populations of breast cancer survivors. The Iowa Women's Health Study compared elderly cancer survivors to women without cancer and found that inactive cancer survivors reported poorer QOL compared to the women without cancer. They reported diminished QOL with respect to general health, vitality, and physical function. The results of this comparison highlight an urgent need to help older female cancer survivors regain or maintain an active lifestyle (Blair, Robien, Inoue-Choi, Rahn, & Lazovich, 2016). In

older women with breast cancer, depression and symptom burden increased while QOL and physical function decreased (Salene et al., 2015).

Few research studies have examined QOL in older adults with lymphoma, which is surprising because advancing age is a major risk factor for developing lymphoma. QOL is a subjective measurement that is influenced by the type of lymphoma, any confounding comorbidities, and social living arrangements. The paucity of dedicated clinical trials in older women with lymphoma is staggering. Older patients diagnosed with non-Hodgkin's lymphoma in 2012 were reported to have a much higher long-term survival expectation compared to those diagnosed in 2008 (Proctor, Wilkinson, & Sieniawski, 2009). A secondary cross-sectional analysis that looked at demographics and disease characteristics associated with lymphoma and QOL in different age groups found that younger patients with lymphoma had lower QOL and greater difficulty coping with their diagnosis than older patients (Leak et al., 2013). They concluded that age is an important characteristic influencing QOL in cancer patients.

Lymphoma treatment has an immediate and possibly long-lasting effect on the older woman's entire gestalt. The geriatric assessment is a valid way to assess overarching health strengths, disabilities, comorbidities, and performance status and gain a solid understanding of the older woman's QOL.

Summary

This chapter reviewed literature related to the concept of inner strength and examined the premises of the theory of inner strength. Understanding the role of inner

strength in the literature discussed "may assist nurses and other health providers in identifying and facilitating positive coping styles and strategies for women cancer survivors" (Dingley & Roux, 2013, p. 32). Nursing has the direct responsibility, as well as the skill and knowledge to champion the development of inner strength in the older woman cancer patient to help her self-manage her illness and symptom burden. Nursing can contribute to, "Expanding the current general model of survivorship care to include a specialty on older adult survivor care would contribute to a better quality of life for the nations aging survivors" (Palos & Zandstra, 2013, p. 88). Knobf et al. (2015) created and drafted the research agenda for the Oncology Nursing Society, 2014-2018, which endorsed and encouraged research in aging populations to enhance protective factors in symptom burden and determine how lifestyle affects symptom burden and treatment responses of older adults.

CHAPTER III

COLLECTION OF DATA

This study used a cross-sectional design to examine the relationship between inner strength, as measured by the Inner Strength Questionnaire (ISQ); symptom burden, as measured by the MD Anderson Symptom Inventory – Core (MDASI-C); and quality of life as measured by the Numeric Single Scale Assessment (NSSA).

Setting

The population for this study was recruited female, hospitalized patients aged 65 and older with a primary diagnosis of lymphoma who were admitted to a 48-bed inpatient lymphoma service at the University of Texas MD Anderson Cancer Center in Houston, Texas. Inclusion criteria required at least one month from initial diagnosis to allow for diagnostic staging and treatment decision planning. Women's cancer research is currently focused on women with breast, ovarian, and uterine cancers, and few studies have examined women with lymphoma—with even fewer focused on older women with lymphoma.

Population and Sample

Women were eligible to participate in the study if they met the following inclusion criteria: a) aged 65 or older; b) diagnosed with lymphoma; c) admitted at least one month or longer since primary lymphoma diagnosis; d) admitted into the inpatient lymphoma service; e) able to speak and read English (one of the study instruments [ISQ]

is validated in English only); and f) willing and able to give written informed consent. The exclusion criteria were: a) medically unstable as determined by primary inpatient medical team; and b) cognitive impairment that would prohibit participation as determined by primary inpatient medical team. A sample size of 100 achieves 80% power to detect a correlation coefficient of 0.28 using a two-sided hypothesis test with a significance level of 0.05. Also, a sample size of 100 achieves 80% power to detect a slope of 0.04 when the standard deviation of the dependent variable MDASI is 2.0 (Anderson et al., 2007), the standard deviation of the independent variable ISQ is 13.8 (Dingley & Roux, 2013) using a two-sided test with a significance level of 0.05. NCSS Treal and PASS 2005 were used to conduct sample size calculations. Each patient was asked to sign the informed consent after the researcher reviewed the document and answered any questions. After signing the informed consent, study participants completed the ISQ, the MDASI-C, and the single item measuring QOL.

Protection of Human Subjects

Approval for this study was obtained from the Institutional Review Board (IRB) at MD Anderson Cancer Center, the IRB at Texas Woman's University, and the chair of the Lymphoma Department at MD Anderson Cancer Center. Appropriate measures were taken to ensure the privacy and protection of the human subjects. Participants were interviewed by the primary researcher of this study or other research personnel certified by the MD Anderson Cancer Center IRB.

The researcher informed volunteers that if they declined to participate their decision would not impact their clinical care and that they could withdraw from the study at any time without penalty. All questions and concerns were addressed before participants were asked to provide informed consent. All participant questionnaires, forms, and other information were stored in a locked cabinet in the primary researcher's office. The forms did not include participant names, however a unique identifying number was used on all data forms and questionnaires to differentiate participants.

Instruments

The instruments used were the Inner Strength Questionnaire (ISQ), the MD Anderson Symptom Management Instrument (MDASI), the Numeric Single Scale Assessment (NSSA), and the Demographic and Medical Characteristic form. The instruments can be found in Appendices A, B, C and D, respectively.

The Inner Strength Questionnaire (ISQ)

The ISQ was used to measure the inner strength of older women with cancer in various stages of their survivorship. This instrument has 27 questions, with 4 subscales, to measure the four concepts of inner strength and uses a 5-point Likert scale with possible responses of *strongly agree*, *agree*, *slightly agree*, *disagree*, and *strongly disagree*. A study with 154 women in the Midwestern United States reported a reliability of 0.86 for the entire ISQ (Roux, Lewis, Younger, & Dingley, 2003). A second study sample of 281 women with cancer, heart disease, and depression reported a total instrument reliability of 0.91 with the ISQ. The instrument was created at a fourth grade

reading level and takes approximately 12 minutes to complete. This ISQ consists of 27 items to measure the four concepts of inner strength, which are: a) anguish and searching (items 14-20) that describe the fear, vulnerability, and searching for meaning experienced to process a challenging life event; 2) connectedness (items 7-13) that describes the nurturing of supportive relationships with self, family, friends, and a spiritual power; 3) engagement (items 1-6) that describes the self-determinism, reframing, and engaging in possibilities; and 4) movement (items 21-27) that describes the dimension of movement, rest, activity, honest self-appraisal, and balance. Respondents are asked to indicate their level of agreement to a series of statements on a 5 point Likert scale (i.e., *strongly agree*, *agree*, *slightly agree*, *disagree*, *strongly disagree*). The scores for each of the four domains are combined to obtain an overall score. The maximum score is 135, with the higher scores indicating a higher level of inner strength.

MD Anderson Symptom Inventory – Core (MDASI-C)

Symptoms were measured using the core MD Anderson Symptom Inventory Core MDASI-C (Appendix A). The core MDASI, with 2 subscales, is a multiple-symptom measure of the severity of cancer-related symptoms and the functional interference caused by symptoms (Cleeland et al., 2000). This instrument is brief, easily understood, takes about five minutes to complete, and has been validated in the cancer population. The MDASI has also been specifically validated in a large sample of patients with breast cancer (Mendoza et al., 2013). Patients rate the severity of 13 physical, affective, and cognitive symptoms on 0–10 numeric scales, ranging from *not present* to *as bad as you*

can imagine. The MDASI also assesses six items related to symptom interference with functioning on a 0–10 numeric scale ranging from *did not interfere* to *interfered completely*.

Numeric Single Scale Quality of Life Assessment (NSSA)

The use of a single item has been proposed as a simple, valid, and reliable, global measure of overall QOL (Sloan et al., 2002), and this approach has been validated as a general measure of global QOL (Bernhard, Sullivan, Hürny, Coates, & Rudenstam, 2001). The NSSA items ask patients to describe their overall QOL and various aspects of well-being during the past week on a 0–10 scale, with 0 being *as bad as it can be* and 10 being *as good as it can be*. For this study, the item "How would you describe your overall quality of life?" was used as a global QOL measure and was expected to take less than one minute to complete.

Demographic and Medical Characteristics

Demographics for each study participant were obtained from the medical record, including: age, age at diagnosis, relationship status, highest education, employment status, race, ethnicity, religious preference, cancer type (Hodgkin's or non-Hodgkin's lymphoma), current chemotherapy cycle, time since diagnosis, and diagnosed comorbidities.

Data Collection

Women who met the inclusion criteria were invited to participate in the study following admission to the inpatient lymphoma service. If the woman indicated interest

in participating, a time was scheduled to discuss the study. After the informed consent was signed, the ISQ, MDASI-C, NSSA were presented. To reduce questionnaire fatigue, the demographic and medical characteristics were obtained from the medical record. Participants completed the surveys using the REDCap electronic survey system. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing an intuitive interface for validated data entry; audit trails for tracking data manipulation and export procedures; automated export procedures for seamless data downloads to common statistical packages; and procedures for importing data from external sources. REDCap has built-in measures to protect participant anonymity (Harris, Taylor, Payne, Gonzales, & Conde, 2009). For example, REDCap can generate study ID numbers for all participants. Surveys were completed via secure link using the institutional iPad and data from paper surveys were entered into REDCap using a unique identifier by the study PI or other authorized research personnel following completion by the participant. This was a onetime encounter and there was no other follow-up. Demographic data and medical characteristics were obtained from patient medical records, including: age, relationship status, highest education, employment status, race, ethnicity, religious reference, cancer type (Hodgkin's or Non-Hodgkin's), current chemotherapy cycle, time since diagnosis, and diagnosed comorbidities (Appendix D).

Data Analysis

De-identified data were analyzed by a biostatistician in collaboration with the researcher upon completion of data collection from all study participants. Demographic and clinical characteristics were summarized using standard summary statistics. For the ISQ and MDASI, descriptive statistics including mean, range, and standard deviation were computed. Ninety-five percent confidence intervals were computed for means as appropriate. Graphical methods including box-plots and histograms were employed to more closely examine the distribution of scores.

The primary objective of this study was to examine how self-reported inner strength (ISQ) scores correlated with self-reported symptom burden (MDASI). To answer research question 1, Pearsons correlation coefficient was calculated to assess the correlation between ISQ and MDASI. A linear regression model was also used, with the MDASI as the dependent variable and ISQ as the independent variable. The model included terms for age, length of survivorship, and demographic variables. To address research question 2, a correlation matrix was prepared for the subscales of both the ISQ and MDASI. Similar regression models were used with each of the MDASI subscales as the dependent variable and the ISQ subscales, age, and length of survivorship as independent variables. To address research question 3, a linear regression model was used with ISQ as the dependent variable and QOL as the independent variable.

Information gathered from these statistics will be used to determine: (a) whether a high presence of inner strength influences the patients level of symptom burden, (b)

whether age or time since diagnosis influences levels of personal inner strength and symptom burden, and (c) whether the presence of inner strength render a higher quality of life in older women with lymphoma. This study is innovative and important because it is the first to examine the relationship between inner strength and symptom burden in the marginalized population of older females with cancer. The development of inner strength in women with cancer can help them to realize their innate power to prosper despite their diagnosis as they create their "new normal."

CHAPTER IV

ANALYSIS OF DATA

The primary purpose of this quantitative, descriptive study was to examine the relationship between inner strength and symptom burden in older women with lymphoma. The relationship of the woman's age and time since diagnosis to her inner strength and symptom burden scores were studied, and the relationship between inner strength, symptom burden, and quality of life was quantified. The study was conducted as a one-time, self-evaluation of inner strength using the Inner Strength Questionnaire (ISQ) and a one-time, self-evaluation of symptom burden measured by the MD Anderson Symptom Inventory Scale (MDASI). The subscale scores for both instruments were determined as a sum of Likert-style ratings for designated items in the inventory. A single Likert-style item was used to assess overall quality of life using the Numeric Single Scale Quality of Life Assessment Scale (NSSA). Participant demographic characteristics and results of the study are presented in this chapter.

Description of the Sample

The sample included 80 women recruited from the Lymphoma service at a large comprehensive inpatient unit in Houston, Texas. Inclusion criteria were: female over the age of 65 years; diagnosed with lymphoma; and admitted to the inpatient unit. Demographic and clinical characteristics were summarized using standard descriptive statistics as presented in Table 1.

Table 1

Demographic and Clinical Characteristics of Study Population

Characteristic	N	%
Current Age		
N	80	
Mean (SD)	72.36	(6.56)
Median (Min-Max)	71	(65-94)
Age at Diagnosis		
N	80	
Mean (SD)	70.36	(7.38)
Median (Min-Max)	68	(55-93)
Time Since Diagnosis in years		
N	80	
Mean (SD)	3.65	2.36
Median (Min-Max)	3	(1-7)
Relationship Status		
Single	5	6.25
Married	50	62.50
Widowed	18	22.50
Divorced	6	7.50
Partnered	1	1.25
Highest Completed Education		
Grammar School (8th grade)	1	1.25
High School	22	27.50
Technical School	3	3.75
Some College	22	27.50
Completed College	16	20.00
Graduate Education	16	20.00
Employment Status		
Full time	8	10.00
Part Time	3	3.75
Retired	55	68.75
Unemployed	14	17.50
Race		
White	72	90.00
Black	4	5.00
Asian	2	2.50
American Indian/Alaskan Native	1	1.25
Other	1	1.25
Ethnicity		
Hispanic or Latino	4	5.00
Non-Hispanic or Latino	76	95.00
Religious Affiliation		
Roman Catholic	13	16.25
Protestant	14	17.50
Christian	17	21.25
Jewish	2	2.50
Buddhist	1	1.25
Other	31	36

The participants were aged 65 to 94 years (M=72.60; SD=6.56), their ages at diagnosis ranged from 55 to 93 years (M=70.36; SD 7.38), and the time between their diagnosis and entry into the study was 1 to 7 years (M=3.65; SD 2.36). An overwhelming majority were Caucasian (90%) and married (63%) with at least a high school education (27%), although many held college (20%) and graduate degrees (20%). More than two-thirds (69%) were retired, although some (10%) worked full time or were unemployed (14%). Religious affiliation was evenly distributed between Catholic (16%), Protestant (17%), and Christian (21%), while the largest percentage reported other religions (36%).

Most of the women were diagnosed with non-Hodgkin's lymphoma (96%), and a majority reported stage 4 disease (69%). All participants were receiving or had received chemotherapy, however only 15% reported receiving radiation therapy and even fewer reported surgery (4%). The most commonly reported comorbidities were hypertension (65%), coronary artery disease (24%), and arthritis (31%).

Findings of the Study

The three research questions in this study were:

1. What is the relationship between the four subscales of inner strength—anguish, connectedness, engagement, and movement—as measured by the Inner Strength Questionnaire (ISQ), and the two subscale scores of the MD Anderson Symptom Inventory (MDASI) core items—symptom severity and symptom interference—in older female lymphoma survivors?

2. How do age and time since diagnosis correlate with the four ISQ subscale scores and the MDASI core items?
3. What is the relationship between the four self-reported ISQ subscale scores and quality of life (QOL) as measured by the Numeric Single Scale Assessment (NSSA)?

To address the first research question, descriptive statistics including the mean, standard deviation, and range was calculated for the total ISQ and the four subscales of inner strength. The results, presented in Table 2, show mean scores near the top of the possible range, indicating positive average subscale ratings by the participants (i.e., mean response indicated high engagement, connectedness, anguish [reverse scored], and movement) that resulted in a high overall inner strength score.

Table 2

Summary Statistics: Four Subscales of the Inner Strength Questionnaire

Variable	N	Mean	SD	Min	Max
Engagement	80	27.68	3.08	15	30
Connectedness	80	33.63	3.65	14	35
Anguish	80	22.34	6.93	8	35
Movement	80	30.48	4.03	18	35
Total ISQ Score	80	114.11	12.11	72	134

Similarly, Table 3 shows the descriptive statistics for the individual MDASI items, the total scores for the severity and interference scales, and the overall MDASI score.

Table 3

Summary Statistics of MD Anderson Symptom Inventory (MDASI) Scores

Variable	N	Mean	SD	Min	Max
Pain	80	3.19	3.54	0	10
Fatigue	80	4.33	3.03	0	10
Nausea	80	1.55	2.80	0	10
Disturbed sleep	80	3.48	3.25	0	10
Distressed upset	80	2.73	2.67	0	10
Shortness of breath	80	2.25	2.78	0	9
Remembering things	80	2.30	2.49	0	10
Appetite	80	3.28	3.39	0	10
Drowsy	80	2.93	2.81	0	10
Dry mouth	80	4.01	3.59	0	10
Sad	80	1.99	2.67	0	10
Vomiting	80	0.61	1.95	0	10
Numbness tingling	80	1.79	2.53	0	10
General activity	80	3.73	3.29	0	10
Mood	80	2.53	2.55	0	9
Work	80	2.93	3.14	0	10
Relationships	80	1.40	2.46	0	10
Walking	80	2.96	3.00	0	10
Enjoyment of life	80	2.80	2.96	0	10
MDASI Severity	80	34.41	23.76	0	90
MDASI Interference	80	16.34	13.10	0	51
Total MDASI Score	80	50.75	33.17	0	141

A Pearson correlation coefficient was calculated to determine the strength of the relationship between the four ISQ scales (i.e., connectedness, engagement, anguish, and movement), and the total ISQ score, the two MDASI scales (i.e., severity and interference) and the total MDASI score. The correlation matrix is presented in Table 4.

Table 4

Pearson's Correlation Matrix for Inner Strength Questionnaire, MD Anderson Symptom Inventory Scale, Age, Time Since Diagnosis, and Quality of Life

	ISQ					MDASI					
	Engagement	Connectedness	Anguish	Movement	ISQ (Overall)	Severity	Interference	MDASI (Overall)	Age	Time Since Diagnosis	Quality of Life
Engagement	1										
Connectedness	0.4478*	1									
Anguish	0.2528*	0.1747	1								
Movement	0.5097*	0.0733	0.2683*	1							
ISQ	0.7036*	0.5398*	0.7788*	0.6383*	1						
Severity	-0.1573	0.1614	-0.0273	-0.3066*	-0.109	1					
Interference	-0.3160*	-0.0995	-0.1715	-0.4464*	-0.3572*	0.5846*	1				
MDASI	-0.2375*	0.0764	-0.0873	-0.3960*	-0.2192	0.9473*	0.8138*	1			
Age	0.2404*	0.1431	0.2709*	0.3422*	0.3733*	-0.0372	-0.1021	-0.067	1		
Time Since Diagnosis	0.026	0.0596	0.1291	-0.0276	0.0893	0.0978	0.1027	0.1107	-0.1022	1	
Quality of Life	0.2477*	0.1162	-0.061	0.2926*	0.1605	-0.4059*	-0.4063*	-0.4512*	0.0313	-0.1145	1

*indicates $p < 0.05$

There was an inverse correlation between the total ISQ score and the total MDASI scale ($r = -0.2192$, $p < .05$), indicating that—on average—participants with higher ISQ scores tended to have lower MDASI scores. Conversely, lower MDASI (symptom burden) scores correlated with higher ISQ (inner strength) scores.

The total ISQ score showed a significant inverse relationship with the MDASI scale ($r = -0.3572$, $p < .05$), indicating that women with high inner strength experienced less interference of symptom burden in their daily lives. There was also an inverse relationship between the total ISQ score and the MDASI score, but it was not statistically significant ($r = -0.109$). Overall, this indicates that as ISQ scores increased, MDASI scores decreased significantly. Similarly, as the ISQ scores increased, scores for the severity scale also decreased, but not significantly. This finding suggests that an increase in inner strength reduces interference of symptoms with the woman's daily life, or stated differently that greater inner strength may reduce symptom burden.

Significant relationships were observed between two of the four ISQ subscales, engagement and movement, and the MDASI scales. The engagement scale of the ISQ showed a significant inverse correlation with the total MDASI scale ($r = -0.2375$, $p < .05$) and with the symptom interference scale ($r = -0.3060$, $p < .05$). Engagement also had an inverse relationship with symptom severity, but it was not significant.

This finding indicates that a woman who reports engagement—defined in inner strength theory as having the qualities of self-determination and reframing, and openness to engaging in possibilities—reports less symptom severity and interference.

The ISQ movement subscale also has a significant inverse relationship with the total MDASI scale (r = -3960) and the two subscales of severity (r = -0.3066) and interference (r = -0.4466). In other words, a woman with a high inner strength quality of movement—described by the inner strength theory as endorsing rest and activity, honest self-appraisal of one's abilities, and balance—reports less symptom severity and interference. Stated another way, as inner strength movement increases, symptom severity and interference decreases. These results suggest that the significant inverse correlation between the symptom interference and ISQ total scores result primarily from high correlation with the movement subscale score as compared with the other ISQ subscales. Movement seems to be the inner strength quality that drives decreased symptom burden.

Pearson's correlation coefficient was also used to measure the relationship of age and time from diagnosis with the four ISQ subscales (i.e., connectedness, engagement, anguish, and movement), the total ISQ score, the two MDASI scales (i.e., severity and interference), and the total MDASI score. As indicated by the correlation matrix presented in Table 4, there was a significant positive correlation between age and the total ISQ score ($r = .3733$, $p < .05$), and the engagement ($r = .2404$, $p < .05$), anguish, $r = -0.2709$, $p < .05$), and movement ($r = 0.3422$, $p < .05$).

Attributes assigned to engagement such as self-determinism, reframing, and engaging in possibilities were reported more often by older women and are associated with higher ISQ scores. Likewise, attributes assigned to movement such as honest self-

appraisal of ones abilities, rest, and balance were reported more often by older women and are also associated with higher levels of inner strength. Age was also inversely related to the MDASI severity and interference scales, but the correlation was not statistically significant. This suggests that older women are more likely to report lower symptom severity and interference (symptom burden). Time since diagnosis showed no significant correlation with any of the ISQ or MDASI scales.

Pearson's correlation coefficient was computed to examine the relationship between the four ISQ subscale scores and the single-item quality of life score. The quality of life score had a significant positive correlation with the ISQ engagement ($r = 0.2477$, $p < .05$), and movement ($r = 0.2926$, $p < .05$) subscales. Interestingly, the quality of life score does not correlate significantly with the ISQ total score ($r = 0.1605$, ns). These results indicate that women who reported more engagement and movement also reported a more positive quality of life. The quality of life score also shows a significant inverse correlation with the MDASI total score ($r = -0.4512$, $p < .05$) and the subscale scores for severity ($r = -0.4059$, $p < .05$) and interference ($r = -0.4063$, $p < .05$). Overall, the inverse correlations between the total MDASI scores, the total ISQ scores, and the single-item quality of life score indicate that greater inner strength, especially with respect to the movement attribute, and quality of life are associated with a lower symptom burden.

A linear regression model was used to test the relationship of the total ISQ score and the four subscales of engagement, connectedness, anguish, and movement; the total

MDASI score and the two subscales of symptom severity and interference; and the single-item quality of life score. In this linear regression model, the total ISQ and four subscale scores were the predictor variables and the total MDASI and its two subscale scores were the outcome variables. The quality of life score was also a predictor variable and the total ISQ scale was its associated outcome variable.

Table 5 presents the results of the linear regression model for the outcome variables of the total MDASI and its two subscale scores; and the predictor variables of the total ISQ, its four subscale scores, and the quality of life score with the outcome variable of total ISQ score.

Table 5

*Regression Models for MD Anderson Symptom Inventory Questionnaire, the Inner Strength Questionnaire, and the Single Quality of Life Question**

Outcome	Predictor	Beta	95% LB	95% UB	p-value
MDASI	ISQ	-0.67	-1.33	-0.02	0.045
Severity	Engagement	-1.08	-3.29	1.12	0.332
	Connectedness	1.48	-0.13	3.10	0.071
	Anguish	0.05	-0.75	0.85	0.905
	Movement	-1.62	-3.20	-0.04	0.045
Interference	Engagement	-0.45	-1.61	0.71	0.439
	Connectedness	-0.11	-0.96	0.74	0.797
	Anguish	-0.14	-0.56	0.28	0.515
	Movement	-1.30	-2.13	-0.47	0.003
ISQ	Quality of life	-0.02	0.20	1.58	0.117

*all models controlled for age at survey and time since diagnosis

The ISQ total score was a significant predictor of the MDASI total score (Beta = -0.67, p = .045). This result indicates that for every one-point increase in the ISQ score, the MDASI score will decrease by 0.067 points. The only significant predictor of the MDASI severity and interference subscale scores was the ISQ movement subscale

score (severity: beta = -1.62, p = 0.045; interference: beta = -1.30, p = 0.003). These results indicate that on average, independent of age and time since diagnosis, those participants with higher ISQ movement subscale scores reported lower MDASI severity and interference subscale scores. Movement appears to be a significant contributor to lower symptom burden. For every one-unit increase in the ISQ movement subscale score, the total MDASI score decreases by 1.62.

Summary

Although the analysis revealed a number of statistically significant correlations between subscale and total scores across the ISQ, the MDASI, and the single-item quality of life score, the absolute value of the correlations was low, ranging from |-0.2192| for the correlation between the total ISQ and the MDASI scores, to |-0.4512| for the correlation between the total MDASI and quality of life scores. The mean absolute value of the significant correlations was .3276, and the variance shared by the statistically significant predictor-outcome variables was $r^2 = 0.1073$. Thus, on average, correlation between the variables accounts for 10.73% of the variance in the measures. Although some of the findings—especially those related to the effect of movement on symptom burden as measured by the MDASI scale—are suggestive, these results indicate that a small amount of symptom burden is accounted for by the ISQ and quality of life measures.

CHAPTER V

SUMMMARY OF THE STUDY

It is well known that adults over the age of 65 years represent 60 percent of the United States population diagnosed with cancer. As the population of the United States continues to increase, so will the population with cancer. Government agencies have slowly begun to promote cancer research designs that include adults over the age of 65. Two important paradigm shifts have occurred in cancer research that could lead to significant advances in cancer care. First, the Institute of Medicine (2010) and other health care agencies have acknowledged that men and women experience symptoms of cancer and its treatment differently, encouraging more gender-specific research. The second shift in cancer research has been a focus on and expansion of knowledge regarding human responses to diagnosis and treatment through examination of the psychological and physiological responses to illness. Although this new awareness of gender differences and personal distress after diagnosis are welcome developments in cancer research, research has yet to explore the unique characteristics of women with cancer and their symptom burden.

Rich qualitative data was reported from 12 years of research on the phenomena of inner strength in women who have experienced difficult life changing situations. Nurse researchers Dingley and Roux (2003) recognized the need to quantify knowledge gained from qualitative research so that interventions could be created to develop inner strength

in women undergoing stressful life changing events. The theory of inner strength and the Inner Strength Questionnaire (ISQ) were then created and used by Dingley and Roux (2003) to conduct the first quantitative research study examining inner strength as a predictor of quality of life and self-management in women with cancer. Their study of 107 women showed that the strongest predictors of quality of life were inner strength, time since diagnosis, and comorbidities, with inner strength being the strongest predictor. The strongest predictors of self-management abilities were depressive symptoms and inner strength. The results of this study contributed to the theory of inner strength and confirmed the influence of inner strength on a woman's quality of life and self-management.

The current study is the first to examine the relationship between inner strength and symptom burden in older women with lymphoma. Most studies among women with cancer focus on breast or gynecological cancers; however, the risk of developing non-Hodgkin's lymphoma increases with age and more than half of patients are 65 years or older at the time of diagnosis (American Cancer Society, 2015).

Knowledge of how inner strength, as defined by the theory of inner strength, intersects with symptom burden can provide a foundation for development of nursing interventions to support and/or encourage inner strength, potentially reducing symptom burden and enhancing quality of life.

Summary

A quantitative, non-experimental design was used to the study the relationship between inner strength and symptom burden in older women with lymphoma. After approval by the MD Anderson Cancer Center and Texas Woman's University Institutional Review Boards, a convenience sample of 80 women was recruited from among patients admitted to the lymphoma inpatient service. After an initial eligibility screening, patients fitting the inclusion criteria were asked to participate in this study. Initially 85 women consented and enrolled in the study, a review of inclusion criteria revealed that two women were less than one month from diagnosis and three women were admitted to the pre-admission clinic, not the full lymphoma inpatient service. These five women were subsequently excluded from the study.

A power analysis was conducted using statistics software programs NCSS Treal and PASS 2005 before initiating the study. The analysis determined that a sample size of 80 participants would achieve 80% power to detect a correlation coefficient of 0.31 using a two-sided hypothesis test with a significance level of 0.05.

Data was collected from 80 women who fit the inclusion criteria and were willing to answer the three questionnaires: the MD Anderson Symptom and Interference (MDASI) questionnaire, the Inner Strength Questionnaire (ISQ), and the Quality of Life Numeric Single Scale Assessment (NSSA) one-item scale. Demographic information was obtained from the medical chart to avoid questionnaire fatigue in this population. If

the information was not available, the participant was asked to provide demographic data as needed.

Discussion of the Findings

The findings of this study indicate that women 65 years of age and older admitted to an inpatient lymphoma unit who report higher levels of inner strength also report experiencing fewer symptoms, significantly less inference from their symptoms, and a more positive quality of life. The two inner strength coping strategies of engagement and movement showed the most significant relationships with inner strength and were responsible for reduced levels of symptom burden. This research also showed a significant correlation between age and inner strength, indicating that older women report less symptom severity and interference and higher scores on the ISQ engagement and movement subscales.

This study found that inner strength increased with age, and higher levels of inner strength are associated with higher engagement (i.e., self-determination, reframing, engaging in possibilities) and movement (i.e., rest, activity, self-assessment) scores. These findings indicate that if skills of engagement such as how to reframe events and engage in possibilities can be shared with older women with lymphoma, inner strength could be increased, reducing symptom burden and life interference. Quality of life scores positively correlated with the engagement and movement ISQ scales, but did not have a significant relationship with the total ISQ score. No significant correlation was found between time from diagnosis and ISQ scale scores. This result contrasts with the findings

of Dingley and Roux (2013), who found that the strongest predictors of quality of life were depressive symptoms, inner strength, and time since diagnosis. This discrepancy may be explained by the difference in population characteristics because the women in this study were older and diagnosed with lymphoma, whereas the Dingley and Roux (2013) study included women 18 years and older and diagnosed with various different cancers.

A group of Swedish researchers used a different theory of inner strength to examine a population of 6,119 participants ages 65 and above. They found that participants who reported poorer self-rated health had a lower degree of inner strength, and higher self-rated health was associated with higher levels of inner strength (Viglund et al., 2014). These findings agree with the results from this study in which higher self-reported inner strength correlated with low symptom burden.

Further review of the literature found no reports examining the relationship between inner strength and symptom burden. No other quantitative studies were found that examined the role of inner strength in the unique population of older women with lymphoma. Additionally, there were no studies that compared symptom burden from cancer treatment with inner strength in an older female population.

Although this analysis found several statistically significant correlations between inner strength, symptom burden, and quality of life, the correlation between these variables accounted for only 10.73 % of the variance in the measures. These results indicate that the ISQ, MDASI, and quality of life measures account for a small amount of

symptom burden. Inner strength, symptom burden, and quality of life are clearly complex phenomena with deep ties to a multitude of variables that were not measured in this study such as culture, ethnicity, economic status, and disease progression. If evidence-based interventions are to be crafted and tested, more studies are urgently needed to further quantify the relationships between inner strength, symptom burden, and quality of life in this underserved population. This study showed that two significant measures of inner strength, engagement and movement, were associated with lower levels of symptom burden. Further exploration of how the life skills of engagement and movement can be taught to older women with lymphoma could help them reduce their symptom burden and achieve a high quality of life.

Conclusions and Implications

There has been a recent movement in psychology to study people's positive traits and how they can be harnessed to improve their sense of well-being (Greenstein & Holland, 2015). This study found that older women diagnosed with lymphoma who reported high inner strength experienced less symptom burden and interference, which could result in a better wellness trajectory. This research evidence could be used to design and test interventions that increase inner strength and decrease symptom burden in this unique patient population. Additional testing of the relationship between inner strength and symptom burden in populations of older women with other forms of cancer is needed to show whether the results from this study can be applied to other populations of female cancer survivors.

Recommendations for Further Study

Evidence-based interventions are needed to explore, recognize, and strengthen the older woman's unique biological, physiological, cultural, and psychosocial inner strengths to support her through all phases of cancer survivorship. Although literature offers various interventions to help manage symptom burden, few studies have explored how to identify, strengthen, support and mobilize the inner strength of the unique cohort of older woman with cancer. The art and science of nursing has front-row ability to discover unexplored relationships using positive aspects of a woman's nature to improve overall health and facilitate recovery from disease.

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APPENDIX A

Inner Strength Questionnaire

Subject ID: _____

Roux, G. Time: ☐☐:☐☐

Inner Strength Form Date: ☐☐/☐☐/☐☐

Inner Strength Questionnaire

Instructions:
Circle one of the choices (5, 4, 3, 2, or 1) that corresponds with strongly agree, agree, slightly agree, disagree or strongly disagree.

Answer how you feel TODAY about YOUR HEALTH....

	Strongly Agree	Agree	Slightly Agree	Disagree	Strongly Disagree
1. I tell myself I can do this.	5	4	3	2	1
2. I can change my attitude when I need to.	5	4	3	2	1
3. I believe I am a strong person.	5	4	3	2	1
4. I am determined to get well.	5	4	3	2	1
5. I believe I have inner strength.	5	4	3	2	1
6. I can decide what to do.	5	4	3	2	1
7. I have at least one person close to me.	5	4	3	2	1
8. I feel the presence of God or a Greater Source of Strength.	5	4	3	2	1
9. I put control of my life in God's or a Greater Power's hand.	5	4	3	2	1
10. I feel close to God or a Greater Source of Strength.	5	4	3	2	1
11. I pray for strength.	5	4	3	2	1
12. I express my fears to my God or a Greater Source of Strength.	5	4	3	2	1
13. I pray for others.	5	4	3	2	1
14. I worry about my health.	5	4	3	2	1
15. I am scared about the future.	5	4	3	2	1

Subject ID: ☐☐☐

Roux, G.

Time: ☐☐ :

Inner Strength Form

Date: ☐☐/☐☐/☐☐

	Strongly Agree	Agree	Slightly Agree	Disagree	Strongly Disagree
16. When I first learned about my health problem, I was afraid of dying.	5	4	3	2	1
17. There are many times when I am afraid of dying.	5	4	3	2	1
18. I feel my situation is out of control.	5	4	3	2	1
19. I dwell on my illness.	5	4	3	2	1
20. When I first learned about my health problem, I felt afraid.	5	4	3	2	1
21. I can live with my physical limitations.	5	4	3	2	1
22. I stay active.	5	4	3	2	1
23. I spend time with my friends or family.	5	4	3	2	1
24. I try to balance work and play.	5	4	3	2	1
25. I take time for myself.	5	4	3	2	1
26. I try to rest my mind periodically.	5	4	3	2	1
27. I set aside time to relax.	5	4	3	2	1

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APPENDIX B

M. D. Anderson Symptom Inventory – Core Questionnaire

Date: _____

Participant Initials: _____

Participant Number: _____

Institution: _____

Hospital Chart #: _____

MD Anderson Symptom Inventory (MDASI) Core Items

Part I. How **severe** are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been ***in the last 24 hours.*** Please select a number from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	Not Present										As Bad As You Can Imagine
	0	1	2	3	4	5	6	7	8	9	10
1. Your **pain** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
2. Your **fatigue (tiredness)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
3. Your **nausea** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
4. Your **disturbed sleep** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
5. Your feelings of being **distressed (upset)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
6. Your **shortness of breath** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
7. Your problem with **remembering things** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
8. Your problem with **lack of appetite** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
9. Your feeling **drowsy (sleepy)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
10. Your having a **dry mouth** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

Date: _____

Participant Initials: _____

Participant Number: _____

Institution: _____

Hospital Chart #: _____

	Not Present										As Bad As You Can Imagine
	0	1	2	3	4	5	6	7	8	9	10
11. Your feeling **sad** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
12. Your **vomiting** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
13. Your **numbness or tingling** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

Part II. How have your symptoms **interfered** with your life?

Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items ***in the last 24 hours***? Please select a number from 0 (symptoms have not interfered) to 10 (symptoms interfered completely) for each item.

	Did Not Interfere										Interfered Completely
	0	1	2	3	4	5	6	7	8	9	10
14. **General activity?**	○	○	○	○	○	○	○	○	○	○	○
15. **Mood?**	○	○	○	○	○	○	○	○	○	○	○
16. **Work (including work around the house)?**	○	○	○	○	○	○	○	○	○	○	○
17. **Relations with other people?**	○	○	○	○	○	○	○	○	○	○	○
18. **Walking?**	○	○	○	○	○	○	○	○	○	○	○
19. **Enjoyment of life?**	○	○	○	○	○	○	○	○	○	○	○

APPENDIX C

Numeric Single Scale Quality of Life Assessment

Date:_____ Institution:_____

Participant Initials:_____ Hospital Chart #: _____

Participant Number: _____

PATIENT QUALITY OF LIFE

Directions: Please fill in the circle below the number (0-10) that best describes your response to the following question **in the past week**, from **0** meaning **"as bad as it can be"** to **10** meaning **"as good as it can be."**

How would you describe:

	As Bad As It Can Be 0	1	2	3	4	5	6	7	8	9	As Good As It Can Be 10
1. Your overall **quality of life**?											

APPENDIX D

Demographics and Medical Characteristics Form

DEMOGRAPHICS AND MEDICAL CHARACTEISTICS

Patient ID number: _____

Current age: _____

Age at Diagnosis: _____

Relationship Status:
- **Living with a partner _____**
- **Married _____**
- **Living alone (divorced, widowed, single) _____**

Highest Education Status
- **Grammar school (8th grade) _____**
- **Junior high school _____**
- **High school _____**
- **Technical school/ some college _____**
- **Completed college _____**
- **Graduate education _____**

Employment Status
- **Full time _____**
- **Part time _____**
- **Retired _____**
- **Unemployed _____**

Race
- **American Indian/Alaska Native _____**
- **Asian _____**
- **Black or African American _____**
- **Other _____**

Ethnicity
- **Hispanic or Latino _____**
- **Non-Hispanic or Latino _____**

Religious Preference
- **Catholic _____**
- **Protestant _____**
- **Christian _____**
- **Other _____**
- **No current religious affiliation _____**

Lymphoma type

- Non- Hodgkins's _____
- Hodgin's _____

Time since Diagnosis:

- 1 day to 90 days _____
- 91 days to 180 days _____
- 181 days to 271 days _____
- 172 days to 362 days _____
- 363 days to 453 days _____
- 454 days to 544 days _____
- 545 days to 575 days_____
- 576 days to 666 days
- Other _____

Current stage of cancer

- Stage 1 _____
- Stage 11 _____
- Stage 111 _____
- Stage 1V _____
- Unknown Stage _____

Most Common Treatment Type

- Chemotherapy _____
- Radiation _____
- Surgery _____

Most Common Co morbidities

- Hypertension _____
- Diabetes _____
- Coronary Artery Disease _____
- Depression/ Anxiety _____
- Arthritis _____