SYMPTOM OCCURRENCE, SEVERITY AND QUALITY OF LIFE AS PREDICTED BY VARIABLES RELATED TO THE CANCER CONDITION AND SELECTED DEMOGRAPHIC VARIABLES

By

JAIMOL SUJITH SREEDHAR

Submitted to the graduate degree program in Nursing and the Graduate Faculty of the University of Kansas in partial fulfillment of the requirements for the degree of Doctor of Philosophy

_____
Chairperson: Phoebe D. Williams, PhD, RN, FAAN

_____
Sandra Bergquist-Beringer, PhD, RN

_____
Geri Neuberger, EdD, RN, APRN

_____
Jianghua He, PhD

_____
Eve-Lynn Nelson, PhD

Date Defended: April 12, 2016

The Dissertation Committee for Jaimol Sujith Sreedhar

certifies that this is the approved version of the following dissertation:

SYMPTOM OCCURRENCE, SEVERITY AND QUALITY OF LIFE AS PREDICTED BY VARIABLES RELATED TO THE CANCER CONDITION AND SELECTED DEMOGRAPHIC VARIABLES

_____

Chairperson: Phoebe D. Williams, PhD, RN, FAAN

Date approved: May 06, 2016

ABSTRACT

Background: Patients with advanced cancer often experience multiple coexisting symptoms during treatments. Identifying symptoms and patients' self-care strategies help health care professionals manage patients' symptoms effectively.

Purpose: The primary purpose of the study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since start of treatment, number of comorbidities), and selected demographic variables (ethnicity, age, gender, marital status, education, economic status). Four secondary purposes were to examine (1) cancer patients' reported symptom occurrence and severity by ethnicity (African-American vs. Caucasian); (2) self-care methods used by ethnicity; (3) difference in symptom occurrence and severity by age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older); and (4) self-care methods used by age groups.

Methods: This study used a descriptive correlational design. Data were collected from a convenience sample of 110 cancer patients receiving cancer treatments at one eastern U.S.A. site. Tools used included the: Demographic Form, Health Form, Karnofsky Performance/Functional Status, and Treatment/ Medication Profile, Therapy-Related Symptoms Checklist (TRSC), Health- Related Quality of Life Linear Analogue Self Assessment (HRQOL-LASA), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C-30 (EORTC QLQ-C 30), and the Symptom Alleviation Self-Care Methods (SA-SCM). Data were analyzed using SPSS version 23.

Findings: Significant relationships were found on multiple linear regression analysis between TRSC symptom occurrence/severity and gender (t (103) = 2.07, p=.04), economic status

[(Annual income> $60,000), ($t$ (103) = -2.53, p=.01)], and disease stage (t (103) = 4.31, p=.000). Significant associations were found between HRQOL and economic status [(annual income > $60,000), ($t$ (103) = 2.11, p=.04)], and ethnicity [(African American, t (103) = 2.01, p=.04), (Asian & Hispanic, t (103) = 2.04, p=.04)]. Path analysis supported the significant findings. Patients with high symptom occurrence/severity reported low HRQOL. The majority of participants reported their use of self-care strategies was helpful.

Clinical Implications: Oncology nurses are in an influential position to educate, motivate, and support patients and families to manage the patients' treatment-related symptoms effectively.

ACKNOWLEDGEMENTS

This doctoral study is dedicated to my family, who made my dream true. My sincere thanks to my loving husband, Sujith Sreedhar, who supported me throughout this long journey. He was always with me during my difficult times, he was aside me when I cried, and he always boosted me with positive energy and hope. Words like "You can do it", " You are strong and able", "You did it so far"," You are special, and not everyone can do this" mean so much to me. Without his constant support, I would have never completed this journey. My kids, Sidharth and Sreyas, understood their mom well and supported me with their little hearts. They are my energy, and they used to come to me during my study time to give me "study gas"(in their language) through their kisses and hugs. They never disturbed me during my studies, and they knew that mom has "homework" to do. I am very thankful to my Father-in-law and Mother-in-law, who helped me immeasurably during my studies. Special thanks and appreciation to my parents and sister who supported and encouraged me in this journey. I am also thankful to my sister-in-laws and brother-in-laws who always encouraged me for my studies. I am very thankful to all members of Sree Narayana Association, Philadelphia for all their prayers, support, and encouragement.

I am thankful to my dissertation committee, Dr. Phoebe D. Williams, Dr. Sandra Bergquist-Beringer, Dr. Geri Neuberger, Dr. Jianghua He (Wendy), and Dr. Eve-Lynn Nelson for their guidance. My sincere appreciation to my program advisor and dissertation committee chair Dr. Phoebe D. Williams, for her constant support, guidance, prompt feedback, and inspiration throughout my study. To Dr. Williams, I wish to say " You are a wonderful professor, researcher, and moreover a kind-hearted person who understand her student in all aspects". Special thanks to Dr. Sandra Bergquist-Beringer, for her patience, guidance, expertise

and advice during the most critical period of my Ph.D. journey. My sincere appreciation is also given to Dr. He for her time, expertise, and guidance for doing my statistical analyses. Special thanks to Dr. Geri Neuberger and Dr. Eve-Lynn Nelson for their guidance and support. I am also thankful to all teachers who taught me various courses in my Ph.D. program.

My sincere gratitude to Mainline Health, who supported me financially for my Ph.D. program and for providing permission for conducting my study. My sincere appreciation to all those who helped me in my data collection. Special thanks to all patients who participated in my study, and without their cooperation I would have never completed this study. I am grateful to my nurse manager, Maria McKenna and clinical coordinator, Brenda Farina at Lankenau Medical Center for all their support and encouragement. They both helped me a lot to adjust my schedule and to make it suitable for my studies. I am thankful for all my colleagues and friends who constantly encouraged me along the way. Special thanks to all my classmates, especially Doncy Eapen, Shirley Wang, and Karen Groller for their constant support. They were available to me whenever I needed to clarify any question. Above all, I thank GOD for all success in my life.

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

LIST OF FIGURES

Chapter I

Introduction

Cancer is a major health problem in the United States (Siegel, Naishadham, & Jemal, 2013) and many other parts of the world (Siegel, Miller & Jemal, 2015). There are more than 100 types of cancers; any part of the body can be affected with cancer (World Health Organization (WHO), 2013). In 2016, an estimated 1,685,210 new cancer cases will be diagnosed in the United States and about 595,690 cancer deaths (American Cancer Society (ACS), 2016). Cancer is the second most common cause of death in the United States, exceeded only by heart disease (ACS, 2016). However, the latest developments in cancer diagnosis and treatment have improved early diagnosis and prompt treatment of cancers (Van Rooyen, Le Roux, & Kotze, 2008), which in turn has increased the number of cancer survivors (DeSantis et al., 2014). There have been notable improvements in survival rates over the past three decades for most cancer types (Siegel et al., 2015). More patients than ever are surviving cancer and thriving after treatment. The 5-year relative survival rate for all cancers diagnosed during 1975-1977 was 49%, and the rate increased to 69% during 2005-2011 (ACS, 2016). The increase in cancer survival rates is likely related to early detection and improved cancer treatment (ACS, 2015; Backman, Browall, Sundberg, & Wengstrom, 2015).

Cancer treatment involves the use of chemotherapy, radiation therapy, or combined treatment with chemotherapy/ radiation therapy. Patients' response and body tolerance to these treatments vary. Patients receiving these treatments, often experience a variety of symptoms that also affect their quality of life (QOL). Identification of common symptoms of cancer patients who are receiving chemotherapy, radiation therapy, and combined treatment with chemotherapy/

radiation therapy, are essential for proper treatment, effective self-care, reduce suffering, and to enhance the quality of life.

Background

Cancer affects everyone – diverse groups, young and old, the rich and poor, men, women and children (WHO, 2013). Cancer is a scary diagnosis for the patient and the family. The journey through the cancer experience is difficult. Cancer causes an enormous challenge for health-care provision and leads to significant financial and emotional burden for patients, families, and society in general (Dalal, & Bruera, 2012; Drageset, Corbett, Selbaek, & Husebo, 2014; WHO, 2015). For both majority and minority (diverse) cultures, cancer often leads to physical, emotional, and spiritual challenges (Kagawa-Singer, 2011). Patients with cancer often experience multiple coexisting symptoms caused by the disease itself, side effects of its treatment, or other related conditions (Jimenez et al., 2011). Patients receiving cancer treatment also experience problems related to their family life and lack of leisure activities (Aumann, Kreis, Damm, Golpon, Welte, & Graf von der Schulenbur, 2015). Identifying symptoms and self-care strategies help healthcare professionals manage their patients' symptoms effectively during treatments. Guiding and motivating patients and families toward self-care activities may reduce symptom burden (McCorkle et al., 2011), influence adherence to the treatment regimen (Williams, Lantican, Bader, & Lerma, 2014), and improve the quality of life (QOL) (Williams et al., 2011; 2013). Symptom experience is the perception of individual patients' symptoms, its occurrence, severity and distress as expressed by patients. Accurate patient- reported symptoms are necessary to manage treatment- related symptoms (Williams, Graham, Storlie et al., 2013). Proper assessment is the key to effective treatment of cancer patients' symptoms.

Nurses play a critical role in assessing patients' symptoms to identify changes in severity of symptoms and quality of life over time. Nurses were identified as the trusted sources of information by patients and their caregivers (Tariman, Doorenbos, Schepp, Becker, & Berry, 2014). Studies have shown that nurses are involved in symptom assessment, monitoring, and management in adult oncology patients during treatments (Williams et al., 2013; Williams, et al., 2014; Williams, Williams, LaFaver-Roling, Johnson, & Williams, 2011; Williams et al., 2015; Tariman, & Szubski, 2015). A systematic tracking of patient-reported symptoms during treatment is essential to prioritize and manage their symptoms effectively (Williams et al., 2014). Williams, Williams, Williams, et al. (2015), reported that an electronic symptom checklist (The Therapy-Related Symptom Checklist, TRSC) can facilitate assessment and management of symptoms; enhance patient-clinician communications; and contribute to improved patient outcomes. Symptoms are guideposts for oncology nursing practice (Armstrong, 2003), and oncology nurses play a major role in symptom assessment and management. Oncology nurses are in an influential position to educate, motivate, and support patients and families to manage their treatment-related symptoms effectively at home.

Purposes

The primary purpose of this study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life (HRQOL), selected variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities), and selected demographic variables (age, gender, ethnicity, marital status, education, economic status). Four secondary purposes were to examine (1) cancer patients' reported symptom occurrence and severity by ethnicity (African-American vs. Caucasian); (2) self-care methods used by ethnicity; (3) difference in symptom occurrence

and severity by age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older); and (4) self-care methods used by age group.

Primary Research Hypothesis

Cancer therapy-related symptom occurrence and severity and health-related quality of life are influenced by variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since treatments started, number of co-morbidities); and by selected demographic variables (age, gender, ethnicity, marital status, education, economic status).

Secondary Research Questions

1) Is there a significant difference in symptom occurrence and severity by ethnicity, as reported on the Therapy-Related Symptoms Checklist (TRSC)?

2) Is there a difference in self-care methods used by ethnicity (African-American vs. Caucasian adult oncology patients), as reported on the Symptom Alleviation: Self-Care Methods tool?

3) Is there a significant difference in symptom occurrence and severity by age group adolescent-young adult (18- 39 years) vs. older adults (40 years or older)?

4) Is there a difference in self-care methods used by age group, as reported on the Symptom Alleviation: Self-Care Methods tool?

Design Overview

The present study used a descriptive correlational design. A convenience sampling method was used, with quota sampling by two variables: ethnicity (African-American vs. Caucasian) and age group (less than 40 years vs. 40 years and older). Adult cancer patients (*N*= 110) undergoing chemotherapy, radiation therapy, or a combination of chemotherapy and

radiation treatments were recruited from inpatient and outpatient chemotherapy and radiation therapy department of a major hospital system in the Northeast region of the United States. The dependent variables were symptom occurrence and severity (measured by the Therapy-Related Symptoms Checklist (TRSC), and health-related quality of life (measured by the Health- Related Quality of Life Linear Analogue Self Assessment, HRQOL-LASA). Another HRQOL tool, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C-30 (EORTC QLQ-C 30) was used in the present study to examine the convergent validity of the HRQOL-LASA tool. Independent variables were patient data documented in the Demographic Data Form, and Health Form and treatment/ medication profile. The Symptom Alleviation: Self-care method form addressed the two secondary research questions (# 2 & #4) of the study (self-care methods by ethnicity and by age group).

Conceptual Framework

The study conceptual framework was a modification of frameworks developed by several scholars in this field (Armstrong, 2003; Dodd et al., 2001; Larson et al., 1994; Williams et al., 1997; 2001; 2006; 2013; 2014; Williams, Williams et al., 2015; Williams, Mowlazadeh, Sisler, & Williams, 2015; Youngblood et al., 1994). According to Larson et al. (1994), the symptom experience is a dynamic interaction of the patient's perception of a symptom, evaluation of its meaning, and response to a symptom. When considering the person, environment, and health and illness, Dodd et al. (2001) proposed interrelations among symptom experience, components of strategies related to symptom management, and symptom status and outcomes including self-care, functional status, and quality of life. Armstrong (2003), using concept analysis, proposed three components, namely, antecedent factors (or factors that influence the experience of the symptom), symptom perception (including frequency and severity or intensity), and the

consequences of the symptom such as quality of life. Meanwhile, P. Williams et al. (2001; 2006; 2011; 2013; 2014) and Youngblood et al. (1994) state that information about common symptoms and monitoring the success of self-reported strategies can guide health care providers (HCPs) in optimizing help for patients during treatments for cancer. That is, when HCPs assist individual patients, they must be able to use (and guide patients to use) medically prescribed treatment measures including use of "self-care", and "dependent or parental care" in the case of pediatric patients (Orem, 2005; A. Williams et al. 2000; 2014; 2015). These influence outcomes of care such as functional status, and quality of life. All the above studies reported that demographic variables and the characteristics of the disease influence symptom occurrence and severity. A number of additional studies showed similar findings (Jimenez et al., 2011; Mao et al., 2007; Mohile et al., 2011; Prigozin, Uziely, & Musgrave , 2010; Walsh, Donnelly, & Rybicki, 2000; Stanton, Bernaards, & Ganz, 2005; Williams et al., 2006, 2010, 2013; 2014;2015).

In the present study the selected **independent variables** were: (a) variables related to the cancer condition - diagnosis/stage, type of treatments, length of time since treatments started, number of co-morbidities, type of treatment received (chemotherapy only, radiation therapy only, or a combination of both radiation and chemotherapy); and (b) selected demographic variables - age, gender, ethnicity, marital status, education, economic status. The **outcome (dependent) variables** were symptom occurrence and severity, and health-related quality of life, as reported by cancer patients. These outcomes have been examined in other cancer related studies (Bayram et al., 2014; Harrow et al., 2014; Hwang, Chang, & Park, 2013; Pud et al., 2014; Williams et al. 2011; 2013; 2014; 2015). The conceptual models (Model 1 and Model 2) for the present study are shown in Figure 1 and Figure 2.

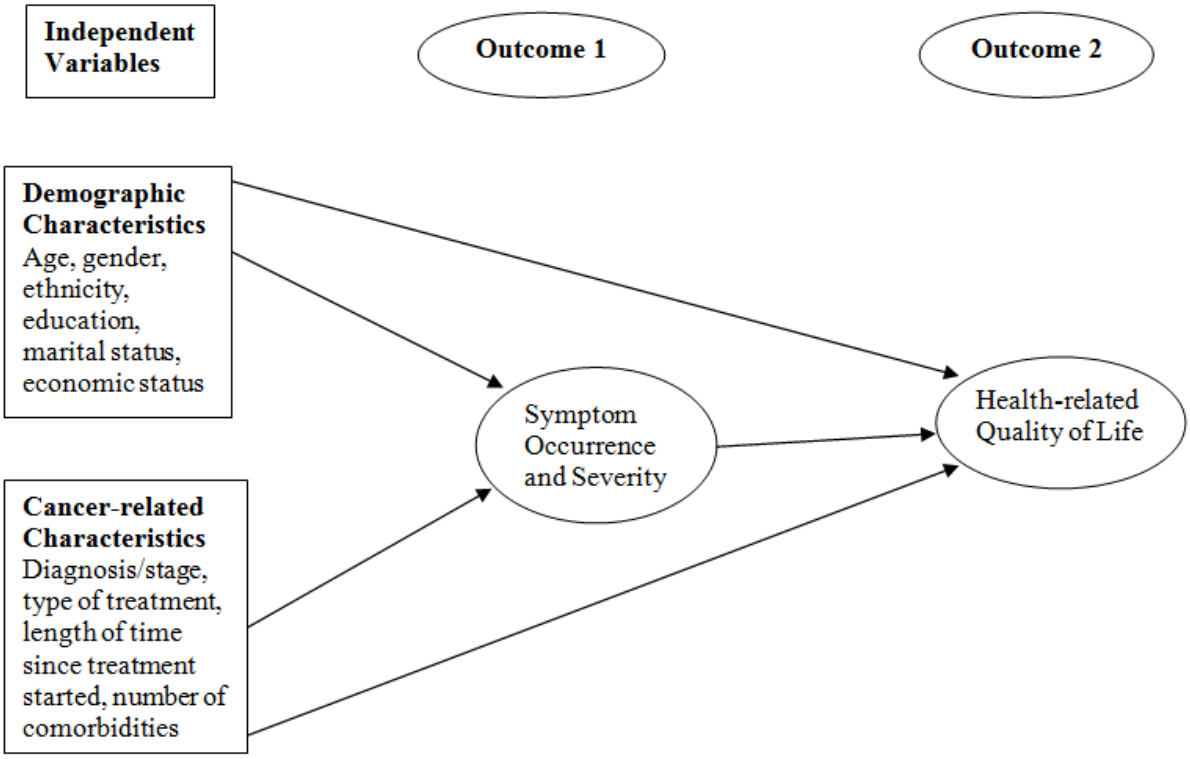

Figure 1. Conceptual Framework (Model 1)

Figure 1. represents the primary research hypothesis, tested by multiple linear regression and path analysis (Munro, 2005; Polit & Beck, 2008; 2012). According to Figure 1 (Model 1), demographic variables and cancer-related characteristics are associated with cancer therapy-related symptom occurrence and severity, and quality of life in cancer patients. The present study also assumed that demographic variables and cancer-related characteristics are associated with cancer therapy- related symptom occurrence/severity and health-related quality of life in cancer patients. Path analysis was conducted to explore the test model: independent variables → Symptom occurrence and severity, and independent variables →HRQOL. Path diagrams were created based on the selected conceptual framework, the final model selected in this study, and

available literature.

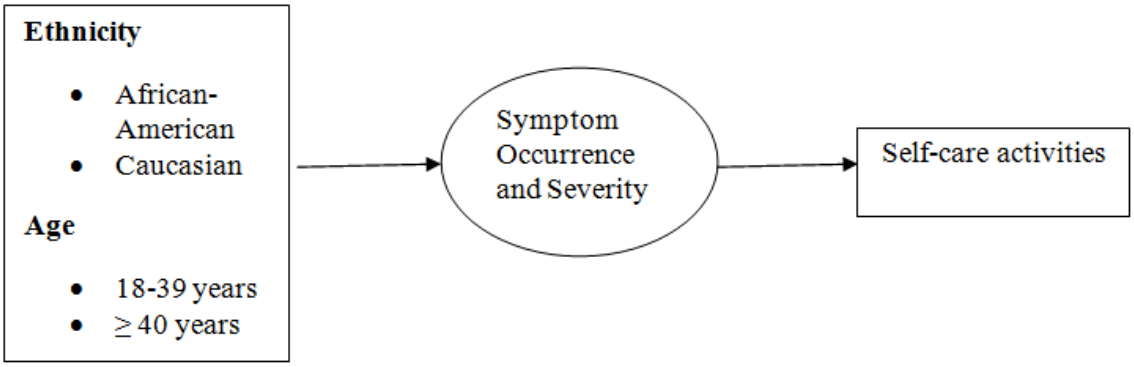

Figure 2. Conceptual Framework - Model 2

Model 2 addresses the four secondary research questions. In this model, symptom occurrence, and severity are associated with ethnicity and age group, and will influence selection and use of self-care activities.

Definition of Terms

The therapeutic and operational definitions of 13 key terms (variables) were defined for the purpose of this study. Both theoretical and operational definitions of each variable are given in Table 1.

Table 1

Theoretical and operational definitions of selected variables

Variables	Theoretical Definition	Operational Definition
1. Age	It is defined as patient's chronological age	It is the patient's actual age in years, as recorded in the demographic data form.
2. Gender	It is defined as the patient's gender, male or female.	It is the patient's gender (male or female), as self-reported in the demographic data form.
3. Ethnicity	It is the cultural group to which the individual patient belongs.	Ethnicity is the patient's cultural group (African-American, Caucasian, Asian, Hispanic, Native American, or other), as self-reported in the demographic data form.
4. Marital Status	It is the condition of being married or unmarried.	It is defined as the condition of being married or unmarried (single, widowed, divorced, or other), as self-reported in the demographic data form.
5. Education	It is the level of schooling completed by the individual patient.	Education is the patient's level of schooling completed (less than high school, or high school graduate or higher), as self-reported in the demographic data form.
6. Economic Status	It is the annual income of the individual patient.	It is the patient's actual annual income (<$30,000, $ 30,000-60,000, $61,000-$90,000, $91,000-$120,000, or >$120,000) as self-reported by the individual patient on the demographic data form.
7. Diagnosis	It is the patient's primary cancer diagnosis.	It is the patient's primary cancer diagnosis (breast cancer, colorectal, lung & larynx, oral & gastrointestinal, lymphoma, leukemia, myeloma, uterine & ovarian, and others) as recorded on the Health Form and treatment/ medication profile.
8. Cancer Stage	It is the extent and severity of cancer and its spread in the individual patient's body.	It is the cancer stage (0,1& 2 or 3&4), as recorded on the Health Form and treatment/ medication profile.
9. Cancer treatment type	It is the type of treatment received by the patient for a diagnosis of cancer.	It is the patient's treatment type (chemotherapy alone, or radiation therapy or combination of chemotherapy & radiation), as recorded on the Health Form and treatment/ medication profile.

Table 1 (continued).

Variables	Theoretical Definition	Operational Definition
10. Length of time since treatment started	It is the duration of time since the patient began treatment with cancer.	It is the patient's actual time duration of treatment (in total weeks), as recorded on the Health Form and treatment/ medication profile.
11. Comorbidity	It is the patient's medical conditions, in addition to the primary cancer diagnosis.	It is the patient's medical conditions in addition to the primary cancer diagnosis, as recorded in the Health Form and treatment/ medication profile.
12. Symptom Occurrence and Severity	It is the patient's symptom occurrence and symptom severity, as self-reported during cancer treatment.	It is the patient's total score on symptom occurrence and symptom severity (0-4) during cancer treatments, as self-reported on the 25-item Therapy- Related Symptom Checklist (TRSC).
13. Health-related Quality of life (HRQOL)	HRQOL is the cancer patient's self-reported overall general wellbeing and ability to enjoy normal life activities or Activities of Daily Living (ADL).	HRQOL is the patient's total score on the Health-Related Quality of Life (HRQOL)-Linear Analogue Scale Assessment (LASA). Scores on the HRQOL-LASA were validated (concurrently) by scores on the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C- 30 (EORTC QLQ-C 30). HRQOL-LASA total scores were used to address the study primary research question (RQ).

Summary

Cancer patients during treatment experience multiple symptoms. A systematic tracking of patient-reported symptoms during treatment is essential to prioritize and manage their symptoms effectively (Williams et al., 2014). Oncology nurses are in an influential position to educate, motivate, and support patients and families to manage their treatment-related symptoms effectively at home. The literature shows a dearth of studies focused specifically on symptom occurrence/ severity, health-related quality of life, and the engagement in self-care as influenced by selected variables including ethnicity and age group. That is, the literature shows the need to

study symptom occurrence/ severity, and the engagement in self-care, as reported by (a) diverse groups particularly African-Americans as compared to Caucasians, and by (b) adolescents and young adults (15-39 years) as compared to older adults (40 years old and older). The present study addresses an identified knowledge gap in an extensive literature review on patients during cancer treatments.

Chapter II

Review of Literature

The main purpose of this study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition, and selected demographic variables. Secondary purposes were to examine cancer patients' reported symptom occurrence and severity, and self-care methods by ethnicity and by age group. A literature review was completed based on the purposes of this study and is discussed in detail in Chapter II.

The literature review is presented in eight sections: a) Ethnicity and cultural differences in cancer symptom experience, b) Influence of age, gender, education, marital status and economic status in the cancer symptom experience, c) Symptom Occurrence and Severity by Age Group- Adolescents and Young Adults vs. Older adults, d) Symptoms related to cancer treatments - chemotherapy, radiation therapy, and combination of chemotherapy and radiation therapy, e) Cancer stage and symptoms, f) Cancer therapy-related symptoms and quality of life, g) Cancer symptom management, and h) Outcomes of interventions to manage cancer patients' symptoms. Shown also in Appendix A are Tables 2 to 5 that summarize selected literature; namely, Table 2 (Selected Literature Review: Descriptive, Comparative, Correlational, Other Studies), Table 3 (Selected Literature : Symptom Occurrence and Severity by Age Grouping), Table 4 (Selected Literature: Review Articles), and Table 5 (Selected Literature Review: Intervention Studies on Cancer Symptom Management).

A. Ethnicity and Cultural Differences and the Cancer Symptom Experience

Symptoms are subjective experiences that evolve and change over time (Schulmeister & Gobel, 2008). Racial and ethnic differences in the pathogenesis of common malignancies and

outcomes from treatment remain a major health concern. Factors attributed to these variations include differences in lifestyle, environment, genetics, and tumor biology (Grenade, Phelps, & Villalona-Calero, 2014). Lifestyle and environmental factors, for example, may include transportation problems, financial issues, health literacy, etc. that may affect access to health care. Moreover, ethnic identity and cultural guidelines are important aspects of an individual that supports his/her social network during the cancer journey.

Mao et al. (2007) conducted a study among cancer survivors to determine the prevalence of ongoing symptom burden, and findings of this study reported that Hispanics and Blacks had lower rates of ongoing symptom complaints compared to Non-Hispanic whites. Moreover, Non-white races were significantly less likely to report ongoing symptoms except for psychological distress. Kwok & Bhuvanakrishna (2014) conducted a systematic literature search to examine studies investigating the relationship between cancer patients' culture/ ethnicity and their pain experience. Eleven studies were included in this review. Six studies showed that there were cultural differences in barriers to pain treatment. Compared to Western patients, Asian and Spanish-speaking Latina patients reported higher barrier questionnaire scores. Finding of this review reported a greater prevalence of pain among Hispanics, blacks, and Spanish-speaking Latina patients compared to white cancer patients. Additionally, Asian Americans reported lower levels of moderate pain compared to other ethnicities. Martinez, Snyder, Malin, & Dy (2014), conducted a study to examine disparities in cancer pain by evaluating differences in the odds of reporting pain and in pain severity by race/ethnicity. Findings of this study indicated that pain severity was higher for black patients and multiracial patients compared to white patients.

Im (2007) conducted a study to determine ethnic differences among four of the most common ethnic groups (Hispanic, non-Hispanic (N-H) White, N-H African-American, and N-H Asian) in their reported cancer pain experiences in the U.S. Findings of this study strongly supported ethnic differences in cancer pain experience. Cancer pain scores from both unidimensional and multidimensional scales were significantly different according to ethnicity. N-H Asians were the ethnic group who reported the lowest cancer pain scores. Hispanics had the worst pain in all pain scales among multiethnic groups of cancer patients. N-H African Americans reported lower cancer pain scores than Whites and Hispanics. Pain was the most distressing and bothering symptom among Hispanics and N-H Whites, and that among N-H African Americans and Asians was lack of energy. Lack of energy was the second most distressing and bothering symptom among Hispanics and N-H Whites, and the pain was the second among N-H African Americans (Im, 2007). Stanton et al. (2005) conducted a study to develop and test Breast Cancer Prevention Trial (BCPT) Symptom Checklist among four different patient populations (*N*= 2208), who had previously been diagnosed with breast cancer or were at risk of breast cancer. White women were more likely to report problems on three BCPT symptom scales and the total score than were women of other ethnicities.

Budhrani, Lengacher, Kip, Tofthagen, and Jim (2014), conducted a study to explore racial/ethnic differences in objective sleep disturbances among breast cancer survivors (BCSs) and their relationship with self-reported symptoms. Three ethnic groups were included in the study - white, non-Hispanic, and minority. Significant correlations were found between sleep onset latency (SOL) and depression, SOL, and fatigue, and sleep efficiency (SE) and fatigue among minority BCSs. The association between depression and SOL and fatigue and SOL were stronger in minority BCSs than white BCSs. Findings of this study reported that white BCSs

slept longer than minority BCSs. This study also indicated the need for inclusion of race/ethnicity as an essential component of comprehensive symptom assessments. Im, Ko, & Chee (2013), conducted a study to cluster cancer patients who reported similar cancer pain experience, and to determine ethnic differences in the clusters. Findings of this study reported that Asian Americans reported lower pain scores than did other ethnic groups, and African Americans had higher functional status scores than did other ethnic groups. African Americans reported higher symptom scores than did whites.

Culture plays a significant role in cancer care. Significant changes in the population of the United States are projected in the next four decades, with an increase in aging and non-Caucasian cultural groups (Cope, 2015). Cultural beliefs and values are increasingly being recognized as important determinants of psychological and behavioral outcomes following cancer diagnosis and treatment (Hughes, Fasaye, LaSalle, et al., 2003). Culture influences the entire way in which meaning and response of cancer are framed. Awareness of patients' cultural differences in symptom experience would better enable clinicians to relieve their patients' suffering and enhance quality of life (Kagawa-Singer, 2011). Oncology nurses need to acquire knowledge and skills about different racial and ethnic groups to better provide culturally sensitive care in the clinical practice setting (Cope, 2015).

B. Influence of Gender, Education, Marital Status, Comorbidities, and Economic Status on the Cancer Symptom Experience, and the Quality of Life (QOL).

Cancer is a major life event that causes enormous problems in all aspects such as physical, social, economic, and mental burdens on patients and families. Also, the diagnosis of cancer causes significant discordance in family life that can lead to marital problems such as divorce or separation (Song, Kwon, Choi, Kim, & Park, 2014). Mao et al. (2007) reported that

women were more likely to report ongoing symptoms independent of cancer survivorship status. The gender differences were greatest for psychological distress and insomnia and smallest for pain. Higher levels of education and higher income were associated with lower levels of ongoing symptoms (Mao et al. 2007). Low education was predictive of worse physical symptoms and related to body concerns (Naik, Uy, Anaya, & Moye, 2015). Jimenez et al. (2011) conducted a study in 406 patients with advanced cancer, to explore their symptom clusters, and to evaluate the characteristics associated with various clusters. Findings of this study showed that age, sex, and the primary type of tumor influenced symptom clusters. The symptom cluster, confusion was more frequent in elderly patients, whereas the neuropsychological symptoms predominated in patients less than 70 years old.

Janz et al. (2009) conducted a study to determine racial/ethnic differences in quality of life between white, African American, and Latina women in the early stages of survivorship. There were significant racial/ethnic differences in quality of life during cancer survivorship. African American women reported significantly lower functional well-being, and all racial/ethnic minority groups reported lower physical well-being relative to white women. African American women reported higher emotional well-being than Whites did.

Pisu et al. (2015) reported findings of the long-term effect of lung cancer and colorectal cancer on patients' economic status. Of 3432 survivors, 14% were African-American, 7% were Hispanic, and 79% were white. African Americans and Hispanics had lower education and income than Whites. Approximately 68% of African Americans, 58% of Hispanics, and 44.5% of whites reported economic problems. African Americans and Hispanics had lower education and income than whites. Lipscomb et al. (2012) reported that marital status mediates the impact

of race and comorbidity status on the likelihood of completing their chemotherapy. Race and comorbidity status each interacted with marital status.

Prigozin et al. (2010) conducted a study to examine symptom severity in relation to education, age, marital status, and type of chemotherapy treatment among 51 Israeli women with early stage breast cancer on adjuvant chemotherapy protocol. Education was inversely related to total symptom severity scores. No significant relationship was found between age and general symptoms and marital status and symptoms. Another study conducted by Walsh et al. (2000) evaluated the influence of age, gender, and performance status on symptom profile among 1,000 patients on initial referral to the Palliative Medicine Program. Analysis of their symptoms revealed a significant difference in the symptom experience by age and gender. Males reported more dysphagia, hoarseness, >10% weight loss and sleep problems. Females reported more early satiety, nausea, vomiting, and anxiety. Stanton et al. (2005) reported that women with lower educational level were more likely to be bothered by six of the eight sets of symptoms on Breast Cancer Prevention Trial (BCPT) Symptom Checklist and by total symptoms than women with higher educational levels. Also, unmarried women were less bothered by vaginal problems than married women, but unmarried women reported more problematic symptoms on four subscales of one tool. A study conducted by Heinze et al. (2015) reported that educated subjects had a lower occurrence of symptoms, and they perceived their identified symptoms as less severe.

Alabbas et al. (2015) conducted a study of 40 colorectal cancer patients to explore the impact of physiological symptoms and complications on patients' QOL. Male patients compared with females were more likely to complain of pain. A greater proportion of male patients complained of abdominal cramps, weight loss, and diarrhea. Social and psychological qualities of life between male and female patients were not significantly different. There was no

significant difference between male and female patients in their report of disease acceptance and ability to enjoy life. No difference was also found between genders in their ability to sleep well. Furthermore, there were no differences between genders regarding job fulfillment.

Thomas et al. (2014) conducted a longitudinal study to determine the possible association between symptom clusters and demographic and medical characteristics, and association between symptom clusters and emotional distress. Patients provided symptom assessment data at baseline, 3, 6, and 12 months. Treatment with radiation or chemotherapy and low income predicted higher somatic symptom burden. Patients with younger age, female gender, low income, and treatment with surgery reported more psychological symptoms. The higher nutritional burden was reported by older age and treatment with surgery. Patients reported higher distress with higher somatic, psychological, and nutritional symptom burden. Another study conducted by Kenzik et al. (2015) reported that the potential risk factors for worse physical and mental health- related quality of life (HRQOL) were being a woman, low education, higher disease stage at diagnosis, and receipt of chemotherapy and radiation. Older age was associated with lower physical HRQOL but with higher mental HRQOL. In addition, researchers in this study also observed negative associations between comorbidities and physical HRQOL.

Song et al. (2014) conducted a study among cancer survivors in South Korea to investigate the association and gender related differences between cancer diagnosis and marital disruption. The odds ratio of marital disruption for the below average economic level compared with the above average economic level was 5.64 (95%CI: 1.03-31.02; p=.05), and that of the average economic level compared with the above average economic level was 1.69 (95% CI 0.47- 6.09; p=.43). The findings of this study suggest that marital disruptions were higher among female cancer survivors than those among their male counterparts.

Langford et al. (2015) conducted a study to identify subgroups of women with distinct experiences with the symptom clusters of pain, fatigue, sleep disturbance, and depressive symptoms and evaluate differences in demographic and clinical characteristics. The sample included were women with breast cancer receiving chemotherapy. Three subgroups were identified based on their experiences with the symptoms of pain, fatigue, sleep disturbance, and depression. Latent class profile analysis was used to determine the patient subgroups (low, moderate and high). Patients in the all high-risk class were less likely to be partnered than patients in the low and moderate classes, which may be indicative of increased social support. Higher risk patients were less likely to be employed and had lower annual household incomes. Also, these patients had a more severe comorbidity profile, lower functional status, and clinically meaningful levels of psychological symptoms.

C. Symptom Occurrence and Severity by Age Group: Adolescents and Young Adults (Less than 40 Years Old) vs. Older adults (Over 40 Years Old)

Adolescents and young adults with cancer are vulnerable to distress due to their developmental stage and cancer diagnosis (Kwak et al., 2013). Adolescents and young adults, 15 to 39 years are more likely to be diagnosed with cancer compared to children under 15 years. The most common types of cancer diagnosed in adolescents and young adults were Hodgkin lymphoma, melanoma, testicular cancer, thyroid cancer, and sarcomas (National Cancer Institute, 2015). Erikson et al. (2013) conducted a literature search to document information about the most common symptom clusters in adolescents receiving cancer treatment. This review identified six common symptoms in adolescents during the treatment period: pain, mood disturbances, fatigue, sleep-wake disturbances, nausea/eating problems, and appearance changes. Adolescents experience multiple symptoms that are inter-related, and clinicians should prioritize

symptom management interventions with the adolescents' input to better manage their distressing symptoms.

Stava, Lopez, and Vassilopoulou-Sellin (2006) conducted a large-scale survey to study the consequences of breast cancer among patients who received cancer treatments. Of the sample who were studied, 655 women were age > 55 years, 580 women were between ages 46 years and 54 years, and 695 women were age <45 years at the time of diagnosis. Breast cancer survivors who were younger received chemotherapy more often than older survivors receive, and were more likely to report circulation problems, memory loss and reported that cancer affected their overall health adversely. Kwak et al. (2003) conducted a longitudinal, multisite study of an ethnically diverse sample of 215 patients with age 14 to 39 years to assess their psychological distress within the first four months of diagnosis, and 6 and 12 months after the diagnosis. Analysis showed that distress symptoms at the time of diagnosis were exceeded the population norms, decreased at the 6-month follow-up, however, increased to a level exceeding population norms at the 12-month follow-up.

Kirchhoff et al. (2014) conducted a study among adolescence and young adulthood (aged 15-39) cancer survivors to evaluate QOL outcomes about a non-cancer comparison group by gender, race/ethnicity, and current age. The majority of survivors reported fair/ poor general health compared to control groups. Chang et al. (2011) compared adolescent and young adult to a cancer patient cohort older than 40 years old by the severity of cancer, treatment status, symptom changes, symptom burden, and difficulty in caring for them. Multivariate logistic regression analysis showed that adolescent and young adult cancer patients were more likely to suffer from moderate/ severe fatigue, drowsiness, cognitive difficulties, distress, and hair loss. While the number of symptoms was similar, interference with function was more severe for

adolescent and young adult cancer patients for mood and relations with others. Symptoms were less likely to improve in adolescent and young adult patients. There were no significant differences in cancer stage, current treatment status and clinician's perception of difficulty in caring for adolescent and young adult patients.

A study by Mao et al. (2007) reported an association between cancer diagnosis and increased symptom burden that differed by age. A greater difference was seen in patients younger than 50 years than among those older than 64 years. Mohile et al. (2011) conducted a study among patients receiving radiation therapy to evaluate the relationship between age, symptoms, interference with daily function, and quality of life (QOL). Findings of this study reported a significant difference in symptom experience between young and older patients during radiation therapy. The total symptom scores worsened during radiation therapy for older and younger patients. There were no differences in the change in total symptom burden and interference with QOL between older and younger patients during radiation therapy. After radiation therapy, younger patients reported significantly worse pain, nausea, and sleep disturbance. Symptom interference with walking was reported as more severe in older patients compared to younger patients. Walsh et al. (2000) reported that younger age was associated with 11 symptoms: blackout, headache, sedation, bloating, sleep problems, vomiting, pain, nausea, anxiety, depression, and constipation. Stanton et al. (2005) reported that women aged 45 to 60 years reported more symptoms than women younger than age 45 years or older than age 60 years. Williams (2012) described adolescent and young adult oncology care as an "emerging specialty" and stated the need for age-appropriate services to adolescent and young adults by oncology nurses. A selected literature review is presented in Table 3 (Appendix A). It is noted that "cut-off ages" (between 'younger' and 'older' patients) varied in the studies above.

D. Symptoms as Related to Cancer Treatments

Advances in both diagnostic and treatment modalities changed the face of cancer care dramatically (Van Rooyen, Le Roux, & Kotze, 2008). Improvement of methods used in cancer therapy resulted in increased treatment effectiveness and prolonged survival of patients. However, cancer is still seen as a stressful disease. Physical and psychological changes are evident and impactful from the time the diagnosis is revealed (de Souza et al., 2014). Cancer patients often experience multiple debilitating and unrelieved symptoms because of the cancer treatment (Golan-Vered & Pud, 2013, Williams et al., 2011). Monitoring patient-reported symptoms are necessary to adjust and improve supportive care during chemotherapy (Mooney, Beck, Friedman, Farzanfar, & Wong, 2014). Below is a discussion of studies on the common symptom experiences during chemotherapy, radiation therapy, and combined treatment of chemotherapy and radiation therapy.

Chemotherapy -related symptoms. Chemotherapy treatments have demonstrated a significant role in symptom occurrence and severity. Women, who are receiving chemotherapy for breast cancer experience multiple symptoms concurrently (Golan-Vered & Pud, 2013; Heinze, 2012; Heinze & Williams, 2015; Prigozin et al., 2010). Cancer patients may experience chemotherapy-related side effects, such as fatigue, stress, and discomfort that can have significant effects on comfort and well-being during and after cancer treatment (Kayl & Meyers, 2006; Miaskowski et al., 2006). A study conducted by Williams et al. (2001) reported significant differences in symptoms between patients receiving chemotherapy and radiation therapy. The majority (> 50%) of patients receiving chemotherapy reported fatigue, hair loss, taste change, loss of appetite, and nausea as their major symptoms. Patients receiving chemotherapy alone reported greater symptom severity (significantly greater severity of eight

symptoms) compared to patients receiving radiation therapy alone (significantly greater severity of five symptoms). Cancer patients receiving chemotherapy treatments experience a wide range of distressing side-effects, including treatment-related fatigue, anxiety, pain, nausea, vomiting, mood changes, depression, lack of appetite, dyspnea, alopecia, changes in skin and nails, oral sores, peripheral neuropathy, and numbness in fingers and hands (Akin, Can, Durna, & Aydiner, 2008; Akin & Durna 2013; Cheung et al., 2012; Cramarossa et al., 2013; Hutter et al., 2013; Kennedy, Harcourt, Rumsey, & White, 2010; Mols, Beijers, Vreugdenhil & van de Poll-Franse, 2014; Schneider, Hershman, & Loprinzi, 2015; Senf, Brandt, Dignass et al., 2010, Williams et al,. 2014). Among reported side effects for women during chemotherapy, alopecia is considered as one of the most traumatizing symptom experience. Moreover, distress from alopecia is strongly associated with poorer body image, overall health status, and psychosocial well-being (Choi et al., 2014).

Insomnia is another distressing side effect of cancer and its treatment. Insomnia affects between 30% to 60% of patients with cancer (Savard, Ivers, Savard, & Morin, 2015). Insomnia is common in most cancers but appears particularly in lung, breast, and head and neck tumors. Older women seem most susceptible to insomnia (Induru, & Walsh, 2014). Symptoms of insomnia include excessive daytime sleepiness, difficulty falling asleep, difficulty staying asleep, and waking up too early (Mustian, Janelsins, Peppone, & Kamen, 2014). Insomnia is found to be associated with concurrent chemotherapy and correlated with the degree of depression and pain (George, Elias, & Shafiei, 2015).

Savard et al. (2015) conducted a population-based epidemiological study among patients with breast cancer (n=465) and prostate cancer (n=263) to assess the effect of adjuvant treatments on insomnia symptoms and somatic symptoms. The Insomnia Severity Index and a

questionnaire to assess various somatic symptoms were used at baseline (perioperative period) and two months, six months, ten months, 14 months, and 18 months later. The study found that in patients with breast cancer, treatment with radiotherapy (overall effect) and chemotherapy (at two months), were associated with increased insomnia severity. In patients with prostate cancer, increased insomnia was related to androgen deprivation therapy. Davis & Goforth (2014) reported that sleep disorders cluster with pain, fatigue, depression, anxiety, and vasomotor symptoms, depending on the stage of disease, treatment, and comorbidities. Colon cancer patients aged <70 years treated with either surgery or surgery plus adjuvant chemotherapy, reported significantly more insomnia, diarrhea, and financial problems compared with the normative population (Verhaar et al., 2015).

Williams et al. (2006) conducted a study and identified oncology patients' reported symptoms using the original Therapy-Related Symptoms Checklist (TRSC). Subjects were adults receiving either chemotherapy for leukemia, lymphoma, or breast cancer or radiation therapy for head and neck or lung cancers. Study findings showed that chemotherapy-associated severe symptoms were fatigue, eating, nausea, pain, numbness in fingers and toes, hair loss, and constipation. Williams et al. (2010), conducted a study in 100 Filipino cancer patients (combined chemotherapy and radiation therapy, n=37 and chemotherapy alone, n=63). Patients receiving chemotherapy alone reported more severe symptoms in TRSC subscales - eating, fatigue, nausea, pain, and hair loss.

Williams et al. (2014) conducted a cross-sectional study to examine symptom occurrence among Mexican American adults (n= 67) undergoing cancer chemotherapy treatment. The analysis revealed that 45% or more of patients reported 12 symptoms on the TRSC: feeling sluggish, hair loss, nausea, taste change, appetite loss, depression, difficulty sleeping, weight

loss, difficulty concentrating, constipation, skin changes, and numbness in fingers and toes. Pain, vomiting, decreased interest in sexual activity, cough, and sore throat were other major symptoms reported by more than one-third of participants.

A study was conducted by Williams, Mowlazadeh, Sisler, and Williams (2015), to examine symptom occurrence and severity as reported by U.S. Veterans at a cancer clinic. This study used the 25-item Therapy-related Symptom Checklist (TRSC). Veterans (*N*=100) undergoing chemotherapy and /or radiation therapy participated in the study. Findings showed that 13 symptoms were reported by more than 35% of patients. Top-ranked symptoms by percentage occurrence and severity were feeling sluggish, taste changes, nausea, pain, constipation, loss of appetite, numbness of fingers and toes, difficulty sleeping, weight loss, hair loss, difficulty concentrating, shortness of breath, and decreased interest in sexual activity.

In another study, within a cohort of 100 parents of Thai pediatric oncology patients during treatments, Williams, Piamjariyakul, Shanberg, and Williams (2015), used the Therapy-Related Symptom Checklist for Children (TRSC-C; Thai version). Parents reported symptom occurrence and symptom severity, and their management of the symptoms. Study findings showed that on the 30-item TRSC-C, 18 symptoms were experienced by 42% to 95% of children. Mean severity of the symptoms was between 1.0 (“a bit”) and 2.0 (“quite a bit”).

Langford et al. (2015) reported evidence that there is inter-individual variability in the symptom experience of patients undergoing chemotherapy. Patients in the all high symptom subgroup reported greater interference of pain with mood and daily activities than patients in the moderate symptom subgroup. Moreover, a higher proportion of patients in the all high class described the affective dimension of the pain experience (e.g., exhausting, miserable, and unbearable).

Cancer-related fatigue is one of the most common reported side effect by cancer patients (Adams, 2009; Henry et al., 2008; Mota, Pimenta, & Caponesro, 2012; Yuen, Mitcham, & Morgan, 2006). Cancer-related fatigue is a complex and multifaceted symptom (Mitchell & Berger, 2006). It is characterized by subjective feelings of tiredness, weakness, lack of energy. Cancer-related fatigue is distinct from the "normal" drowsiness experienced by healthy individuals in that it is not relieved by rest or sleep (Hofman et al., 2007; Minton, Richardson, Sharpe, Hotopf, & Stone, 2011; National Cancer Institute, 2013).

Cancer-related fatigue may be an early symptom of the malignant disease; reported by as many as 40% of patients at diagnosis (Hofman et al., 2007). The prevalence of cancer-related fatigue varies based on the type of cancer diagnosis, disease stage, and treatment protocols. The majority of study reports estimate that approximately one-third of cancer survivors experience fatigue (Minton et al., 2013), and up to 80% of those treated with chemotherapy experience fatigue (Hofman et al., 2007). In patients who receive chemotherapy, the prevalence of cancer-related fatigue is between 75 and 90%, and this has a linear increase with progression of treatment (Narayanan & Koshy, 2009). Molassiotis, Sylt, & Diggins, 2007, reported that cancer-related fatigue during and after chemotherapy are the most disruptive symptom in patients' lives and a difficult symptom to manage in practice. It affects patients at all stages of treatment (Minton et al., 2011).

Pettersson, Bertero, Unosson, and Borjeson (2014), conducted a study to describe the prevalence, frequency, and severity of symptoms and the distress during the early treatment of colorectal cancer patients undergoing chemotherapy. A total of 104 patients, 58 men, and 46 women participated in the study. Numbness/tingling in the hands/feet (64 %), lack of energy (62 %), feeling drowsy (49 %), and nausea (45 %) were the highly prevalent symptoms. Lack of

energy was the symptoms with the highest scores for frequency, severity, and distress followed by difficulty in sleeping, and numbness in the hands/feet. Lack of energy was noted as occurring almost constantly by 26 % and was rated as being severe or very severe by 12 % and as quite distressing or very distressing by 15 %.

The severity of cancer-related fatigue varies during each chemotherapy treatment cycle, the most fatigue in the days immediately following each treatment (National Cancer Institute, 2013; Prue et al., 2010). Since there is no test to diagnose cancer-related fatigue (Morrow, Shelke, Roscoe, Hickok, & Mustian, 2005), nurses play a critical role in assessing cancer-related fatigue to identify changes in severity of fatigue over time. Cancer-related fatigue being the most distressing symptom during active chemotherapy, its relationship with overall comfort play an important role in cancer care (Hartvig, Aulin, Hugerth, Wallenberg, & Wagenius, 2006). In a study conducted with 154 lung cancer patients at any stage of their chemotherapy, lack of energy, coughing, pain, lack of appetite, nausea, feeling nervous, difficulty sleeping, feeling sad, and worrying were most common. Among those symptoms, lack of energy was most distressing (Akin, Can, Aydiner, Ozdilli, & Durna, 2010).

Women with breast cancer often experience severe psychological problems, such as reduced self-esteem, feeling of losing their femininity, anxiety, depression, concern about impaired body image, desperation, guilt and shame, fear of a relapse, isolation and fear of death (Lewis, Sheng, Rhodes, Jackson, & Schover 2012; Ohaeri, Ofi & Campbell, 2012). Breast cancer and its treatment may result in significant difficulties with sexual functioning and sexual life (Sbitti et al., 2011). Menopausal symptoms are a frequent and troublesome side effect of cancer chemotherapy in women of all ages (Hickey, Peate, Saunders, & Friedlander, 2009). Park

and Yoon (2013) reported that women with breast cancer had alterations in menopausal symptoms, sexual dysfunctions, and depression during chemotherapy.

According to Golan-Vered and Pud (2013), neuropathic pain, depression, sleep disturbance, and fatigue are major symptoms among women with breast cancer during chemotherapy. Cancer-related fatigue was reported as one of the most prevalent and significant problem experienced by breast cancer patients (Ho, Fong, & Cheung, 2014). According to Kidwell et al. (2014), anxiety, depression, poor sleep quality, and difficulty concentrating as major reported symptoms of postmenopausal women with breast cancer during chemotherapy. The level of uncertainty and anxiety may increase when breast cancer women experience unexpected side effects during chemotherapy (Lien et al., 2010). Myers (2012) reported cognitive impairment as a major symptom for women with breast cancer during and after chemotherapy.

Heinze and Williams (2015) reported findings of a study conducted among breast cancer survivors (*N*=195), who completed treatment six months before the survey. Participants who received chemotherapy as their treatment reported significantly higher TRSC scores. Breast cancer survivors in that study reported an average of 12 symptoms on the TRSC. Higher TRSC symptoms were reported by breast cancer patients who had experienced chemotherapy treatments, and the effects were long-lasting (Heinze, Williams, Pierce, Diaz,& Kirschner, 2015).

Mooney et al. (2014) developed an automated telephone-based symptom monitoring system to bridge the communication gap about unrelieved symptoms during chemotherapy between patients and oncology providers. Randomized parallel group clinical trial design was used in this study. All patients were asked to report on ten symptoms—pain, fatigue, nausea/vomiting, fever, trouble sleeping, anxiety, depressed mood, sore mouth, diarrhea, and

constipation by calling the automated monitoring system daily. Symptoms were common in both groups. Fatigue was the most prevalent moderate-to-severe symptom reported by 89.2 % of participants followed by trouble sleeping (74.9 %) and pain (70.4 %). Depressed mood and nausea/vomiting were also prevalent at moderate-to-severe levels in over half the patients. Automated telephone-based symptom monitoring is an easy method to monitor patients' symptoms. However, symptom management did not improve, providers did not intensify symptom treatment, and there were no gains in symptom relief.

The complexity of regimens makes patients experience potentially toxic or disturbing adverse effects, requiring prompt and effective self-care (Williams et al., 2013). Early detection of symptoms and careful dose selection are essential for preventing the simultaneous occurrence of severe symptoms (Golan-Vered & Pud, 2013). Patient-reported symptoms might guide physicians and oncology nurses to plan effective treatment. There is increasing interest to integrate patient-reported symptoms into routine clinical practice. This will enhance patient-clinician communication, symptom detection, symptom control, quality of care, and patient satisfaction (Basch, 2014).

TRSC is a valuable tool that can be administered at any clinical oncology setting to identify common symptoms. Studies conducted by Heinze, 2012 ; Heinze and Williams , 2015; Piamjariyakul et al., 2010; Williams, Graham, Storlie, Pedace, Haeflinger et al., 2013; Williams, Graham, Storlie, Pedace, Otte, et al., 2011; Williams, Lopez, et al., 2010; Williams, Piamjariyakul, et al., 2006; Williams, Schmideskamp, Ridder, & Williams, 2006; Williams, Williams, LaFaver-Roling, et al., 2011; Williams, Williams, Smith, et al., 2011; Williams et al., 2012; Williams et al., 2011, 2013, 2014 found that use of the TRSC improved symptom monitoring, documentation and management/ interventions.

Coolbrandt et al. (2015), conducted a qualitative study to explore methods used by patients to manage their chemotherapy-related symptoms in their home, factors influence their self-management and roles of professional caregivers. Data were collected from 28 adult patients with cancer being treated with chemotherapy using semi-structured interviews. Patients expressed very personal symptom experiences and symptom-management styles, which are influenced and shaped by personal factors and characteristics (e.g. perceived level of control, coping with cancer and cancer treatment,), and environmental factors (e.g. professionals' attitude, available information resources). Researchers of this study recommend that professional care should be tailored to the individual patient's perspective and should address personal, social, and environmental determinants of their behavior.

Armes et al. (2014) conducted a study to develop and test an outcome measure [Patient-Reported Chemotherapy Indicators of Symptoms and Experience (PR-CISE)] for use in an ambulatory chemotherapy settings and to assess its acceptability, feasibility, and preliminary efficacy in clinical practice. Three areas were covered by PR-CISE- symptom management, safe medication administration, and experience in supportive care. Across the whole sample, 25% reported moderate or severe nausea; however, rates varied between centers. Results of this study showed that monitoring outcomes demonstrate potential differences quality of patient care and provide a stimulus to enhance patients' health and experience.

Increasing patient comfort and well-being during the chemotherapy process is a goal of all oncology nurses (Catlin & Taylor-Ford, 2011). Chemotherapy-related symptoms might occur at any stage of cancer treatment. Therefore, ongoing assessment of symptoms is necessary for effective treatment. Oncology nurses play a major role in symptom assessment to provide patient-centered education and treatment. This may reduce complications, increase treatment

adherence, and help cancer patients manage their symptoms effectively during treatments. There are a number of studies conducted on cancer survivors; however, there is a lack of literature on symptom assessment of cancer patients undergoing chemotherapy by ethnicity and age grouping. Therefore, the present study makes a valuable contribution to cancer chemotherapy-related symptom documentation, management, and outcome.

Radiation therapy-related symptoms. Radiation therapy is one of the main methods of cancer treatment alone or in combination with chemotherapy. It is used in about 60% of oncological patients (Brzozowska, Idziak, Burdan, & Mazurkiewicz, 2015). In 2001, Williams et al. reported that radiation therapy patients reported sore throat, skin changes, weight loss and decreased interest in sex as their major symptoms. In another U. S. study (Williams et al., 2006) the investigators found that, the main symptoms associated with radiation therapy were on the TRSC *subscales* eating, fatigue, skin changes, oropharynx, and constipation. In 2010, Williams et al. (2010a, b) replicated the 2006 study on adult cancer patients in two countries (Manila, Philippines, and Xian, China). Similar findings were obtained as those reported in the 2006 study.

Cancer-related fatigue is a major symptom related to radiation therapy, and in one study, up to 90% of patients treated with radiation therapy reported this symptom (Hofman et al., 2007). Hofso, Rustoen, Cooper, Bjordal, and Miaskowski (2013) evaluated changes in and predictors of severity, occurrence, and distress of six common symptoms (difficulty sleeping, feeling drowsy, sweats, lack of energy, worrying, and pain) during radiation therapy for breast cancer. Younger patients were more likely to report the occurrence of lack of energy. Fatigue-related symptoms (lack of energy, difficulty sleeping, and feeling drowsy) were reported by more than 50% of these patients at the initiation of radiation therapy. Brzozowska et al. (2015) also

reported that radiotherapy is associated with a high risk of radiation-induced side effects, such as dermatitis, enteritis, cystitis, pericarditis, coronary heart disease, cardiomyopathy, anomalies of heart valves, pneumonia, depression, sexual function disorders, and development of the second malignant tumor.

Dose-limiting potential side effects of radiation therapy include mucositis, diarrhea, skin toxicity, and xerostomia. Cancer-related fatigue is a common side effect that is not necessarily dose-limiting but considerably troublesome to patients receiving cancer treatment (Stubbe, & Valero, 2013), and is complex and may involve multiple contributing factors (Mustian et al., 2007). According to Muehlbauer et al. (2009), diarrhea occurs up to 50% in patients receiving radiation therapy to the pelvis or abdomen. Diarrhea can cause fluids and electrolytes imbalance, malnutrition, dehydration, and hospitalization, all of which can lead to cardiovascular compromise and death. Diarrhea can adversely affect the quality of life, the integrity of cancer treatment, and therefore, it needs to be vigorously managed to avoid complications, hospitalization, or serious harm.

Mucositis is a common side effect of radiation therapy especially seen during treatment for head and neck malignancies (Gussgard, Jokstad, Hope, Wood, & Tenenbaum, 2015). Mucositis may result in dose limitation, pain, the greater chance of infection, and dysphagia, and may lead to difficulty swallowing food and fluid, poor nutrition and hydration status, and possible weight loss (Keefe et al., 2007; Worthington, 2011). Radiation treatments also may cause a variety of physical skin reactions and contributes to pain, discomfort, irritation, itching, and burning. Skin changes is another common problem that can occur in up to 95% of patients undergoing radiation therapy. Patients with a higher risk of skin reaction include those receiving

treatment to the perineum, axilla, breast, and face, as well as to areas of disrupted skin integrity such as from surgery, burns, or other lesions (McQuestion, 2011).

Xerostomia, or dryness of the mouth, due to lack of normal salivary secretion, is another serious side effect of radiation therapy that can be acute or late (Bruce, 2004). Acute effects may present during treatment or up to 3 months after treatment and is usually self-limiting. Late effects may appear more than three months after radiation therapy ends and may be permanent. Alsadius et al. (2013), conducted a study in prostate cancer patients to examine the association between urinary and long-term gastrointestinal symptoms with perceived fecal or urine body odor after radiation therapy and its effect on quality of life. Males who perceived fecal or urine body odor reported a lower physical health, more frequent feelings of depression, and a lower QOL compared with those who did not perceive such body odor. The two most common complaints associated with prostate radiotherapy were urinary symptoms and sexual dysfunction. Erectile dysfunction is one of the most concerning toxicities after radiotherapy (Rana et al., 2015).

Sun et al. (2014) conducted a study among early-stage lung cancer patients to examine the quality of life and symptoms after stereotactic body radiotherapy. Nineteen non- small cell lung cancer patients who were medically not suitable for surgery or chose not to undergo surgery were included in the study. Patients completed a baseline assessment of functional and cognitive status, symptoms, psychological distress, and overall Quality of Life (QOL). Questionnaires were administered at 6 and 12 weeks after accrual. The most severe symptoms at baseline were pain, lack of energy, cough, nervousness, difficulty sleeping, shortness of breath, and worry. At the 12-week evaluation, severity scores for pain, lack of energy, and cough increased; but nervousness, difficulty sleeping, and worry decreased.

Symptoms related to combined chemotherapy and radiation Therapy. A study was conducted by Williams et al. (2010a), using the TRSC examined patient-reported symptoms and self-care strategies of Chinese adult cancer patients during treatments. A total of 222 patients were included in the study, of which 73 were on combined chemotherapy and radiation therapy. Findings of this study reported that Chinese patients on combined radiation therapy and chemotherapy reported more symptoms with greater severity than those receiving either chemotherapy or radiation therapy alone. Major symptoms reported by patients on combined chemotherapy and radiation therapy were the subscales on fatigue, eating, hair loss, and decreased interest in sexual activity. The study was replicated by Williams et al. (2010b), among 100 Filipino patients, of which 37 were on combined chemotherapy and radiation therapy. Patients receiving combined chemotherapy and radiation therapy reported more severe symptoms on the *subscales* fatigue, eating, oropharynx, nausea, pain, decreased sex interest, and constipation. Patients who received both chemotherapy and radiation therapy reported significantly greater symptom severity than patients on chemotherapy alone.

Piamjiariyakul et al. (2009) reported similar findings of symptom occurrence and severity when using the TRSC to study 202 Thai oncology patients. In this study, 52 patients were undergoing both radiotherapy and chemotherapy, 103 had chemotherapy alone, and 47 had radiation therapy alone. In addition, they found that, (a) higher functional status (measured by the Karnofsky scale) was significantly related to lower symptom occurrence and symptom severity on the TRSC; and (b) Thai patients who received both chemotherapy and radiation therapy had greater symptom occurrence and symptom severity compared to those receiving either chemotherapy or radiation therapy alone.

Likhacheva et al. (2013) conducted a prospective study to assess symptoms in 52 patients with locally advanced cervical cancer undergoing concurrent chemoradiotherapy with weekly cisplatin, or every three weekly cisplatin/ 5Fluorouracil. Major symptoms reported were diarrhea, nausea, anorexia, stomatitis, drowsiness, and fatigue. This treatment regimen was associated with higher levels of fatigue, depression, anorexia, stomatitis, and diarrhea than the WP regimen. Kirchheiner et al. (2015) reported patient symptoms before, during and early after treatment with external-beam radiotherapy, chemotherapy and image-guided adaptive brachytherapy for locally advanced cervical cancer. The most frequently reported symptoms during active treatment were: fatigue (78%), diarrhea (68%), urinary frequency (60%) and nausea (54%); these symptoms recover to some degree three months after the end of treatment.

Xiao et al. (2013) studied patients with head and neck cancers being treated with concurrent chemo-radiotherapy to identify their symptom clusters. Two symptom clusters were identified. The head and neck specific cluster is composed of dysphagia, radio mucositis, dry mouth, pain, radiodermatitis, taste disturbance, and fatigue. The gastrointestinal cluster includes nausea, vomiting, and dehydration. These findings will contribute to the assessment, prevention, and management of multiple symptoms.

E. Cancer Stage and Symptoms

Cancer always referred to by the stage at which it was diagnosed (National Cancer Institute, 2015). Cancer symptoms may vary by cancer stage and extend of metastasis. Alexiusdottir et al. (2012) conducted a study among the 768 colon cancer patients to identify their symptoms related to TNM stage and the location of the tumor. Nearly 60% had anemia at the time of diagnosis, 53% had visible blood in stools, and 65% had changes in bowel habits. Seventy five percentage of patients with right-sided tumors had anemia and were diagnosed

incidentally (40%) than those with left-sided tumors (20%). Left-sided tumors were associated with changes in bowel habits (74% compared to 57%, $p < 0.05$) and blood in stools (68% compared to 41%, $p < 0.05$). Visible blood in stools was significantly associated with lower TNM-stage, whereas abdominal pain, general and acute symptoms were associated with higher TNM-stage.

Walling et al. (2014), surveyed 5422 patients with colorectal and lung cancer from the diverse, nationally representative Cancer Care Outcomes Research and Surveillance Consortium cohort to obtain data about symptoms (pain, fatigue, depression, nausea/vomiting, cough, dyspnea, diarrhea). Of the 5422 patients, 93.5% (n= 5067) reported, at least, one symptom in the four weeks before their survey and 51% reported, at least, one moderate/severe symptom. Lung cancer patients reported more symptoms compared to colorectal cancer patients. However, most recently diagnosed lung and colorectal cancer patients had cancer-related symptoms regardless of stage, and more than half had, at least, one moderate/severe symptom.

A large multicenter study was conducted by Cleeland et al. (2013) to examine the effects of cancer stage and disease site on the percentages of patients' rating of symptoms as moderate to severe. The severity of 13 symptoms "core" oncology symptoms was rated by ambulatory patients (N=3106) with cancer of the breast, lung, prostate, or colon/rectum. Disease stage was classified as no evidence of disease, locoregional, metastatic, locoregional/ metastatic. Fatigue/tiredness was the most severe symptom reported, followed by sleep disturbance, dry mouth, pain, and numbness/tingling. More patients with lung cancer diagnosis and patients receiving treatment reported moderate to severe symptoms. Percentages of symptomatic patients increased by disease stage, less adequate response to therapy, and declining performance status.

F. Cancer Therapy-Related Symptoms and Quality of Life

Cancer has become a chronic disease for an increasing number of patients, and its prevalence rates are rising. Therefore, more patients are living with side effects of cancer and its treatment, which can have a negative impact on patients' QOL (Mols et al., 2014). Achievement of good QOL is an important goal in cancer treatment (Fingeret, Nipomnick, Crosby & Reece, 2013). Cancer patients experience multiple symptoms that affect their quality of life to varying degrees (Cramarossa et al., 2013; Reyes-Gibby et al., 2013). Moreover, cancer treatment may result in severe and often debilitating symptoms that contribute significant distress and severe impairment of daily function and QOL (Harrow et al., 2014; Hwang, Chang, & Park, 2013; Pud et al., 2014; Samuels, Maimon, & Zisk-Rony, 2013; Weis, 2011). Personal characteristics as well as treatment- and disease-related characteristics may also influence QOL among breast cancer patients (Bayram et al., 2014). Psychosocial distress related to cancer diagnosis and treatment is a major factor that affects QOL (Heinze, Williams, & Bott, 2015).

Younger women with breast cancer have reported greater QOL disturbances than older women (So, Choi, Chan, & Chair, 2011). Poor management of chemotherapy-induced symptoms may also have detrimental impacts on patients' QOL. In addition, frequent hospitalizations and an inability to complete self-care activities negatively affect patients' QOL (Cramarossa et al., 2013). Body image disturbances among breast cancer patients contribute psychosocial problems, which may reduce their QOL (Bayram et al., 2014).

Heinze et al. (2015) examined ongoing symptoms in breast cancer survivors. Data on symptom occurrence and severity, QOL, daily activities, subject characteristics, and medical information were collected using an electronic version of the Therapy-Related Symptom Checklist (TRSC), Daily Activities Rating Scale, Health-Related Quality of Life- Linear Analog

Self Assessment (HRQOL-LASA), a Demographic Form, and a Health Form. Results showed that, as expected, high total TRSC scores were significantly related to low scores on the Health-Related Quality of Life-Linear Analog Self-Assessment.

Chemotherapy-induced nausea and vomiting are distressing symptoms among breast cancer patients, and it has a substantial negative impact on all aspects of patients QOL (Hassan & Yusoff, 2010). Chemotherapy-induced peripheral neuropathy is another frequently reported side effect, which adversely affects daily functioning and negatively influences QOL (Miltenburg & Boogerd, 2014). Masmoudi, Frikha, and Daoud (2009) conducted a study to assess QOL among outpatient breast cancer patients on chemotherapy. Findings of the study reported that there was a significant deterioration in physical functioning, cognitive functioning, and social functioning during chemotherapy between baseline and during the third cycle of chemotherapy. In conclusion, women with breast cancer undergoing chemotherapy have a decline in overall HRQOL (Jeste et al., 2012).

Cancer-related fatigue has a significant impact on patients' quality of life (QOL) and ability to carry out normal daily activities (Carroll, Kohli, Mustian, Roscoe, & Morrow, 2007; Mitchell et al., 2007). Compared with other symptoms, such as pain or nausea, cancer-related fatigue is more distressing and long-lasting, with a strong impact on activities of daily living and quality of life (Weis, 2011). Additionally, cancer-related fatigue is an important and highly prevalent symptom that negatively affects cancer patient's quality of life, and therefore, should be a high priority for treatment (Brown & Kroenke, 2009; Morrow et al., 2005). Cancer-related fatigue has a strong and direct negative impact on all aspects of the QOL of patients with cancer, particularly, their physical wellbeing (Morrow, 2007), and total symptom severity (Hoffman, 2007). Lis, Rodeghier, Grutsch, and Gupta (2009) reported that cancer-related fatigue decreases

cancer patients' overall satisfaction and health-related quality of life. A study conducted by Garabeli, Cavalli, Kluthcovsky et al. (2012) in breast cancer survivors reported that fatigued women had poorer health-related quality of life than non-fatigued women in all domains. Insomnia is another problem cancer patients suffer with and that increases cancer symptom burden and impairs quality of life (Induru & Walsh, 2014).

Kenzik et al. (2015), examined associations of symptoms with physical and mental health-related quality of life (HRQOL) in patients with colorectal cancer (*N*= 3040) and lung cancer (*N*=2297). HRQOL was measured by using physical component summary (PCS) and mental component summary scores. Symptoms were associated with HRQOL impairments in newly diagnosed patients. Findings of this study suggested that cancer patients were in need of supportive care strategies that can address symptoms with the objective of improving their HRQOL.

Kirchheiner et al. (2015) evaluated QOL of cervical cancer patients before, during and early after treatment with external-beam radiotherapy, chemotherapy, and image-guided adaptive brachytherapy. In fifty consecutive patients, HRQOL and patient symptoms were prospectively assessed with the EORTC-QLQ-C30 and cervical cancer specific questionnaire before and during treatment, one week after image-guided adaptive brachytherapy and three months after that. HRQOL was compared to an age-matched, female normative reference population. Global health status and physical and role functioning showed a highly significant decline during treatment and compared to the reference population, the global health status and emotional, and role functioning remains impaired. These results can contribute to patients' counseling about what to expect about frequency and intensity of side effects, functional impairments in daily life and the expected time for recovery.

The follow-up, education, and management of chemotherapy-related symptoms helped cancer patients cope effectively with their condition and improved their QOL (Bayram et al., 2014). Alabbas et al. (2015), assessed the impact of physiological symptoms and complications of colorectal cancer on patients' QOL. Social and psychological QOL were not significantly different between male and female patients. Male and female patients did not differ in their report of disease acceptance and ability to enjoy life. This study suggests the importance of gender-based treatments in improving patients' QOL.

Harrow et al. (2014) identified the importance and need for new service models to improve the quality of life of women with breast cancer. Therefore, nurses should assess the patients' symptoms during treatment and provide timely intervention to optimize their quality of life (Huang et al., 2013). Even though a number of studies have evaluated QOL among cancer survivors, only a limited number of studies have evaluated QOL during chemotherapy/radiation treatment. Available literature clearly reports the evidence that cancer therapy-related symptoms significantly lower QOL among cancer patients. Therefore, the present study findings will add a valuable contribution to improve cancer patients' QOL during active cancer treatments, and can further indicate the directions needed for better cancer therapy-related care.

G. Cancer Symptom Management

The control of cancer-related and treatment-related symptoms and symptom reduction is an essential component of cancer care for patients with advanced disease (Cleeland et al., 2013). Cancer care ensures effective symptom management and best possible quality of life not only regarding physical health, but also by addressing the psychosocial, and spiritual needs of patients and their families (McCabe, 2008). Oncology patients' symptom clusters may have a common underlying cause. About half of all patients with cancer use complementary or alternative

medicine (Huebner, 2014). Patients want to achieve different goals using complementary or alternative medicine. They aim at reducing side effects and/or stress, and thereby increasing the quality of life, and obtaining better control of the disease (Paul et al., 2013). Several studies have focused on the use of complementary or self-care methods to alleviate cancer therapy-related symptoms. Findings overall showed that a change in diet/nutrition/lifestyle and mind/body control were used most often to manage cancer-therapy related symptoms among patients in the Midwest (Williams et al., 2006; Puerto Rico (Gonzalez et al.2011); Thai patients (Piamjiariyakul et al., 2010), Chinese patients (Williams et al., 2010a), and Filipino patients (Williams et al., 2010b). There is a need for further research into symptom monitoring and self-care practices among adult oncology patients.

The key factors and behaviors that lead to symptom management and the problems relating to self-care in Taiwanese outpatients with breast cancer in the context of chemotherapy were described by Kuo, Liang, Tsay, Wang, & Cheng (2015). This study was a qualitative study conducted among 17 women with breast cancer who were aged 30-64 years and had undergone chemotherapy. Four main categories of tasks were identified and were communicating chemotherapy-related concerns, chemotherapy-related symptom management, management of emotional/interpersonal disturbances, and acquiring relevant resources. Heinze and Williams (2015) conducted a study to describe the self-care strategies used to alleviate symptoms reported by breast cancer survivors. The self-care strategies most commonly reported were diet/nutrition/lifestyle and the least common strategies were herbs/vitamins/ complementary therapy.

Enhancing patient comfort and well-being during the chemotherapy treatment is a major goal of all oncology nurses (Catlin & Taylor-Ford, 2011). Identification of common symptoms

and self-care practices are important to help patients manage their symptoms at home. It will also help physicians to identify and treat their patients' symptoms more effectively and efficiently. Obeidat and Khrais (2014) reported information needs of Jordanian women with breast cancer and the majority of women wanted information about breast cancer diagnosis, chances of cure, and treatment side effects. Assessing symptom self-management among men with newly diagnosed prostate cancer can help healthcare providers develop strategies that will enhance health-related quality of life (Hsiao, Moore, Insel, & Merkle, 2014).

Guiding and motivating patients and families toward self-care activities may reduce symptom burden and can enhance patients' cancer experience across the illness journey (McCorkle et al., 2011). Williams et al. (2013) conducted a quasi-experimental, intervention study among a sample of 110 oncology patients from an oncology clinic in the U.S. The findings were that the cohort of oncology patients (*n* =55) who used the TRSC to self-report their symptoms and had their health care providers use the patient-reported symptoms as guide during clinic visits had (a) more symptoms identified and managed, (b) significantly higher HRQOL, and (c) better functional status -- as compared to 'usual care' patients (*n*=55),who did not use the TRSC (Williams et al., 2013). Williams et al. (2015) reported that the most frequently reported self-care strategies among Thai adults during cancer treatments were in the categories of medicines (prescribed, over-the-counter); diet and nutrition (e.g., diet change, small frequent feedings, spices, nutritional supplements); and lifestyle change (e.g., rest, naps). Herbal, vitamin, and biologic treatments were least used; two reported use of vitamins for weight loss. In another study, Williams et al. (2015), in their study conducted among Thai children as well as adolescents, and found that parents reported the use of complementary care strategies, especially diet and nutrition. Thai parents' care strategies included adding flavoring to food items,

changing the variety of foods, providing small frequent meals, and offering soft or liquid diets. Prescribed medications were also used to alleviate symptoms including antiemetic for nausea, mouth sprays for sore mouth, inhalers for shortness of breath, analgesics for fever and pain, and laxatives for constipation.

H. Outcomes of Interventions to Manage Cancer Patients' Symptoms

Interventions to manage patient reported symptoms may improve breast cancer outcomes and quality of life (Kidwell et al., 2014). Sherman et al. (2012) conducted a study to examine the effects of telephone counseling and psychoeducation and on the adjustment of women with early-stage breast cancer. Findings were that psychoeducation by videotapes and telephone counseling decreased side effect distress, side effect severity, and increased psychological well-being.

In an evidence-based practice (EBP) study, Williams et al. (2011) conducted an educational intervention study to manage patient-reported symptoms on the TRSC during cancer treatment. Findings showed that patient education, counseling, and follow-up by advanced practice nurses (APRNs) decreased patients' self-reported symptom severity, and improved health-related QOL. Other studies have reported that satisfied patients, patients with fulfilled information needs, and patients who experience fewer information barriers, in general, had a better QOL and less anxiety and depression (Husson et al., 2011). Juarez, Mayorga, Hurria, and Ferrell (2013) also reported that a psychosocial intervention improved QOL and patient outcomes among breast cancer survivors.

Donovan et al. (2014) examined the feasibility, system usability, participant satisfaction, and efficacy of the Written Representational Intervention to Ease Symptoms (WRITE Symptoms) among women with ovarian cancer. WRITE Symptoms is an educational

intervention delivered through web-based message boards between a study participant and a nurse. Measures were obtained at baseline and two and six weeks post intervention. Participants found the intervention and assessment system easy to use and reported high levels of satisfaction. Findings of this study support the potential efficacy of WRITE Symptoms for improving symptom-related distress and reduce patients' symptom severity.

McMillan and Small (2007), conducted a study to test an intervention for hospice caregivers to help them better manage symptoms experienced by cancer patients. Hospice and home care cancer patients and their caregivers (*N*=329), were randomly assigned to three groups: 1) a control group receiving only standard care (*n* = 109), 2) a group receiving standard care plus friendly visits (*n* = 109), and a group receiving standard care plus the creativity, optimism, planning, expert (COPE) information intervention (*n* = 111). Symptom distress was significantly improved in the COPE intervention group.

A randomized control trial was conducted by Doorenbos, Given, Given, and Verbitsky (2006), to determine whether age, comorbidity, stage of cancer, depressive symptomatology, symptom limitations, sex, and site of cancer moderates the effects of the cognitive behavioral intervention on physical function. Two hundred thirty-seven individuals with solid tumor cancer (118 experimental and 119 control group) participated in this 10-contact, 18-week randomized control trial. Data collection occurred by trained telephone interviewers using a computer-assisted telephone interviewing system. Cognitive behavioral theory guided the nurse-delivered problem-solving experimental intervention. The intervention goal was to provide empirically based strategies to enhance self-efficacy. Women with breast cancer had significantly better physical functioning than women with lung cancer. The intervention was shown to influence

physical function trajectories differently for individuals with different personal and health characteristics.

In a study at Mayo Clinic, Williams et al. (2013) showed that patients (*n*=58) who received nurse led education/ counseling during visits to clinic reported significantly higher HRQOL (as measured by the HRQOL-LASA), and higher functional status as measured by the Karnofsky scale compared to patients (*n*= 55) who did not receive the education/ counseling (see Appendix A). Moreover, these patients also reported *less* symptom severity over time (range 3-11 clinic visits; average = 5). Similar findings were reported by Williams et al. (2011).

Sherwood et al. (2005) conducted a study to evaluate the effectiveness of a cognitive behavioral intervention in decreasing symptom severity in cancer patients undergoing chemotherapy. Nurses with experience in oncology delivered a five-contact, eight-week intervention aimed at teaching patients problem-solving techniques to affect symptom severity. Patients with lower symptom severity at baseline and those in the experimental group had significantly lower symptom severity at 10 and 20 weeks of treatment with chemotherapy than patients in the control group.

As previously mentioned, selected publications are presented in tabular form (Tables 2-5) in Appendix A. Table 2 includes 56 research studies related to cancer patients' symptoms and quality of life; 22 of these were conducted in the United States of America and 34 in Europe, Asia, and other countries. Table 3 consists of 6 studies related to symptom occurrence and symptom severity by age grouping (patients younger than 40 years old vs. patients 40 years old and above). Table 4 includes 23 review articles related to cancer- related symptoms and HRQOL; 10 reviews were focused on fatigue, three were on nausea and vomiting, two on

neuropathy and the remaining were on other single symptoms. Table 5 includes 14 "intervention" studies conducted to manage cancer patients' symptoms.

Summary

The studies reported that cancer patients experience various symptoms with different severity, influenced by demographic and health characteristics. Cancer therapy-related symptoms are highly prevalent occurs at any stage of cancer treatment. Severe unmanaged symptoms can reduce treatment compliance (Williams et al., 2011). Some studies have shown that proper assessment, management of symptoms, education, counseling, and follow-up helped cancer patients and families and enhanced HRQOL. Oncology nurses can identify and treat cancer therapy-related symptoms more efficiently to optimize cancer patients' symptom management, promote overall wellbeing, and HRQOL. However, although an extensive amount of literature has been reviewed, there was a lack of studies focused specifically on symptom occurrence, severity, quality of life, and the engagement in self-care as influenced by selected variables such as ethnicity and age grouping. That is, the literature shows the need to study symptom occurrence, severity, and the engagement in self-care, as reported by (a) diverse groups particularly African Americans vs. Caucasians, and by (b) an emerging age grouping: adolescents and young adults (18-39 years) as compared to older adults (40 years old and older).

Chapter III

Methods

The primary purpose of the study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities), and selected demographic variables (ethnicity, age, gender, marital status, education, economic status). The secondary purposes were to compare symptom occurrence and severity and self-care methods by ethnicity and by age grouping. Chapter III describes the research design, sample, setting, data collection procedures, study variables and their measures, and plan for data analyses.

Design, Sample, and Setting

Research Design and Setting

This study used a descriptive correlational design. Data were collected from three groups of patients receiving cancer treatments, specifically those receiving: 1) chemotherapy alone, 2) radiation therapy alone, or 3) the combination of chemotherapy and radiation therapy. The study was conducted in a major hospital system in the Northeast region of the Unites States.

Recruitment occurred at the outpatient chemotherapy infusion unit, radiation oncology department, cancer treatment center, and the inpatient oncology unit of a major hospital system in the Northeast region of the United States. This hospital system is located in a large metropolitan area and is among the regions' most honored and respected hospital system with in-patient beds and various outpatient services, including cancer care to a diverse ethnic and socio-economic groups. It is recognized for its comprehensive oncology program, cancer research, and clinical trials. Physicians in the outpatient chemotherapy infusion unit, radiation oncology

department, cancer treatment center, and inpatient oncology unit are experts in cancer care and are board certified in their specialties. The cancer treatment center provides various services to cancer patients such as office visit, follow-up, referral services, laboratory services, chemotherapy infusion, support groups, nutritional counseling, education, resource materials, social work services, and financial assistance. The radiation oncology department provides services such as radiation treatment for outpatients and inpatients, physician and clinical nurse consultations, and follow-up visits. Consultation rooms located within each department were used with prior permission for data collection by the study researcher.

Sample

A convenience sampling method was used, with the intention for quota sampling by two variables: ethnicity (African-American vs. Caucasian), and age group (less than 40 years vs. 40 years and older). Specifically, the sampling plan was for 110 participants to include 50% of African-Americans, 50% Caucasian, and to include at least 30% of subjects in the age group of less than 40 years old. However the actual study did not accrue 30% of subjects less than 40 years old; rather it was only 10% (n=11) of subjects under 40 years of age. The student researcher received approval from her advisor to end data collection with 110 participants, as there was a lack of availability of the sample less than 40 years of age group at the study site. Subjects were recruited to participate in the study regardless of socioeconomic background and both male and female cancer patients with various cancer diagnoses and undergoing chemotherapy, radiation therapy, or a combination of chemotherapy and radiation treatments.

Sample size. Sample size consideration used a rule of thumb for multiple linear regression of at least10 subjects per coefficient (Cleophas &Zwinderman, 2012; Wilson Van Voorhis & Morgan, 2007). There were 11 independent variables in the conceptual model 1

(Figure 1). Variables found significant in univariate analysis and other clinically significant variables were entered in multiple linear regression. Sample size was 110 for the present study.

Inclusion and exclusion criteria. Inclusion criteria were adult cancer patients who: a) had received at least one week of chemotherapy/radiation treatment, b) were at least 18 years old, c) had a score of 50 or above on Karnofsky performance/ Functional Status Scale, d) were able to speak, read, and write English, e) had no history of mental illness, and f) had signed an informed consent. Excluded were those who had only surgery without chemotherapy/ radiation therapy, and, palliative /hospice patients. Subjects were screened based on these inclusion and exclusion criteria.

Subject recruitment. Participants were recruited through "flyer"/advertisement about the study. A copy of the flyer is shown in Appendix B. The study researcher (this student), with hospital permission, posted copies of an IRB approved "flyer" describing the study at the inpatient unit nurses' station and on the outpatient clinic bulletin boards. The study researcher also requested staff nurses to distribute copies of the "flyer" on inpatient and outpatient units to patients receiving cancer treatment. The flyer included a phone number to call the study researcher. Interested clients contacted RN/other clinical staff and for more information called the study researcher. During days that the study researcher (this student) was at the study site, patients who were interested in the study were approached, and the study was explained, including the consent form (Appendix C) and authorization form for use and disclosure of protected health information form (Appendix D); questions were encouraged. The study researcher gathered information from the patient, family, and clinical staff to obtain Karnofsky Performance/Functional Status score and patients with score 50 or above were allowed to participate in this study.

Data Collection Procedures

With the consent signed, the study researcher collected demographic information from the patient and collected health history and treatment / medication profile information from the patient's medical record. Next, patients were instructed to self-report symptoms on the Therapy-Related Symptoms Checklist (TRSC), and to complete the Health- Related Quality of Life Linear Analogue Self Assessment (HRQOL- LASA), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C-30 (EORTC QLQ-C 30), and the Symptom Alleviation Self-Care Methods (SA-SCM) Tool. The study researcher provided assistance in the completion of these forms and clarified participants' questions as needed. Completion of the surveys took approximately 20- 30 minutes.

Data Collection Instruments

The data collection instruments are described below.

1. The Therapy–Related Symptom Checklist (TRSC), Appendix E. The TRSC is a 25-item checklist for patients to self-report symptom occurrence and severity during cancer treatments, either chemotherapy and/or radiation therapies. The TRSC was developed using the principal component analysis, and has good psychometric properties which includes concurrent, construct, and discriminant validity, and reliability with all Cronbach alpha coefficients greater than 0.80 (A. Williams et al., 2000; 2014; P. Williams et al., 1997, 2000, 2001, 2010, 2015; Williams, Graham et al., 2013; Williams, Williams, Lafever-Roling, et al., 2011). A study conducted by Heinze (2012), reported a Cronbach's alpha of 0.91 for the total TRSC scale score. Gonzalez et al. (2011); Heinze, (2012); Heinze and Williams, (2014); and Piamjiariyakul et al.(2010) also reported evidence of the reliability and construct validity of the

TRSC tool. The TRSC and Oncology Treatment Toxicity Assessment Tool (OTTAT) were correlated at 0.97 (Piamjiariyakul et al., 2009; Williams et al., 1997, 2000 & 2001).

The TRSC is a Likert- type patient self- report instrument, with 14 subscales or symptom clusters. Six subscales have multiple items, while 8 are single-item subscales (pain, numbness in fingers and/or toes, bleeding, hair loss, skin changes, constipation, soreness in vein, and decreased interest in sexual activity). Two subscales contain four items each. Specifically, the *Fatigue* subscale consists of the items feeling sluggish, depression, difficulty concentrating, and difficulty sleeping. The *Eating* subscale includes taste change, loss of appetite, weight loss, and difficulty swallowing. The *Oropharyngeal* subscale has three items (sore mouth, sore throat, and jaw pain. Three subscales have two items each: *Nausea* subscale (nausea and vomiting), *Fever* subscale (fever and bruising), and *Respiratory* subscale (cough and shortness of breath). Participants were asked to report their symptom occurrence and rate the severity of their symptoms on a 5-point scale: 0 (none), 1 (mild), 2 (moderate), 3 (severe), or 4 (very severe). Space to write in and rate other symptoms was provided. The ratings on the 25 items are summed (range 0 – 100); higher scores (total score) on the TRSC indicate greater frequency (occurrence) and greater symptom severity (Williams et al., 1997 2001; 2011, 2013, 2014). Heinze, Williams, and Bott (2015) reported the use of an electronic version of the TRSC survey among breast cancer survivors using TRSC. Alemi et al. (2014) and Williams et al. (2015) also reported the use of an electronic version of the tool to gather data on adult oncology patients' TRSC symptoms, reassure patients, and enhance patient- clinician communications.

2. Health- Related Quality of Life - Linear Analogue Self Assessment (HRQOL-LASA), **Appendix F**. The HRQOL-LASA measures health-related quality of life of cancer patients. The HRQOL-LASA is a six-item scale used in the clinical setting to assess HRQOL of

cancer patients (Bretscher et al., 1999; Halyard & Ferrans, 2008; Heinze, 2012; Heinze, Williams, & Bott, 2015; Hyland & Sodergren, 1996; Williams et al., 2011, 2013). The six-item scale assesses selected mental, physical, emotional, social, and spiritual experiences using a visual analog scale. Each item is rated on a 10-point scale ranging from 0 (as bad as can be) to 10 (as good as can be). Participants were instructed to circle the number (0-10) to "describe their feelings during the past week, including today". A sample item is: How would you describe "your overall emotional well-being?". Another item is "your level of social activity". Total scale scores range from 0 to 60, a high score on the HRQOL-LASA indicates a high quality of life (Williams et al., 2011, 2013).

The HRQOL-LASA items have been validated as general measures of global QOL dimensional constructs in many settings, including sites used by cancer patients (Bretscher et al., 1999; Halyard & Ferrans, 2008; Williams et al., 2011, 2013). Cronbach's alpha for the HRQOL-LASA tool in a study conducted in breast cancer survivors was 0.93 (Heinze, 2012). HRQOL-LASA is a new scale to assess HRQOL. As an evidence of its convergent validity, significant correlations were examined between the HRQOL-LASA, and the scores on EORTC symptoms subscale, physical functioning subscale, and Global Health Status. Convergent validity of two QOL tools HRQOL-LASA and EORTC QLQ-C 30 was calculated in the present study and findings were reported in Chapter IV.

3. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C- 30 Version -3.0 (EORTC QLQ-C 30), Appendix G. The EORTC QLQ C-30 scale is a 30-item tool that incorporates nine multi-item scales. This includes five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), six single-item symptoms: dyspnea, sleep disturbance, appetite loss,

constipation, diarrhea, financial difficulties, and a global health and quality of life scale (Aaronson et al., 1993; Sato et al., 2014). It is a Likert scale with 4 or 7 points. Linear transformation of the raw score as per the scoring manual was used to standardize the raw score so that scores range from 0 to 100. All of the scales and single-item measures range in score from 0 to 100. A high functional scale score represents a high or healthy level of patient functioning; a high global health status score represents a high quality of life. According to Aaronson et al. (1993), a high score for a symptom scale /item represents a high level of symptomatology/ problems.

The results of an international field study conducted by Aaronson et al. (1993) reported the practicality, reliability, and validity of the EORTC QLQ-C 30. The study was conducted from centers in 13 countries. The original questionnaire was administered to 305 patients with nonresectable lung cancer before treatment and once during treatment. Clinical variables included for assessment were disease stage, weight loss, performance status, and treatment toxicity. EORTC QLQ-C30 met the minimal standards for reliability (Cronbach's alpha coefficient > or = .70) either before or during treatment except the role functioning multi-item scale. Aaronson et al. (1993) also reported validity of EORTC QLQ C-30 scale using three types of validity analysis. All inter-scale correlations among the various QLQ-C30 scales were statistically significant (P<.01). Known group comparison method and responsiveness to change in health status also supported the clinical validity of the QLQ-C30. Michelson et al. (2000) reported satisfactory levels of Cronbach's alpha above 0.82 for all functions except cognitive function (0.55). Cronbach's alpha ranged from 0.73 to 0.94 in the Japanese version of the EORTC QLQ C-30 scale (Sato, Shimizu, & Miyashita, 2014). The instrument has been translated and validated into 81 languages. The QLQ-C30 Version 3.0 is the most recent version

(EORTC QLQ-C30 Quality of Life group, 2014) and was used in the present study. EORTC QLQ C-30 scale was used to examine the convergent validity of HRQOL-LASA and results are reported in chapter IV.

4. Symptom Alleviation: Self-Care Method (SA: SCM) Form (Appendix H). This form was based on the TRSC. If a patient reported a symptom, then the patient was asked to report self-care methods used for symptom alleviation. The SA: SCM form also instructs patients to rate how often they use each self-care method using the scale 1 (*seldom done*) to 4 (*very often done*) and to indicate whether the method helped or not (yes/no answer) to relieve the symptoms. Cronbach's alphas greater than 0.70 have been reported for the English version of Symptom Alleviation: Self-Care Method Form (Williams et al. 2011). Cronbach's alpha of 0.89 was obtained by Gonzalez et al. (2011) for the Spanish version of this form.

Patient report of self-care methods were content analyzed (Krippendorf, 2005; Polit & Beck, 2012), classified into categories, and used by Williams et al. (2006a, 2010a, b), and others (Gonzalez et al., 2011; Heinze, 2012; Heinze and Williams, 2014; Piamjariyakul et al., 2010). Self-care strategies used by Williams et al (2010a) were diet/nutrition/lifestyle change, mind/body control, biologic treatments, herbal treatments, prescribed medicine and other. Self-care strategies developed by Williams et al (2006a, 2010a, b), were regrouped and used in the present study namely: a) Diet and Nutrition, b) Lifestyle changes, b) Spiritual, Mind and Body control, c) Herbal and Vitamin Treatment, d) Medication, and f) Other (do nothing/no response).

5. Demographic Data Form (Appendix I). The demographic data form used for this study is a modification of those used in previous studies (Heinze, 2010a, b; Piamjariyakul et al., 2006; P. D. Williams et al., 2006a, b; 2009; 2010a, b; 2011a, b). The form was employed to collect data about participants' demographic characteristics such as age, gender, ethnic

background, marital status, education, and economic status. Demographic characteristics included in the present study were based on available literature and their impact on symptom experience and HRQOL.

6. Health Form, Karnofsky Performance/Functional Status, and Treatment/ Medication Profile (Appendix J). These forms were used to collect information from medical record on the participants' diagnosis and treatment such as cancer stage, date treatment started, type of treatments, chemotherapy drugs, and dose, and radiation therapy dose. On the Karnofsky Performance/ Functional Status Scale, a higher score indicates higher functional status. Functional status is based on the patients' ability to carry on normal activity, ability to work, the requirement of assistance needed for daily activities.

Various studies reported good psychometric properties of this tool. Specifically, Schag, Heinrich, and Ganz, (1984) reported the Pearson product moment correlation for inter- observer reliability and was 0.89. This scale has been used extensively in clinical and oncology research (Piamjariyakul et al.,2010; Williams, Balabagno, et al., 2010; William et al., 1997, 2000; Williams, Graham, et al., 2013; Williams, Lopez, et al., 2010).

Protection of Human Subjects

The student researcher completed Collaborative Institutional Training Initiative before submission of IRB application at the hospital. Approval of the study site IRB was obtained (Appendix K) from the hospital where data were collected. The student researcher also completed KUMC Human Subjects Protection Training and Health Insurance Portability and Accountability Act (HIPAA) training. The student researcher signed a conflict-of-interest form at the hospital where the study was conducted. The KUMC-Human Subjects Committee (HSC) approved a Memorandum of Agreement (MOU) at this student’s graduate school.

The Consent Form (Appendix C) included the background, purpose, procedures, risk, benefit, alternatives, cost/payment, the right to withdraw, confidentiality and privacy authorization, subjects rights and withdrawal from the study. The Consent form also included the student researcher's contact information including a phone number, so that participants could contact the researcher if there were any question, concern, or complaint. The study researcher disclosed all information about this study and subjects were given enough time to read the consent form and clarify their questions before they sign the form. All study subjects were informed about the use and disclosure of protected health information for research. A signed copy of informed consent and authorization form for use and disclosure of protected health information form, which was approved the study site IRB (Appendix D) was given to each study participant. All rights of human subjects were maintained throughout the study. Patients enrolled into the study were assigned an identification (ID) number that corresponds with their identity to maintain confidentiality.

Plan for Data Analysis

Data were cleaned to reduce errors prior to entry into the database. The process occurred as data were received, and continued throughout the data collection period. The Statistical Package for the Social Sciences (SPSS) version 23 for Windows were used for all statistical analyses. SPSS - AMOS was used to develop the path diagram. Identification (ID) numbers were assigned to each participant for the purpose of data de-identification. De-identified study data were stored on the study researcher's password-protected computer. Hard copy forms have been kept in the lock-box in the study researcher's office. Data will be stored according to the requirements and time specifications for Lankenau Institute for Medical Research and KUMC.

All variables were examined for variability and shape of the distribution. Demographic data were used to describe the likeness and diversity of the study participants. Descriptive statistics such as mean, standard deviation, and percentages were used to depict demographics, patient health information and the specific dependent variables (symptom occurrence and severity and HRQOL). The reliability of TRSC, HRQOL-LASA, and EORTC QLQ C-30 were investigated. Convergent validity of two QOL tools used in the study (HRQOL-LASA & EORTC QLQ C-30) were also calculated (Polit & Beck, 2008; 2012). The assumptions of multiple linear regression were tested before conducting multiple linear regression. The researcher in the present study evaluated whether important assumptions of regression were met, which included normality, linearity, constance of variance (hemodeskedicity), and non-multicollinearity. Findings of model assumptions are reported in Chapter IV.

Analysis of the Primary Research Hypothesis

Tests of associations. Symptom occurrence/ severity and health-related quality of life (two outcome variables) have been associated in previous studies with independent variables related to the cancer condition and demographic variables. Independent variables in this study were then regrouped before conducting the univariate analysis including age, ethnicity, education, marital status, cancer diagnosis, disease stage, and length of time since treatment started. Age groups of participants were collapsed into three categories and were 18-39 years, 40-59 years, and > 59 years. Ethnicity groups included Caucasians, African Americans, and Asians/ Hispanics. Participants' educational levels were collapsed to two categories and were high school, and college/post college; and marital status to three groups and were married, single, and others. Participants' economic status were collapsed into three categories and were annual income <$ 30,000, $30,000-$ 60,000, and > $60,000. Participants' cancer diagnoses were

collapsed to four groups and were breast/ovarian/uterine, colorectal/ oral/G.I, lung/larynx, and others. Disease stage was collapsed into two groups and were stage 0, 1, 2 and stage 3&4, and length of time since treatment started to two groups and were 2-10 weeks and >10 weeks.

First, the univariate relationship between each of the six demographic variables (age, gender, ethnicity, marital status, education, economic status) and the outcome variable symptom occurrence and severity were examined. The dependent variable symptom occurrence and severity was measured in this study by the total scores on TRSC. Then, the univariate relationship between each of the five variables related to the cancer condition (diagnosis/stage, type of treatments, the length of time since the start of treatment, the number of comorbidities) and the outcome variable symptom occurrence and severity were examined. Next, the univariate relationship between each of the six demographic variables (age, gender, ethnicity, marital status, education, economic status) the outcome variable quality of life was examined. Quality of life in this study was measured by the total scores on HRQOL-LASA tool. Finally, the univariate relationship between each of the five variables related to the cancer condition (diagnosis/stage, type of treatments, the length of time since the start of treatment, the number of co-morbidities) and the outcome variable quality of life were examined. For all analyses, an alpha of .05 was considered statistically significant. Independent two-sample t-test, ANOVA, and linear regression were used to perform the univariate analyses. Specifically, independent two-sample t-tests were conducted to examine the relationship between independent variables (gender, education, cancer stage, and time since treatment started) with symptom occurrence/ severity and HRQOL. The relationship of age, ethnicity, economic status, marital status, cancer diagnosis, and treatment type, with symptom occurrence/ severity, and HRQOL were examined using ANOVA. Simple linear regression was conducted to examine the relationship between the

number of comorbidities and dependent variables (symptom occurrence/ severity, and HRQOL). Findings of univariate analysis provided a basic understanding of the relationship between selected independent variables and dependent variables.

Variables found significant in univariate analyses and other clinically relevant variables chosen for their significance in previous research studies were examined in multiple linear analyses (see Figure 1. Conceptual framework - Model 1). Dummy variables were created for all categorical variables entered into the model selection (Plichta & Garzon, 2009). Dummy variables were created for variables ethnicity (African American, and Asians/Hispanics), economic status (annual income 30,000- $60,000, and annual income > $60,000), cancer treatment type (radiation therapy alone, and combined chemotherapy and radiation therapy). This yield a total of 11 independent variables in multiple linear regression. In the present study, only eleven variables could be entered into the final model selection in multiple linear regression based on the sample size of *N*= 110 [one variable for every ten sample (Cleophas & Zwinderman, 2012; Wilson Van Voorhis & Morgan, 2007)].

The primary research hypothesis was addressed using multiple linear regression analyses to examine relationships among the independent variables selected in the final model and each outcome variables: symptom occurrence and severity, and HRQOL. Stepwise, forward selection, and backward elimination methods of linear regression were conducted in SPSS- 23 to identify the independent variables related to symptom occurrence and severity and HRQOL. In model selection for the dependent variable symptom occurrence and severity, the probability of F (p-value) used for entry was .05 and removal was .10. Use of these values provided the best model with maximum significant variables in the final model. In the model selection for the dependent variable, quality of life, the probability of F (p-value) used for entry was .15 and

removal was .20 as the default values of entry .05 and removal.10 did not select many variables to enter for model selection. The Type I error (α) for final significance for each of the model was .05.

Path analysis. A path analysis was conducted to explore the relationship between the independent variables selected in the final model and their effects on two outcome variables: independent variables → symptom occurrence/ severity and HRQOL (http://www.ats.ucla.edu/stat/stata/faq/pathreg.htm). Path analysis is a method used to answer questions regarding the relationship between a set of independent variables and a dependent variable (Munro, 2005; Olobatuyi, 2006; Polit & Beck, 2008; 2012; http://www.ats.ucla.edu/stat/stata/faq/pathreg.htm). Path analysis is useful when we have a clear hypothesis to test. It helps to measure the direct and indirect effects that one variable has upon another (Olobatuyi, 2006). As an example, a study conducted by Neuberger, Kasal, Smith, Hassanein, and DeViney (1994) used path analysis to predict exercise and aerobic fitness levels for clients with arthritis. The results of this study supported the need to improve exercise adherence and the aerobic fitness level of individuals with arthritis. The present study examined the direct effect of symptom occurrence and severity on HRQOL by path analysis. This study also used path analysis to examine the direct and indirect relationship between selected demographic and disease-related variables and HRQOL. The level of significance for path analysis for the present study was .05. Results of path analysis were reported as standardized regression coefficients (Beta) or path coefficient, and are the direct effect of the specific independent variable on the dependent variable (Gray et al., 2007).

Analysis of Four Secondary Research Questions

The secondary purposes were to compare (a) symptom occurrence and severity by ethnicity: African-American vs. Caucasian; (b) the self-care methods used to alleviate symptoms reported by ethnicity: African-American vs. Caucasian; (c) symptom occurrence and severity by age group, adolescent-young adult (18-39 years) vs older adults (40 years or older); and (d) the self-care methods used to alleviate symptoms reported by age group, adolescent-young adult (18-39 years) vs older adults (40 years or older). Independent two-sample t-test was conducted to examine the differences in symptom occurrence and severity by ethnicity and by age group.

Patients' reported self-care methods were addressed using content analysis. Content analysis involves breaking down data into smaller units, coding and naming the units according to the content they represent, and grouping/ clustering of coded materials based on shared concepts (Polit & Beck, 2008; 2012). Clustering is a way to represent the results of the content analysis (Krippendorff, 2005). The classification system from literature were regrouped and used to categorize the self-care methods in the present study (Heinze, 2012; Heinze & Williams, 2015; Piamjariyakul et al., 2010; Williams, Balabagno, et al., 2010; Williams, Lopez, et al., 2010; Williams, Mowlazadeh, et al., 2015; Williams, Piamjariyakul, et al., 2006; Williams, Williams, Smith, et al., 2011; Williams et al., 2001; 2006a; 2009, 2010a, b; 2011, 2012, 2014). One of the classification system used in literature was 1) Diet/nutrition/lifestyle, 2) Mind/body control, 3) Herbs/vitamins/complementary therapy, 4) Medications, 5) Other, and 6) Do nothing (Heinze, & Williams, 2015). In the present study, the categories regrouped and used as follows: 1) Diet/nutrition, 2) Lifestyle changes, 3) Spiritual, Mind, and Body Control, 4) Herbal and Vitamin Treatment, 5) Medication, and 6) Other (Do nothing/no response).

Summary

The primary purpose of the study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition , and selected demographic variables. The secondary purposes were to compare symptom occurrence and severity and self-care methods by ethnicity and by age group. This study used a descriptive correlational design. Convenience sampling method was used in the present study. Data were collected from 110 cancer patients on treatments. Recruitment occurred in the inpatient and outpatient chemotherapy/radiation therapy departments, cancer treatment center, and inpatient oncology units of a major hospital system in the Northeast region of the Unites States. Approval was obtained from KUMC Human Subjects Committee (HSC), and Institutional Review Board (IRB) of the hospital where the study was conducted before data collection began. Tools used in the study included the Demographic Form to collect demographic information from the patient and the Health Form, Karnofsky Performance/Functional Status, and Treatment/ Medication Profile to complete a health history and treatment/ medication profile based on the patient's medical record. Patients were instructed to self-report symptoms on the Therapy-Related Symptoms Checklist (TRSC), and to complete Health- Related Quality of Life Linear Analogue Self Assessment (HRQOL- LASA), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C-30 (EORTC QLQ-C 30), and the Symptom Alleviation Self-Care Methods (SA-SCM) Tool. All rights of human subjects were maintained throughout the study. Both descriptive and inferential statistics conducted for data analysis using SPSS -23. Analyses were done based on primary research hypothesis and secondary research questions.

Chapter IV

Results

The primary purpose of the study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities), and selected demographic variables (ethnicity, age, gender, marital status, education, economic status). Four secondary purposes were to examine (1) cancer patients' reported symptom occurrence and severity by ethnicity (African-American vs. Caucasian); (2) self-care methods used by ethnicity; (3) difference in symptom occurrence and severity by age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older); and (4) self-care methods used by age group. This chapter presents the results of the study, including the sample characteristics and the findings of primary and secondary research questions.

Reliability and Validity Assessment

Internal consistency reliability of the TRSC, the HRQOL-LASA, and the EORTC QLQ C-30 was investigated using Cronbach's alpha. Cronbach's alpha of the TRSC in the present study was 0.862, indicating a higher reliability among the items in the tool. Cronbach's alpha of the HRQOL-LASA was 0.929, indicating a high consistency among the items in the tool. In the present study, Cronbach's alpha of the EORTC QLQ-C 30 was calculated for Global health status, functional scales, and symptom scales. Cronbach's alpha for Global health status was 0.889 and indicating high reliability. Cronbach's alpha for Physical functioning (0.850), Role functioning (0.845), Emotional functioning (0.873), Cognitive functioning (0.686), and Social functioning (0.832) indicating high reliability of EORTC QLQ-C 30. Cronbach's alpha for the

symptoms scale was 0.847.Cronbach's alpha in the present study for the Symptom Alleviation Self-Care Methods was 0.728 indicating a higher reliability (Polit & Beck, 2008; 2012).

Convergent validity. Calculation of the convergent validity of two QOL tools HRQOL-LASA and EORTC QLQ-C 30 revealed that the two tools correlated well. Correlation of total score of HRQOL-LASA and scores on global health status, functional scales, and symptom scales of EORTC QLQ-C 30 were calculated. All correlations, HRQOL-LASA and global health (r = .687, p=.01), HRQOL-LASA and functional scale (r = .670, p= .01), and HRQOL-LASA and symptoms scale (r = - .517, p= .01) were found satisfactory.

Sample Demographics and Health Related Information

Sample demographics and health related information are provided in Table 6.

Table 6

Sample Characteristics/ Health Information (N=110): Age group, Gender, Ethnic Background, Education, Marital Status, Cancer Diagnosis, Cancer Stage, Number of Comorbidities, Treatment type, and Time since Treatment Started.

Variables	**Categories**	**Frequency**	**Percent**
Age Group	18-39 years	11	10
	40- 59 years	35	31.8
	60-79 years	57	41.8
	80-99 years	7	6.4
Gender	Male	47	42.7
	Female	63	57.3
Ethnic Background	White	60	54.5
	African American/Black	40	36.4
	Asian	8	7.3
	Hispanic	2	1.8
	Native American	0	0
	Other	0	0
Education	Elementary	0	0
	High school diploma	49	44.5
	College Degree	44	40
	Post College Degree	17	15.5

Table 6 (continued).

Variables	Categories	Frequency	Percent
Marital status	Married	60	54.5
	Single	22	20
	Widowed	9	8.2
	Divorced	15	13.6
	Other	4	3.6
Economic Status Annual Income [a]	< $ 30,000	38	34.5
	$ 30,000- $60,000	32	29.1
	$ 61,000- $90,000	13	11.8
	$91,000- $ 120,000	9	8.2
	>$ 120,000	16	14.5
	Did not answer	2	1.8
Cancer Diagnosis	Breast Cancer	37	33.6
	Colorectal	16	14.5
	Lung & Larynx	16	14.5
	Oral & Gastrointestinal	5	4.5
	Lymphoma, Leukemia, & Myeloma	10	9.1
	Uterine & Ovarian	12	10.9
	Others (Prostate, testicular, renal, axillary, bone & unknown origin)	14	12.7
Cancer Stage [b]	0	1	0.9
	1	18	16.4
	2	28	25.5
	3	31	28.2
	4	26	23.6
	Not known	6	5.4
Number of comorbidities	0	31	28.2
	1	24	21.8
	2	26	23.6
	3	24	21.8
	4	3	2.7
	5	1	0.9
	6	1	0.9
Treatment Type	Chemotherapy	48	43.6
	Radiation therapy	36	32.7
	Chemo and radiation therapy	26	23.6

Table 6 (continued).

Variables	Categories	Frequency	Percent
Length of Time since Treatment started	2-10 weeks	86	78.2
	11-20 weeks	17	15.5
	21-30 weeks	4	3.6
	31-40 weeks	2	1.8
	41-50 weeks	1	0.9

[a] Missing values = 2 (1.8%)
[b] Missing values = 6 (5.4%)

All participants (*N*=110), provided demographic information. The majority of participants were 60-79 years of age (*n*=57, 41.8 %). Only 11 participants were under 40 years (10%). The majority (*n*=63, 57.3%) of participants were females; 47 (42.7%) were males. The majority (*n*=60, 54.5%) of participants were Caucasian, and 40 (36.4%) were African American/Black. There were eight (7.3%) Asians and two Hispanics (1.8%) who participated in the study. The educational level for 49 (44.5%) participants was a high school diploma, and 44 (40%) had a college degree. Seventeen participants (15.5%) reported that they had a post-college degree. The majority (*n*=60, 54.5%) were married; 22 (20%) were single, and 15(13.6%) were divorced. Economic status was reported by 108 participants, and 2 (1.8%) did not answer that section and was considered as missing data. Thirty-eight (34.5%) participants had an annual income of $ < 30,000; 32(29.1%) had an annual income level of $ 30,000- $60,000; 22(20%) had an annual income level of $ 61,000- $120,000. Only 16 (14.5%) participants reported an annual income greater than $120,000.

Thirty-seven (33.6%) participants were diagnosed with breast cancer, and 16(14.5%) were diagnosed with lung cancer. Other cancer diagnoses were colon cancer, rectal cancer, ovarian cancer, cervical cancer, endometrial cancer, prostate cancer, leukemia, and lymphoma. Cancer stages of participants were stage 3(*n*=31, 28.2%), stage 2(*n*=28, 25.5%), and stage 4

(*n*=26, 23.6%). For six participants (5.4%), the cancer stage was not known/ not given in their medical records and was considered as missing data. Thirty-one (28.2%) participants did not report any associated medical conditions. Related to comorbidities, 26 participants had two comorbidities, 24 had three comorbidities, and another 24 participants had one comorbidity. Duration of cancer treatment/time since the start of cancer treatment was calculated in number of weeks. This period ranged from 2- 50 weeks. The majority (*n*=86, 78.2%) reported that time since treatment started between 2-10 weeks before the study and 17 participants (15.5%) started their treatment between 11-20 weeks before the study.

Among the110 participants, 48 (43.6%) were receiving chemotherapy alone. The chemotherapy alone group consisted of 22.5% females; 43.75% Caucasian and 43.75% African American/ Black. The educational level of 45.83% of participants receiving chemotherapy alone was high school diploma; 49.92% were married and 43.68% had an annual income level of $30,000-60,000. Predominant cancer diagnoses of patients receiving chemotherapy alone were breast cancer, colon cancer, and lung cancer. Among the total study participants (*N*=110), 36 (32.7%) participants were receiving radiation therapy alone as their cancer treatment. In this group twenty-three (63.88%) were females; 69.44% were Caucasians; 27.77% were African American/ Black; 41.66% had the educational level of high school diploma, 69.44% were married; 38.88% had an annual income level of <30,000. Predominant diagnoses for radiation therapy alone group were breast cancer and prostate cancer. Another 26 (23.6%) patients were receiving combined treatment with both chemotherapy and radiation therapy. In this group, fifteen (57.69%) patients were females; 53.84% were Caucasians; 43.75% were African American/ Black; equal numbers (*n*=12, 46.15%) had educational level of high school diploma

and 46.15 % had college degree; 42.30% were married; 53.84%% had annual income level of < $30,000. Predominant cancer diagnoses were breast cancer, colorectal cancer, and lung cancer.

Symptom Occurrence and Severity

Findings are reported in Table 7 on the mean severity of symptoms and percentage occurrence of all symptoms on the Therapy-Related Symptoms Checklist by treatment type.

Table 7

Treatment Type and Symptom Severity on the TRSC Subscale/ Items (N= 110)

TRSC Subscales /Symptoms	CT Alone (*n* = 48) Mean Severity	% Occurrence	RT Alone (*n* = 36) Mean Severity	% Occurrence	CT-RT (*n* =26) Mean Severity	% Occurrence
1. Fatigue						
Feeling Sluggish	1.96	85.4	1.92	80.6	1.46	84.6
Depression	0.71	50	1.31	61.1	0.38	26.9
Difficulty Concentrating	0.88	47.9	1.22	63.9	0.88	57.7
Difficulty Sleeping	1.56	72.9	1.42	63.9	1.27	69.2
2. Eating						
Taste Change	2.13	83.3	0.94	41.7	1.35	61.5
Loss of Appetite	1.81	79.2	1.03	50	1.65	73.1
Weight Loss	1.25	52.1	0.67	36.1	1.35	65.1
Difficulty Swallowing	0.46	20.8	0.5	27.8	0.62	26.9
3. Oropharynx						
Sore Mouth	0.67	41.7	0.44	16.7	0.62	30.8
Sore Throat	0.48	31.2	0.25	19.4	0.58	23.1
Jaw Pain	0.40	14.6	0.19	11.1	0.04	3.8
4. Fever						
Fever	0.23	12.5	0.22	13.9	0.12	7.7
Bruising	0.35	16.7	0.39	27.8	0.19	7.7
5. Nausea						
Nausea	1.04	54.2	0.67	38.9	0.88	53.8
Vomiting	0.31	18.7	0.19	8.3	0.27	19.2
6. Respiratory						
Cough	0.75	41.7	0.61	44.4	0.54	30.8
Shortness of Breath	0.92	58.3	0.67	38.9	0.54	34.6

Note. CT alone = Chemotherapy alone; RT alone = Radiation therapy alone,
CT- RT = Chemotherapy and Radiation therapy

Table 7 (continued).

TRSC Subscales /Symptoms	CT Alone (n = 48) Mean Severity	% Occurrence	RT Alone (n = 36) Mean Severity	% Occurrence	CT-RT (n =26) Mean Severity	% Occurrence
7. Pain	1.27	62.5	1.14	55.6	1.19	65.4
8. Numbness in Fingers and/or Toes	1.08	50	0.83	44.4	0.46	34.6
9. Bleeding	0.33	18.7	0.11	8.3	0.23	15.4
10. Hair Loss	1.77	64.6	0.97	30.6	0.81	38.5
11. Skin Changes	0.77	45.8	0.89	47.2	0.85	57.7
12. Constipation	1.50	60.4	0.39	27.8	0.81	50
13. Soreness in Vein	0.21	12.5	0.11	8.3	0.31	19.2
14. Decreased Interest in Sexual Activity	1.17	50	1.0	55.6	0.85	34.6
15. Other Problems						
Blood clot forming	0.09	2.1	0	0	0	0
Hemorrhoids	0.09	2.1	0	0	0	0
Nail changes	0.04	2.1	0.05	2.8	0	0
Fingers locking up	0.04	2.1	0	0	0	0
Shingles	0.09	2.1	0	0	0	0
Infection	0.09	2.1	0	0	0	0
Joint/muscle pain	0.09	2.1	0	0	0.1	3.8
Abdominal pressure/ cramping/bloating	0	0	0.05	2.8	0.12	3.8
Diarrhea	0	0	0	0	0.12	3.8
Indigestion	0	0	0	0	0.04	3.8
Low hemoglobin	0	0	0	0	0.12	3.8
Feeling lonely	0	0	0	0	0.12	3.8
Skin crack at radiation site	0	0	0	0	0.08	3.8

Note. CT alone = Chemotherapy alone; RT alone = Radiation therapy alone, CT- RT = Chemotherapy and Radiation therapy

As reflected in Table 7, findings were reported as the mean severity scores on all items in the TRSC and the percentage occurrence of each symptom with reference to each treatment type group. Among patients receiving chemotherapy alone, 13 symptoms (feeling sluggish, depression, difficulty sleeping, taste change, loss of appetite, weight loss, nausea, shortness of breath, pain, numbness in fingers and/or toes, hair loss, constipation, decreased interest in sexual activities) were reported by 50% or more patients. Five symptoms (difficulty concentrating, sore mouth, sore throat, cough, skin changes) were reported by 30% to 49% of patients receiving chemotherapy treatment. Among patients receiving radiation therapy alone, seven symptoms (feeling sluggish, depression, difficulty concentrating, difficulty sleeping, loss of appetite, pain, decreased interest in sexual activities) were reported by 50% or more of patients, whereas eight symptoms (taste change, weight loss, nausea, cough, shortness of breath, numbness in fingers and/or toes, hair loss, skin changes) were reported by 30% to 49% of patients. Among patients receiving combined treatment of chemotherapy and radiation therapy, ten symptoms (feeling sluggish, difficulty concentrating, difficulty sleeping, taste change, loss of appetite, weight loss, nausea, pain, skin changes, constipation) were reported by 50% or more patients. Six symptoms (sore mouth, cough, shortness of breath, numbness in fingers and/or toes, hair loss, decreased interest in sexual activities) were reported by 30% to 49% of patients receiving combined treatment with chemotherapy and radiation therapy.

As identified in Table 7, "mean severity" included scores of zero. Among patients receiving chemotherapy alone, 11 symptoms (feeling sluggish, difficulty sleeping, taste change, weight loss, nausea, pain, numbness in fingers and/or toes, hair loss, constipation, and decreased interest in sexual activity) were reported with mean severity score equal to or greater than one. Among patients receiving radiation therapy alone, seven symptoms (feeling sluggish, depression,

difficulty concentrating, difficulty sleeping, loss of appetite, pain, and decreased interest in sexual activity) were reported with mean severity score equal to or greater than one. Among patients receiving chemotherapy and radiation therapy, six symptoms (feeling sluggish, difficulty sleeping, taste change, loss of appetite, weight loss, and pain) were reported with mean severity score equal to or greater than one. Overall, the mean severity score was greater than one.

The mean TRSC score across all patients (*N*=110) was 21.58 (SD= 13.70). Patients receiving chemotherapy alone reported more severe symptoms compared to patients receiving radiation therapy alone and patients receiving a combination of chemotherapy and radiation therapy. Mean TRSC total score for patients receiving chemotherapy alone was 24.69, radiation therapy alone was 19.22 and combined treatment with chemotherapy and radiation therapy was 19.12. These findings showed that patients receiving chemotherapy alone reported the most severe symptoms compared to patients receiving radiation therapy alone and patients receiving combined chemotherapy and radiation therapy.

Other symptoms reported. Seven other symptoms were added by patients receiving chemotherapy alone : blood clot forming(2.1%), hemorrhoids(2.1%), nail changes(2.1%), fingers locking up(2.1%), shingles (2.1%), infection (2.1%), and joint/muscle pain (2.1%). Patients on radiation therapy alone group added abdominal pressure/cramping/bloating (2.8%), and nail changes (2.8%) as other symptoms that were not reported in TRSC. Symptoms added by chemotherapy and radiation therapy group included diarrhea (3.8%), indigestion (3.8%), low hemoglobin (3.8%), feeling lonely (3.8%), and skin crack at radiation site (3.8%).

Symptom Alleviation: Self- care Methods Related to Treatment Types

Self - care strategies, reported based on responses to the Symptom Alleviation: Self-Care Method tool were classified into six categories:1) Diet and Nutrition (Dietary changes, small

meals), 2) Lifestyle changes (Rest, taking naps), 3) Spiritual, Mind, and Body Control (Massage, yoga, meditation, prayer), 4) Herbal and VitaminTreatment, 5) Medication (Zofran, laxatives, pain medications), 6) Other (Do nothing/ no response). Table 8 shows the self- care strategies used by all study participants to relieve each symptom.

Table 8

Symptom Alleviation: Self-care Methods by Categories (N = 110)

TRSC Subscales /Symptoms	Self-care Categories A	B	C	D	E	F
1. Fatigue						
Feeling Sluggish	3	42	10	3	2	59
Depression	1	5	13	1	5	89
Difficulty Concentrating	1	4	9	1	2	95
Difficulty Sleeping	2	7	12	0	17	73
2. Eating						
Taste Change	28	3	2	3	1	68
Loss of Appetite	26	3	2	1	1	69
Weight Loss	18	0	0	4	2	92
Difficulty Swallowing	11	1	2	2	2	97
3. Oropharynx						
Sore Mouth	2	0	1	3	16	90
Sore Throat	3	0	0	1	8	99
Jaw Pain	2	0	0	0	3	107
4. Fever						
Fever	1	0	0	0	4	106
Bruising	0	0	0	0	1	109
5. Nausea						
Nausea	5	1	0	1	18	71
Vomiting	1	0	0	0	11	99
6. Respiratory						
Cough	1	0	1	0	9	99
Shortness of Breath	0	18	2	0	1	92

Note. A. Diet& Nutrition, B. Lifestyle changes, C. Spiritual, Mind and Body Control, D. Herbal and Vitamin Treatment, E. Medications, F. Others (Do nothing/ no response).

Table 8 (continued).

TRSC Subscales /Symptoms	A	B	C	D	E	F
7. Pain	0	1	1	1	35	74
8. Numbness in Fingers and/or Toes	0	12	3	1	6	92
9. Bleeding	0	0	0	0	3	107
10. Hair Loss	0	0	19	0	0	91
11. Skin Changes	0	0	1	1	20	90
12. Constipation	9	0	0	0	24	81
13. Soreness in Vein	0	1	1	1	1	107
14. Decreased Interest in Sexual Activity	0	2	2	0	0	106
15. Other Problems						
Hemorrhoids	0	0	0	0	1	-
Joint/muscle pain	0	3	0	0	0	-
Abdominal pressure cramping/bloating	0	0	0	1	2	-
Diarrhea	0	0	0	0	2	-
Indigestion	1	1	0	0	1	-
Low hemoglobin	0	0	0	0	1	-
Feeling lonely	0	0	2	0	0	-

Note. A. Diet& Nutrition, B. Lifestyle changes, C. Spiritual, Mind and Body Control, D. Herbal and Vitamin Treatment, E. Medications, F. Others (Do nothing/ no response).

The most frequently used self-care strategy was medication (prescribed, and over-the-counter). Medications were often used for pain (*n*= 35), constipation (*n*= 24), skin changes (*n*= 20), nausea (*n*= 18), difficulty sleeping (*n*= 17), and sore mouth (*n*= 16). The most commonly used medications for difficulty sleeping were ambien, lorazepam, xanax, and melatonin. To help manage sore mouth and sore throat, some mentioned frequent gargling and use of baking soda for mouth rinsing. Medications used for pain were oxycodone, ibuprofen, tylenol, morphine, and tylenol# 3. Miralax, dulcolax, and senna were commonly used for constipation. Diet and nutrition were the next commonly reported category of self-care strategies to alleviate for TRSC symptoms related to taste change (*n*= 28), loss of appetite (*n*= 26), weight loss (*n*= 18) and difficulty swallowing (*n*= 11). Specifically participants reported that they changed their diet, had small frequent meals, drank more fluids, ate more seasonal food/fruits, ate soft food, enhanced their fiber intake, drank more soup, imagined food taste good, tried different foods each day, drank nutritional supplements, etc. Lifestyle changes included taking rest, nap, exercise, walking, going to bed early, try to stay active and busy, etc were used to alleviate TRSC symptoms on feeling sluggish (*n*= 42), shortness of breath (*n*= 18), numbness in fingers/toes (*n*= 12), and difficulty sleeping (*n*= 7). Spiritual, Mind, and Body Control strategies were used to alleviate symptoms on hair loss (*n*= 19), depression (*n*= 13), and feeling sluggish (*n*= 10). Methods used for Spiritual, Mind, and Body Control including meditation, yoga, relaxation, watching TV, reading books, prayers, thinking positively, talk to friends, family, etc. Most patients reported that the self-care methods they used were helpful to alleviate their symptoms.

Health-Related Quality of Life

HRQOL was measured using two scales - HRQOL-LASA and EORTC QLQ-C 30. However, the dependent variable HRQOL in the present study was measured using HRQOL-

LASA total score. Scores on HRQOL-LASA ranged between 16 and 60, with a mean score of 44.23 (SD=10.60). Scores on the EORTC QLQ-C 30 functional scale were between 2.22 and 100, with a mean score of 74.62 (SD=18.24). Scores on the EORTC QLQ-C 30 global health scale were between 0 and 100, with a mean score of 66.06 (SD=19.99). Scores on the EORTC QLQ-C 30 symptom scale were between 2.56 and 76.92, with a mean score of 29.84 (SD= 16.25).

Primary Research Hypothesis

1. Association between Cancer Therapy-Related Symptom Occurrence and Severity, and Selected Demographic and Disease-related Variables

Findings of univariate analyses. Univariate analyses were conducted to examine the relationship between each independent variable and symptom occurrence and severity (as measured by TRSC total scores). Regrouped variables as discussed in data analysis plan (Chapter III) were used for the univariate analyses. Independent two-sample t-tests were conducted to examine the relationship between gender and symptom occurrence/severity, and education and symptom occurrence/severity. The analyses showed that there was no significant relationship between gender and TRSC scores, t (108) = -.74, p=.45, and education and TRSC total scores t (108) = .17, p=.86. The relationship between other selected demographic variables and TRSC total scores were examined using ANOVA. The analyses showed that there was no significant association between age and TRSC total scores, F (2,107) =1.63, p=.20, and marital status and TRSC total scores F (2,107) =.47, p=.62. A significant relationship was found between ethnicity and TRSC total scores F (2,107) =3.34, p=.04, as well as economic status and TRSC total scores F (2,105) =5.22, p=.007. This means that there was a significant difference in TRSC total scores between participants from different ethnic groups (Caucasians, African

American, and Asians/Hispanics), and between various socio-economic groups (Annual income <$ 30,000, $ 31,000-$60,000, and >$60,000).

Association between cancer diagnosis and cancer treatment type with TRSC total scores were examined by ANOVA. Findings showed that there was no significant relationship found between cancer diagnosis and TRSC total scores F (3,106) = .06, p = .98. There was no significant relationship found between cancer treatment type and TRSC total scores F (2,107) = 2.24, p= .11. Independent two-sample t-tests were conducted to examine the relationship between cancer stage with TRSC total scores, and time since treatment started with symptom occurrence/severity. There was a significant relationship between TRSC total scores and cancer stage t (102) = - 4.51, p=.000). This means that there was a significant difference in TRSC total scores between participants with cancer stages 0, 1, 2 and cancer stage 3 and 4. There was no significant relationship found between TRSC total scores and time since treatment started t (108) = .47, p = .64. Simple linear regression was conducted to examine the relationship between the number of comorbidities and TRSC total scores. There was no significant relationship found between a number of comorbidities and TRSC total scores t (109) = .21, p=.83.

Tests of model assumptions. Study variables were examined for normality, linearity, constance of variance (hemodeskedicity), and non-multicollinearity to evaluate whether the assumptions of regression were met. Assumptions of normality were satisfied as the visual inspection of histogram and P-P plots. Histogram showed slight right skewness. However, it was bell shaped, indicating normality. The assumption of linearity was also moderately satisfied as all correlations showed negligible to moderate relationships (.01to .47). Visual analysis of partial plots also showed a moderate linear association. Constance of variance was found satisfied by analyses of visual inspection of P-P plots, histogram and scatter plots. There was no

indication of multicollinearity as values of the correlation matrix, tolerance, variance inflation factor, and condition indices were within an acceptable range. Specifically, values of tolerance were greater than .20, variance inflation factor (VIF) was less than 10, and condition indices were less than 30.

Model selection and findings. Findings of univariate analysis provided a basic understanding of the relationship between selected independent variables and dependent variable (symptom occurrence and severity). Variables entered into model selection were those variables found significant in univariate analyses and other clinically relevant variables (based on clinical experience and literature support). The principal investigator's clinical experience in the field of oncology nursing also contributed towards decision making related to the list of variables entered for model selection. There was ample literature support for the relationship of variables gender, education, treatment type, the number of comorbidities, and time since cancer treatment started with symptom occurrence and severity. Therefore, these variables were included in the final model selection. Clinically relevant variables chosen included: gender, education, the number of co-morbidities, treatment type, and time since treatment started were reported in many studies as a significant predictor of symptom severity and HRQOL among cancer patients (see Chapter II for their discussion). Variables age, marital status, and cancer diagnoses were not entered for model selection, as they were not found significant in univariate analyses or due to lack of significant literature support for these variables. The sample size in the present study was only 110 and as per rule of thumb, only eleven variables could be included in multiple linear regression. In conclusion, the independent variables entered for model selection were gender, ethnicity (Caucasian Vs. African American, and Asians/Hispanics), education (high school vs. college/ post-college), economic status (< $30,000 Vs.$30,000- $60,000, and > $60,000),

number of comorbidities, cancer treatment type (chemotherapy alone vs. radiation therapy alone, and combined chemotherapy and radiation therapy), time since treatment started, and cancer stage (stage 0,1,2 vs. stage 3&4).

Multiple linear regression analyses (stepwise, forward selection, and backward elimination methods) were conducted in SPSS- 23 to finalize the independent variables related to symptom severity and occurrence (TRSC total scores). All three methods provided the final models with same variables. The variables included in the final model were gender, economic status (annual income >$ 60,000), cancer stage. Multiple linear regression also showed how much of a variance in the TRSC total scores could be explained by the combination of selected independent variables. The multiple correlation coefficient (R), indicates the overall measure of the strength of association between linear combination with gender, economic status (annual income >$ 60,000), disease stage with total TRSC scores, and R in this model was .49 and was moderate. A variance of 24% in the total TRSC score was contributed in this model by a linear combination of gender, economic status (annual income >$ 60,000), and disease stage. Findings of the regression analysis showed a significant relationship between selected independent variables and TRSC total scores, F (3,100) = 10.77, p =.000, R^2 = .24. Table 9 shows the final model with regression coefficients.

Table 9

Linear Regression Analysis of Selected Variables and TRSC Total Scores

Variables	B	95% CI lower	95% CI upper	t	*p*-value*
Gender	4.93	.21	9.64	2.07	.04
Economic status Annual income <$30,000 vs. > $60,000	-6.27	-11.19	-1.35	-2.53	.01
Cancer Stage Stage 0,1,2 vs. stage 3 &4	10.38	5.60	15.16	4.31	.000

Note. B = Unstandardized coefficients, 95% CI = 95% Confidence interval, t = t-test statistic *N*= 104, *p-value ≤ 0.05

Table 9 shows significant association between symptom occurrence and severity with gender *t* (103) = 2.07, *p*=.04, economic status [(Annual income> $60,000, *t* (103) = -2.53, *p*=.01)], and symptom occurrence and severity and disease stage, *t* (103) = 4.31, *p*=.000 after controlling for other variables in the model. This indicates that there was a significant difference in TRSC total scores between male and female patients. Female patients reported significantly higher TRSC scores (Mean = 22.41, SD = 12.46) compared to male patients (Mean = 20.47, SD = 15.27). This also showed that there was inverse relationships that existed between economic status and TRSC total scores. Patients with higher economic status reported lower symptom occurrence/severity. There was significant difference reported in symptom occurrence and severity between patients with cancer stage 0, 1, 2 and cancer stage 3 and 4. This indicates that patients with higher cancer stage (stage 3 and 4) reported more severe symptoms.

2. Association between HRQOL-LASA Total Score and Selected Demographic and Disease-related Variables

Findings of univariate analyses. Independent two-sample t-tests were conducted to examine the relationship between gender and HRQOL-LASA total scores, and education and HRQOL-LASA total scores. The analyses showed that there is no significant relationship

between gender and HRQOL-LASA total scores, t (108) = .30, p=.77), and education and HRQOL-LASA total scores, t (108) = -.63, p=.53). The relationship between other selected demographic variables and HRQOL-LASA total scores were examined using ANOVA. The analyses showed that there was no significant relationship between HRQOL-LASA total scores and age F (2,107) =.30, p=.74, marital status F (2,107) =.37, p=.70, ethnicity F (2,107) =2.29, p=.11, and economic status F (2,105) =1.2, p=.31. Association between cancer diagnosis and cancer treatment type with HRQOL-LASA total scores were also examined by ANOVA. The analyses showed that there was no significant relationship found between cancer diagnosis and HRQOL-LASA scores F (3,106) = .40, p= .76. No significant relationship was found between cancer treatment type and HRQOL-LASA total scores, F (2,107) =.36, p= .70. Independent two-sample t-test was conducted to examine the relationship between cancer stage with HRQOL-LASA total scores, and time since treatment started with HRQOL-LASA total scores. No significant relationship was found between cancer stage and HRQOL-LASA total scores t (102) = 1.85, p=.07). There was no significant relationship found between HRQOL-LASA total scores and time since treatment started t (108) = -.12, p =.91. No significant relationship was found between the number of comorbidities and HRQOL-LASA total scores t (109) = -.33, p=.74. Univariate analyses did not find any significant relationship between selected demographic and disease-related variables and HRQOL-LASA total scores.

Model selection and findings. Findings of univariate analyses provided a basic understanding of the association between selected independent variables and HRQOL. Based on findings from univariate analysis, clinical significance, and support from literature review, variables entered into model for linerar regression analysis included gender, ethnicity (Caucasian Vs. African American, and Asians/Hispanics), education (high school vs. college/ post-college),

economic status (< $30,000 Vs.$30,000- $60,000, and > $60,000), number of comorbidities, cancer treatment type (chemotherapy alone vs. radiation therapy alone ,and combined chemotherapy and radiation therapy), time since treatment started, and cancer stage (stage 0,1, 2 vs. stage 3&4).

Multiple linear regression using stepwise, forward selection, and backward elimination methods were conducted in SPSS- 23 to finalize the independent variables related to HRQOL-LASA total scores. All three methods yielded a final model with same variables. The variables included in the final model were ethnicity (Caucasians vs. African American, and Asians/ Hispanics), economic status (annual income <$30,000 vs. >$ 60,000) and cancer stage (Table 10). Multiple linear regression also showed how much of a variance in the HRQOL-LASA scores could be explained by the combination of selected predictor variables. The multiple correlation coefficient (R), the overall measure of the strength of association between linear combination with ethnicity, economic status (annual income >$ 60,000), disease stage with HRQOL-LASA scores in this model was .34. A variance of 11.7% in the total HRQOL-LASA score was contributed in this model by a linear combination of ethnicity, economic status (annual income >$ 60,000), and disease stage. The results of the regression was significant, F (4, 99) = 3.28, p =.01, R^2 = .12.

Table 10

Linear Regression Analysis of Selected Variables and HRQOL-LASA Scores

Variables	B	95% CI lower	95% CI upper	t	*p*-value*
Economic status					
Annual income> $60,000	4.74	.29	9.21	2.11	.04
Ethnicity					
African American/ Black	4.67	.06	9.28	2.01	.04
Asian & Hispanic	6.95	.20	13.70	2.04	.04
Cancer Stage	-3.50	-7.51	.51	-1.73	.09

Note. B = Unstandardized coefficients, 95% CI = 95% Confidence interval, t = t-test statistic, *N*= 104, *p-value ≤ 0.05

Findings of the multiple linear regression show a significant association between HRQOL- LASA total scores and economic status (annual income > $60,000, t= 2.11, *p*=.04), and ethnicity [(African American, t= 2.01, *p*=.04), (Asian & Hispanic, t= 2.04, *p*=.04)]. Specifically, there was a significant difference in the quality of life for patients with annual income <$30,000 and > $60,000. Patients with annual income >$60,000 reported higher HRQOL compared to patients with annual income <$30,000. African American/Black and Asians and Hispanics reported significantly higher quality of life compared to Caucasians. This study also found that there was lower symptom severity among participants from higher economic groups, and this may be a reason for their difference in HRQOL.

3. Relationship of Selected Demographic and Disease- Related Variables with Cancer Therapy-Related Symptom Occurrence and Severity and HRQOL

The present study assumed that demographic variables and cancer-related characteristics are associated with cancer therapy-related symptom occurrence and severity, and quality of life of cancer patients. Path analysis was conducted to explore the test model (model 1): Independent Variables → Symptom occurrence/ severity and HRQOL. Path diagram was created based on the selected conceptual framework, the final model selected in this study, and available literature.

Variables included in path diagram were gender, cancer stage, annual income >$60,000, and ethnicity (African American and Asians/Hispanics). Variables age, education, marital status, the number of comorbidities, diagnosis group, treatment type, and time since treatment started were excluded from this path analysis as they were not included in the final model and were not found significant.

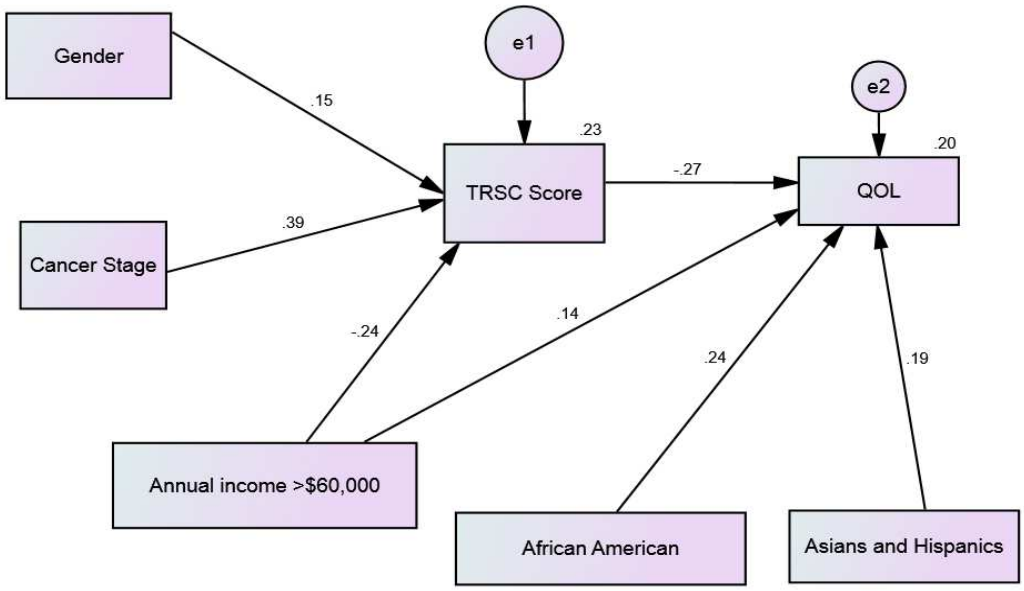

Figure 3. Path diagram 1: Relationship between selected variables with symptom occurrence and severity and quality of life.

Path diagram (Figure 3), shows the relationship between selected demographic variables, disease-related variables, symptom occurrence and severity (TRSC total scores), and health-related quality of life (HRQOL-LASA total scores). Specifically, findings of the path analysis showed that there was a significant negative relationship between economic status [(Annual

income >$60,000), β= -.23, *p*=.005)] and TRSC total scores. This indicates that patients with high socioeconomic status (annual income> $60,000) reported lower symptom occurrence and severity (TRSC total scores). Significant positive correlation was found between cancer stage and TRSC total scores (β= .39, *p*= .000). This shows that patients who were diagnosed with stage 3 &4 cancers reported higher symptom occurrence and severity compared to patients with cancer stage 0, 1, and 2. The relationship between gender and symptom occurrence and severity was not found significant (β= .15, *p*=.09).

There was significant relationship found between HRQOL- LASA total scores and ethnicity [(African American/Black, β= .24, *p*= .01); (Asians and Hispanics, β=.19, *p*= .02)]. There was a positive relationship between economic status (annual income >$60,000) and HRQOL- LASA total scores was not found significant. The significant inverse relationship found between TRSC total scores and HRQOL- LASA total scores (β= -.27, *p*= .002). This indicates that participants with higher symptom occurrence and severity reported lower quality of life. It was clear from the analysis that selected demographic and disease-related variables to contribute towards 23% variance in symptom occurrence and severity (TRSC scores) and 20% variance in HRQOL-LASA scores.

4. Relationship between HRQOL and Symptom Occurrence/Severity

Pearson correlation coefficient, *r* calculated to find out the relationship between HRQOL and symptom occurrence/severity. Findings showed that there was a significant (r= -.278, p= 0.003) inverse relationship between HRQOL-LASA and symptom severity. Patients with high symptoms reported low HRQOL. Findings of path analysis also supported this finding (Figure 3) that there was a significant inverse relationship between symptom severity and HRQOL-LASA (β= -.27, p= .002).

Secondary Research Questions

There were four secondary questions addressed in this study. They were to compare (a) symptom occurrence and severity by ethnicity: African-American vs. Caucasian; (b) the self-care methods used to alleviate symptoms reported by ethnicity: African-American vs. Caucasian; (c) symptom occurrence and severity by age group, adolescent-young adult (18-39 years) vs older adults (40 years or older); and (d) the self-care methods used to alleviate symptoms reported by age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older).

1. Symptom Occurrence and Severity by Ethnicity- African-American vs. Caucasian

TRSC total scores of African-American (n=40) and Caucasian (n=60) patients were compared using independent two-sample t-test. Mean TRSC score of African-American was 25.95 (SD = 12.57), and the mean score for Caucasian was 19 (SD= 13.29). Results showed that African- American patients reported higher symptom occurrence and severity compared to Caucasians. Findings of this test showed that there was a significant difference in symptom occurrence and severity, t (99) =-2.62, p=.01, between African-American and Caucasian patients.

2. **Symptom Occurrence and Severity by Age Group - Adolescent-young adult (18-39 years) vs. Older Adults (40 years or older)**

TRSC total scores of adolescent-young adult [(18-39 years), (n=11)] and older adults [(40 years or older), (n=99)] patients were compared using independent two-sample t-test. Mean TRSC scores of adolescent-young adult (18-39 years) was 27.55 (SD = 14.31) and the mean TRSC score of older adults (40 years or older) was 20.92 (SD = 13.55). However, findings of this study showed that there was no significant difference in symptom occurrence and severity (t (108) = 1.53, p=.13) by age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older).

3. Self-care Methods Used to Alleviate Symptoms Reported by Ethnicity - African-American vs. Caucasian

Self-care methods used to alleviate symptoms were determined by content analysis. Self - care strategies were classified and grouped into six categories and were a) Diet and Nutrition, b) Lifestyle changes b) Spiritual, Mind, and Body control c) Herbal and Vitamin Treatment, d) Medication, and f) Other (do nothing/no response). Table 11 shows Self-care Methods by Categories used by African-American vs. Caucasian.

Table 11

Symptom Alleviation: Self-care Methods by Categories used by Caucasian (n= 60) vs. African-American(n=40)

TRSC Subscales /Symptoms	Self-care Categories											
	Diet&Nutrition		Lifestyle changes		Spiritual, Mind and Body Control		Herbal and Vitamin Treatment		Medication		Other	
	A	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**
1. Fatigue												
Feeling Sluggish	1	1	24	11	6	4	0	1	1	2	28	22
Depression	0	0	12	2	11	1	0	1	6	2	44	35
Difficulty-Concentrating	0	0	5	2	6	2	0	1	1	0	49	36
Difficulty Sleeping	1	0	6	5	6	6	0	0	10	3	40	26
2. Eating												
Taste Change	11	16	2	1	1	0	3	1	2	0	43	19
Loss of Appetite	11	10	2	1	1	1	2	2	0	0	40	27
Weight Loss	5	8	1	1	0	0	2	1	0	0	53	30
Difficulty Swallowing	1	3	1	1	1	0	0	1	2	2	56	33
3. Oropharynx												
Sore Mouth	1	0	0	0	0	1	2	1	10	5	49	33
Sore Throat	2	0	0	0	0	0	0	0	3	6	56	34
Jaw Pain	1	2	0	0	0	0	0	0	0	2	59	38
4. Fever												
Fever	0	0	0	0	0	0	0	0	2	2	58	38
Bruising	0	0	0	0	0	0	0	0	1	0	59	40
5. Nausea												
Nausea	3	2	1	0	0	0	0	0	16	15	41	24
Vomiting	0	0	0	0	0	0	0	0	4	7	56	33

Note. A= Caucasian B= African-Americans

Table 11 (continued).

TRSC Subscales /Symptoms	Self-care Categories											
	Diet&Nutrition		Lifestyle changes		Spiritual, Mind and Body Control		Herbal and Vitamin Treatment		Medication		Other	
	A	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**
6. Respiratory												
Cough	1	0	0	0	1	0	0	0	4	4	54	36
Shortness of Breath	0	0	7	10	0	0	0	0	0	1	53	29
7. Pain	0	0	2	0	0	0	0	0	19	14	41	26
8. Numbness in Fingers and/or Toes	0	0	6	6	1	0	0	0	4	1	49	33
9. Bleeding	0	0	0	0	0	0	0	0	1	2	59	38
10. Hair Loss	0	0	11	5	1	0	0	0	1	0	48	35
11. Skin Changes	0	0	0	0	0	0	0	0	16	3	44	37
12. Constipation	6	4	0	0	0	0	0	0	10	7	44	29
13. Soreness in Vein	0	0	0	0	0	0	0	0	2	0	58	40
14. Decreased Interest in Sexual Activity	0	0	1	0	2	0	0	0	0	0	57	40

Note. A= Caucasian B= African-Americans

As shown in Table 11, medications (prescribed and over-the-counter) were the most commonly used self-care strategy by Caucasians for symptoms pain (*n*=19), nausea (*n*=16), skin changes (*n*=16), constipation (*n*=10), and sleeping difficulty (*n*=10). Lifestyle changes were the second most frequently reported self-care strategy used by Caucasians for symptoms of feeling sluggish, skin changes (*n*=24), depression (*n*=12), and hair loss (*n*=11). Diet/ nutrition ranked as the third most frequently reported self-care strategy used by Caucasians for symptoms taste change (*n*=11), loss of appetite (*n*=11), and constipation (*n*=6). Among African-Americans, the most commonly used self-care strategy was medications for symptoms nausea (*n*=15), pain (*n*=14), constipation (*n*=7), and sore throat (*n*=6). Diet/ nutrition ranked the second most frequently reported self-care strategy used by African-Americans for symptoms taste change (*n*=16), loss of appetite (*n*=10), and weight loss (*n*=8). Lifestyle changes were the third most frequently reported self-care strategy used by African-Americans for symptoms feeling sluggish (*n*=11), shortness of breath (*n*=10), and numbness in fingers and/or toes (*n*=6). Herbal and vitamin treatment were the least commonly used self-care strategy by both Caucasians and African- Americans. Feeling sluggish was the top-ranked symptom with a maximum reported self-care strategies by Caucasians. Taste change was the top-ranked symptom with a maximum reported self-care strategies by African- Americans.

Table 12 displays the frequency and usefulness of cancer patients' self-care methods for symptom alleviation by ethnicity (Caucasians vs. African- Americans). Participants' frequency of self-care strategies used are given in four categories, from the lowest frequency category (seldom done) to the highest frequency category (very often done). Participants also reported whether the self-care strategies they used helped them to alleviate their symptoms.

Table 12

Frequencies of Symptom Alleviation Occurrence and Usefulness by Caucasian (n = 60) vs. African-American (n=40)

TRSC Subscales /Symptoms	Alleviation Occurrence								Helped to alleviate symptoms	
	1		2		3		4			
	A	B	A	B	A	B	A	B	A Frequency(%)	B Frequency(%)
1. Fatigue										
Feeling Sluggish	0	1	12	7	15	8	5	2	30(93.75)	18(100)
Depression	0	0	6	1	6	4	4	0	16(100)	4(80)
Difficulty- Concentrating	0	0	5	2	3	1	3	1	10(90.91)	4(100)
Difficulty Sleeping	1	1	5	7	5	2	9	4	17(85)	13(92.86)
2. Eating										
Taste Change	0	3	4	2	4	10	9	5	13(76.47)	19 (95)
Loss of Appetite	1	1	2	2	10	5	7	5	18 (90)	13 (100)
Weight Loss	0	0	2	3	2	6	3	0	7(100)	8(88.89)
Difficulty Swallowing	0	0	1	3	1	2	2	2	4(100)	7(100)
3. Oropharynx										
Sore Mouth	0	0	5	2	3	2	4	2	11(91.67)	7(85.71)
Sore Throat	0	0	2	3	1	2	1	1	4(100)	6(100)
Jaw Pain	0	0	0	1	0	0	1	1	1(100)	2(100)
4. Fever										
Fever	0	0	1	1	1	1	0	0	2(100)	2(100)
Bruising	0	0	0	0	0	0	1	0	1(100)	0

Note. TRSC = Therapy-Related Symptom Checklist; A= Caucasian; B= African-Americans
1 = Seldom done; 2= Done occasionally; 3= Often done; 4 = Very often done.

Table 12 (continued).

TRSC Subscales /Symptoms	Alleviation Occurrence 1		2		3		4		Helped to alleviate symptoms	
	A	B	A	B	A	B	A	B	A Frequency(%)	B Frequency(%)
5. Nausea										
Nausea	3	4	7	5	4	4	5	3	17(89.47)	15(80)
Vomiting	0	0	1	3	2	2	0	2	2(66.67)	7(100)
6. Respiratory										
Cough	1	0	4	2	1	2	0	0	4(57.14)	4(100)
Shortness of Breath	0	1	1	5	2	4	4	1	7(100)	11(100)
7. Pain	1	1	7	5	8	7	3	1	17(89.47)	14(100)
8. Numbness in Fingers and/or Toes	0	1	5	1	0	3	6	2	7(63.63)	6(85.71)
9. Bleeding	0	0	1	2	0	0	0	0	1(100)	2(100)
10. Hair Loss	2	1	2	1	3	1	5	4	12(100)	5(71.42)
11. Skin Changes	0	0	6	0	5	2	5	1	12(75)	3(100)
12. Constipation	0	1	3	5	6	3	6	2	14(93.33)	10(90.9)
13. Soreness in Vein	0	0	2	0	0	0	0	0	2(100)	0
14. Decreased Interest in Sexual Activity	0	0	2	0	1	0	0	0	3(100)	0

Note. TRSC = Therapy-Related Symptom Checklist; A= Caucasian; B= African-Americans
1 = Seldom done; 2= Done occasionally; 3= Often done; 4 = Very often done.

Data displayed in Table 12 shows that the alleviation methods used by Caucasians for twelve symptoms were 100 % effective regardless of the method of self-care or the frequency with which it was performed. Strategies used were to relieve symptoms depression, weight loss, difficulty swallowing, sore throat, jaw pain, fever, bruising, shortness of breath, bleeding, hair loss, soreness in vein, and decreased interest in sexual activities. Methods used to alleviate symptoms by African- Americans were 100% effective for the symptoms feeling sluggish, difficulty concentrating, loss of appetite, difficulty swallowing, sore throat, jaw pain, fever, vomiting, cough, shortness of breath, pain, bleeding, and skin changes. Vomiting, cough, and numbness in fingers/toes were the three symptoms reported with least effective self-care strategies by Caucasians. Hair loss, depression, and nausea were the three symptoms reported with least effective self-care strategies by African- Americans. Bruising, soreness in vein, and decreased interest in sexual activities were the three symptoms with no reported useful self-care strategies by African- Americans.

4. Self-care methods used to alleviate symptoms reported by age group- Adolescent-young adult (18-39 years) vs. older adults (40 years or older)

Table 13 displays self-care methods by categories (Diet and Nutrition; Lifestyle changes; Spiritual, Mind and Body control; Herbal and Vitamin Treatment; Medication, and Other (do nothing/no response) used by Adolescent-young adult (18-39 years) and older adults (40 years or older) for symptom alleviation.

Table 13

Symptom Alleviation: Self-Care Methods by Categories used by Adolescent-Young Adults (18-39 years) vs. Older Adults (40 years or older)

TRSC Subscales /Symptoms	Self-care Categories											
	Diet&Nutrition		Lifestyle Changes		Spiritual, Mind and Body Control		Herbal and Vitamin Treatment		Medication		Other	
	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40
1.Fatigue												
Feeling Sluggish	1	2	6	31	1	10	1	0	0	3	4	55
Depression	0	0	0	6	2	9	0	1	0	5	9	80
Difficulty-Concentrating	1	0	0	4	1	8	0	0	0	1	9	86
Difficulty Sleeping	1	2	3	7	2	10	0	0	1	16	7	66
2. Eating												
Taste Change	4	31	0	2	0	2	0	1	1	2	6	62
Loss of Appetite	2	28	0	0	0	2	0	4	0	1	9	65
Weight Loss	3	8	0	0	0	1	2	4	0	0	6	86
Difficulty Swallowing	1	6	0	0	0	1	0	0	0	4	10	88
3. Oropharynx												
Sore Mouth	0	2	0	0	0	1	0	0	3	17	8	81
Sore Throat	1	1	0	0	0	0	0	0	1	7	9	91
Jaw Pain	1	1	0	0	0	0	0	0	1	1	10	97
4. Fever												
Fever	0	1	0	0	0	0	0	0	1	3	10	96
Bruising	0	0	0	0	0	0	0	0	0	1	11	98

N*ote.* TRSC= Therapy-Related Symptom Checklist

Table 13 (continued)

TRSC Subscales /Symptoms	Self-care Categories											
	Diet&Nutrition		Lifestyle Changes		Spiritual, Mind and Body Control		Herbal and Vitamin Treatment		Medication		Other	
	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40
5. Nausea												
Nausea	0	5	0	1	0	0	0	1	4	26	4	67
Vomiting	0	0	0	0	0	0	0	0	2	8	9	91
6. Respiratory												
Cough	0	1	0	0	0	1	0	0	0	9	11	88
Shortness of Breath	0	0	0	15	0	2	0	0	0	1	11	81
7. Pain	0	0	0	1	1	0	0	0	5	30	6	68
8. Numbness in Fingers and/or Toes	0	0	0	12	0	2	0	0	1	3	10	82
9. Bleeding	0	0	0	0	0	0	0	0	0	3	11	96
10. Hair Loss	0	0	1	14	0	1	0	0	0	2	10	82
11. Skin Changes	0	0	0	0	0	0	0	0	1	19	10	80
12. Constipation	1	8	0	0	0	0	0	0	1	21	9	72
13. Soreness in Vein	0	0	0	0	1	0	0	0	1	1	9	98
14. Decreased Interest in Sexual Activity	0	0	0	2	0	2	0	0	0	0	11	95

Note. TRSC= Therapy-Related Symptom Checklist

As displayed in Table 13, among Adolescent-young adult (18-39 years), the most commonly used self-care strategy was medications for symptoms pain, nausea, constipation, and skin changes. Second most commonly used strategy was diet changes for symptoms taste change, loss of appetite, and weight loss. Third commonly used strategy used by adolescent-young adults was lifestyle changes for symptoms feeling sluggish and difficulty sleeping. The top-ranked symptom alleviation method used by older adults (40 years or older) was medications for symptoms pain, constipation, nausea, skin changes, sore mouth, and difficulty sleeping. Tied for the second most commonly used symptom alleviation method were diet/ nutrition and lifestyle changes. Diet/ nutrition was commonly used method for symptoms taste change, loss of appetite, and constipation. Lifestyle changes were used to alleviate symptoms such as feeling sluggish, shortness of breath, hair loss, and numbness in fingers and toes. Third commonly used strategy was spiritual, mind and body control for symptoms feeling sluggish, difficulty sleeping, depression, and difficulty concentrating.

Table 14 displays the frequency and usefulness of cancer patients' self-care methods for symptom alleviation by age grouping - Adolescent-young adult (18-39 years) vs. older adults (40 years or older). Participants' frequency of self-care strategies used are given in four categories, from the lowest frequency category (seldom done) to the highest frequency category (very often done).

Table 14

Frequencies of Symptom Alleviation Occurrence and Usefulness by Age Grouping - Adolescent-Young Adult (18-39 years) vs. Older Adults (40 years or older)

	Alleviation Occurrence								Helped to alleviate symptoms	
TRSC Subscales /Symptoms	1		2		3		4			
	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18- 39	≥ 40
									Frequency (%)	Frequency (%)
1. Fatigue										
Feeling Sluggish	0	1	0	20	6	17	1	6	6(85.71)	43(95.56)
Depression 0	0	0	0	7	1	9	1	3	1(50)	19(100)
Difficulty- Concentrating	0	0	1	6	0	4	1	3	1(50)	13(100)
Difficulty Sleeping	0	2	1	13	1	7	2	11	2(50)	31(93.94)
2. Eating										
Taste Change	0	3	0	7	2	14	2	13	4(100)	32(62.16)
Loss of Appetite	1	2	0	4	1	15	0	12	2(100)	31(93.93)
Weight Loss	0	0	0	5	3	6	1	2	4(100)	12(92.31)
Difficulty Swallowing	0	0	1	3	0	3	0	5	1(100)	11(100)
3. Oropharynx										
Sore Mouth	0	0	2	6	0	5	1	6	3(100)	17(100)
Sore Throat	0	0	1	4	1	2	0	2	2(100)	8(100)
Jaw Pain	0	0	1	0	0	0	0	2	1(100)	2(100)
4. Fever										
Fever	0	0	0	2	1	1	0	0	1(100)	3(100)
Bruising	0	0	0	0	0	0	0	1	0	1(100)

Note. TRSC= Therapy-Related Symptom Checklist; 1 = Seldom done; 2= Done occasionally; 3= Often done; 4 = Very often done.

Table 14 (continued)

TRSC Subscales /Symptoms	Alleviation Occurrence 1		2		3		4		Helped to alleviate symptoms	
	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18-39	≥ 40	18- 39 Frequency (%)	≥ 40 Frequency (%)
5. Nausea										
Nausea	0	8	4	8	2	8	1	7	6(85.71)	30(96.77)
Vomiting	0	0	1	3	0	4	1	1	2(100)	7(87.5)
6. Respiratory										
Cough	0	1	0	6	0	3	0	0	0	8(80)
Shortness of Breath	0	1	0	6	0	6	0	5	0	18(100)
7. Pain	1	1	3	9	0	16	1	4	4(80)	28(93.33)
8. Numbness in Fingers and/or Toes	0	1	0	6	0	3	1	7	0	13(76.47)
9. Bleeding	0	3	0	0	0	0	0	0	0	3(100)
10. Hair Loss	0	3	0	3	1	2	0	9	1(100)	17(100)
11. Skin Changes	0	0	0	6	1	7	0	6	1(100)	15(78.94)
12. Constipation	0	1	1	8	1	8	0	9	2(100)	24(92.31)
13. Soreness in Vein	1	0	1	1	0	0	0	0	2(100)	1(100)
14. Decreased Interest in Sexual Activity	0	0	0	2	0	2	0	0	0	4(100)

Note. TRSC= Therapy-Related Symptom Checklist; 1 = Seldom done; 2= Done occasionally; 3= Often done; 4 = Very often done.

Data displayed in Table 14 shows that thirteen symptom alleviation methods used by Adolescent-young adult (18-39 years) were 100 % effective regardless of the method of self-care or the frequency with which it was performed. Those effective strategies were used for symptoms taste change, loss of appetite, weight loss, difficulty swallowing, sore mouth, sore throat, jaw pain, fever, vomiting, hair loss, skin changes, constipation, and soreness in vein. Methods used by older adults (40 years or older) for thirteen symptoms were 100% effective and were used for symptoms depression, difficulty concentrating, difficulty swallowing, sore mouth, sore throat, jaw pain, fever, bruising, shortness of breath, bleeding, hair loss, soreness in vein and decreased interest in sexual activity. Depression, difficulty concentrating, and difficulty sleeping were the three symptoms reported with least effective self-care strategies by adolescent-young adults. Taste change, skin changes, and numbness in fingers and/or toes were the three symptoms reported with least effective self-care strategies by older adults.

Summary

Data analyses included descriptive statistics, independent two-sample t-test, ANOVA, Pearson correlation coefficient, model selection methods, multiple linear regression, path analysis, and content analysis to address study questions. The primary research hypothesis was that cancer therapy-related symptom occurrence and severity and health-related quality of life are influenced by selected variables related to the cancer condition and by selected demographic variables. There was significant association between symptom occurrence and severity with gender (t= 2.07, *p*=.04), economic status [(Annual income> $60,000) (t= -2.53, *p*=.01)], and disease stage (t= 4.31, *p*=.000). Significant association found between economic status [(annual income > $60,000), (t= 2.11, *p*=.04)], and ethnicity [(African American, t= 2.01, *p*=.04), (Asian & Hispanic, t= 2.04, *p*=.04)] and HRQOL- LASA total score. There was significant inverse

relationship found between TRSC total score and HRQOL- LASA total score. Patients with higher symptom severity reported lower HRQOL. Path analysis showed that there was a significant negative correlation between economic status [(Annual income >$60,000) (β= -.23, *p*=.005)] and symptom severity. This indicates that patients with high socioeconomic status reported lower symptom occurrence and severity. Significant positive correlations found between cancer stage and TRSC total score (β= .39, *p*= .000). There was significant association found between HRQOL-LASA total score and ethnicity [(African American/Black, β= .24, p= .01), (Asians and Hispanics, β=.19, p= .02)]. There was also a significant inverse relationship between symptom severity and HRQOL- LASA (β= -.27, p= .002). It is clear from the analysis that selected demographic and disease-related variables to contribute towards 23% variance in symptom severity and 20% variance in HRQOL-LASA scores.

With secondary research questions, findings showed that there was a significant difference in symptom occurrence and severity between African-American and Caucasian patients. However, there was no significant difference in symptom occurrence and severity by age grouping (adolescent-young adult, 18-39 years) vs. older adults (40 years or older). Content analysis showed that most commonly used self-care strategies by Caucasians were medications and lifestyle changes and that of African- Americans were medications, and diet and nutrition. Twelve symptoms alleviation methods used by Caucasians were 100 % effective, and thirteen symptoms reported as 100 % effective by African- Americans. Adolescent-young adult (18-39 years) reported medications and diet/ nutrition as the most commonly used self-care strategies. Older adults reported medications, diet/nutrition, and lifestyle changes as commonly used self-care strategies. Thirteen symptoms alleviation methods used by adolescent-young adults were 100 % effective, and twelve symptoms reported as 100 % effective in older adults.

Chapter V

Discussion, Implications, and Conclusion

The primary aim of this research study was to examine the relationship among cancer therapy-related symptom occurrence, and severity, health-related quality of life, selected variables related to the cancer condition (diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities), and selected demographic variables (ethnicity, age, gender, marital status, education, economic status). There were various previous studies that examined the TRSC, HRQOL-LASA, and Symptom Alleviation: Self-care Methods tool, but no study was found that examined all three tools together as in this study with three groups of cancer patients during treatment (chemotherapy, radiation therapy, and chemo and radiation therapy). The present study also uniquely used path analysis to explore the test model, independent variables → symptom occurrence/severity, and HRQOL. In addition, this study examined (a) cancer patients' reported symptom occurrence and severity by ethnicity (African-American vs. Caucasian); (b) self-care methods used by ethnicity; (c) difference in symptom occurrence and severity by age grouping, adolescent-young adult (18-39 years) vs. older adults (40 years or older); and (d) self-care methods used by age grouping.

Reliability and Validity of Study Tools

The reliability of the TRSC in the present study was 0.862 as measured by Cronbach's alpha, indicating a high internal consistency of items in the tool. Cronbach's alphas above .80 were previously reported for the TRSC (A. Williams et al., 2000; 2014; P. Williams et al., 1997, 2000, 2001, 2010, 2015; Williams, Graham et al., 2013; Williams, Williams, Lafever-Roling, et al., 2011). The reliability of the HRQOL-LASA in the present study as measured by Cronbach's alpha was 0.929, indicating a higher reliability among the items in the tool. This study provides

additional support for the tool HRQOL-LASA as a general measure of global QOL dimensional constructs (Bretscher et al., 1999; Halyard & Ferrans, 2008; Williams et al., 2011, 2013).

Cronbach's alphas for the EORTC QLQ C-30 Global health status (0.889), functional scales (0.686 to 0.873), and symptom scales (0.847) indicate high reliability. Results were similar to those previously reported. Aaronson et al. (1993), reported that the EORTC QLQ C-30 scale met the minimal standards for reliability (Cronbach's alpha coefficient > or = .70) either before or during treatment except the role functioning multi-item scale. Cronbach's alpha ranged from 0.73 to 0.94 in the Japanese version of the EORTC QLQ C-30 scale (Sato, Shimizu, & Miyashita, 2014). Michelson et al. (2000) reported satisfactory levels of Cronbach's alpha above 0.82 for all functions except cognitive function (0.55). As evidence of its convergent validity, significant correlations were found between the HRQOL-LASA, and the EORTC symptoms subscale, physical functioning subscale, and Global Health Status. For Symptom Alleviation: Self-Care Method tool, Cronbach's alpha in the present study was 0.728, indicated good reliability. Cronbach's alphas above 0.70 have been reported for this tool (Gonzalez et al., 2011; P. D. Williams et al. 2011b). Results suggest that these tools may be used in future research studies.

The Sample

Sample size and sample distribution was comparable to previous studies conducted among adult oncology patients to examine their symptom occurrence and severity. The majority of participants were 60-79 years of age (*n*=57, 41.8 %). The majority (*n*=63, 57.3%) of participants were females; and 47 (42.7%) were males. The majority (*n*=60, 54.5%) of participants were Caucasian, and 40 (36.4%) were African American/Black. The majority (*n*=60, 54.5%) were married, and the educational level for 49 (44.5%) participants was a high

school diploma. Among 110 patients, 48 (43.6%) patients were receiving chemotherapy alone, 36 (32.7%) patients were receiving radiation therapy alone, and 26 (23.6%) patients were receiving combined treatment with both chemotherapy and radiation therapy. The distribution of the sample by treatment moderately was similar to the study conducted by Williams et al. (2010), where 65% (*n*=63) were females who were receiving chemotherapy, and 70% females (*n*=37) receiving the combination of chemotherapy and radiation therapy. Another study conducted by Williams et al. (2014) among 67 Mexican- Americans undergoing chemotherapy, mean patient age was 58.1 years; mostly females (76%), and the majority (70%) had some high school or some college education.

Primary Research Hypothesis

Cancer Therapy-Related Symptom Occurrence and Severity

This study finding showed significant relationships between symptom occurrence/severity (as measured by TRSC total score) and gender, economic status (Annual income> $60,000), and cancer stage. Results indicating females report higher symptom occurrence and severity and was similar to those by Mao et al. (2007), who found that women were more likely to report ongoing symptoms independent of cancer survivorship status. Jimenez et al. (2011) conducted a study in 406 patients with advanced cancer, to explore symptom clusters in advanced cancer and also found that sex influenced symptom cluster. Walsh et al. (2000) reported that there was a significant difference in symptom experience by age and gender. The present study found a significant difference in symptom severity and gender, not by age.

The present study did not find any significant relationship between education and symptom occurrence and severity. In contrast, Prigozin et al. (2010) reported that education was

inversely related to total symptom severity scores. Heinze et al. (2015) also reported an inverse relationship between education and symptom severity scores. The present study did not find a significant relationship between age and general symptoms and marital status and symptoms. The present study supports findings reported by Heinze et al. (2015), who also did not find a significant relationship between age and general symptom severity scores, and marital status and symptom severity scores.

Findings of the present study found a significant difference in symptom occurrence and severity scores (TRSC total scores) between patients with annual income <$ 30,000 and > $60,000. Specifically, there was a significant inverse relationship between income status and symptom severity. This means that patients with higher annual income reported lower symptom occurrence and severity compared to patients with lower annual income. The present study supports findings of Mao et al. (2007) that higher level of socioeconomic status is associated with lower level of symptom severity. The current study also supports findings of studies conducted by Thomas et al. (2014) that low-income level predicted higher somatic symptom burden and Langford et al. (2015), that high-risk patients with severe symptom clusters (pain, fatigue, sleep disturbance, and depressive symptoms) had low economic status.

The present study found a significant relationship between cancer stage and symptom severity. Participants with higher cancer stage (stage 3 &4) reported higher TRSC scores. These findings support those by Alexiusdottir et al. (2012), and Cleeland et al. (2013). The present study did not find any significant relationship between the number of comorbidities and symptom severity. In contrast, Langford et al. (2015) reported that patients with high symptom clusters had severe comorbidity profile and the present study findings contradict this report.

The present study findings showed that patients receiving chemotherapy alone reported the most severe symptom severity scores (TRSC total scores) compared to those receiving radiation therapy alone, and those receiving chemotherapy and radiation therapy. In contrast, the study conducted by Williams et al. (2010) reported that the mean TRSC scores of patients receiving chemotherapy alone was 17.71, patients receiving radiation therapy alone was 15.65, and patients receiving a combination of chemotherapy and radiation therapy was 20.06.

In the present study, 13 symptoms (feeling sluggish, depression, difficulty sleeping, taste change, loss of appetite, weight loss, nausea, shortness of breath, pain, numbness in fingers and/or toes, hair loss, constipation, decreased interest in sexual activities) were reported by 50% or more patients receiving chemotherapy alone. This is consistent with other studies that report cancer patients receiving chemotherapy treatments experience a broad range of distressing side-effects, including treatment-related fatigue, anxiety, pain, nausea, vomiting, mood changes, depression, lack of appetite, dyspnea, alopecia, changes in skin and nails, oral sores, peripheral neuropathy, and numbness in fingers and hands (Akin, Can, Durna, & Aydiner, 2008; Akin & Durna 2013; Cheung et al., 2012; Cramarossa et al., 2013; Hutter et al., 2013; Kennedy, Harcourt, Rumsey, & White, 2010; Mols, Beijers, Vreugdenhil & van de Poll-Franse, 2014; Schneider, Hershman, & Loprinzi, 2015; Senf, Brandt, Dignass et al., 2010, Williams et al,. 2014; 2015).

In the present study, patients receiving chemotherapy reported eleven symptoms (feeling sluggish, difficulty sleeping, taste change, weight loss, nausea, pain, numbness in fingers and/or toes, hair loss, constipation, and decreased interest in sexual activity) with a mean severity score equal to or greater than one. These findings support those by Heinze and Williams (2015), and Williams et al. (2014, 2015). Specifically, Heinze and Williams (2015) found that breast cancer

survivors who received chemotherapy reported higher TRSC scores and an average of 12 symptoms on the TRSC. Williams et al. (2015), conducted a cross-sectional study to examine symptom occurrence among Mexican American adults (*N*= 67) undergoing cancer chemotherapy treatment. Findings of this study reported that 45% or more of patients reported 12 symptoms on the TRSC: feeling sluggish, hair loss, nausea, taste change, appetite loss, depression, difficulty sleeping, weight loss, difficulty concentrating, constipation, skin changes, and numb fingers and toes. The present study also found similar findings.

In this study, 50% of patients receiving radiation therapy alone reported experiencing seven symptoms in common (feeling sluggish, depression, difficulty concentrating, difficulty sleeping, loss of appetite, pain, and decreased interest in sexual activity) with mean severity score equal to or greater than one. Findings of the present study support those reported by Williams et al. (2006, 2010). Major symptoms associated with radiation therapy alone patients were on TRSC subscales eating, fatigue, skin changes, oropharynx, and constipation (Williams et al., 2006). Williams et al. (2010) replicated the study among Filipino and Chinese oncology adult patients, and the study findings were same as that of their 2006 study. Williams et al. (2015) conducted a study to examine symptom occurrence and severity as reported by U.S. Veterans at a cancer clinic. Findings of the study showed that thirteen symptoms were reported by more than 35% of patients. Major symptoms reported in the present study was consistent with findings reported by Williams et al. (2015).

The present study findings showed that chemotherapy alone group reported more severe symptoms compared to those receiving chemotherapy and radiation therapy. Feeling sluggish, difficulty sleeping, taste change, loss of appetite, weight loss, and pain were major symptoms reported by chemotherapy and radiation therapy combined treatment group in the present study.

However, Piamjiariyakul et al. (2009) found that patients receiving chemotherapy and radiation therapy reported more severe symptoms in eating, oropharynx, nausea and fatigue subscales. Williams et al. (2010) reported that Chinese patients on combined chemotherapy and radiation therapy treatment reported more symptoms with greater severity than those receiving either chemotherapy or radiation therapy alone. The present study report contradicts these findings.

Health-Related Quality of Life

Findings of the present study showed a significant relationship between ethnicity and economic status with HRQOL- LASA total scores. African Americans and Asians/Hispanics in the present study had a significantly higher HRQOL-LASA score compared to Caucasians. This difference may be due to cultural difference in experiencing and reporting their HRQOL. These findings support those by Janz et al. (2009) that reported significant racial/ethnic differences in quality of life during cancer survivorship. In the Janz et al. (2009) study, African American women reported significantly lower functional well-being, and all racial/ethnic minority groups reported lower physical well-being relative to white women. However, in the present study, Caucasians reported lower QOL compared to African Americans and Asians/Hispanics. Participants from higher economic status (annual income > $60,000) reported higher HRQOL. These support findings reported by Cramarossa et al. (2013) that economic problems negatively affect QOL in cancer patients. The present study did not find a significant relationship between disease-related characteristics and HRQOL. In contrast, Bayram et al. (2014) reported that personal characteristics as well as treatment- and disease-related characteristics may influence QOL among breast cancer patients.

The present study findings showed no gender differences in HRQOL, similar to findings reported by Alabbas et al. (2015). Kenzik et al. (2015) reported that old age was associated with

lower physical HRQOL. The present study did not find any significant association between age and HRQOL and contradicted findings of So, Choi, & Chair, 2011 and Kenzik et al., 2015. Findings of the present study showed that there was a significant inverse relationship between HRQOL and symptom severity. That is, patients with high symptoms scores (indicating higher symptom occurrence and severity) reported low HRQOL. Findings of the present study support findings of studies conducted by Harrow et al., 2014; Hwang, Chang, & Park, 2013; Pud et al., 2014; Samuels, Maimon, & Zisk-Rony, 2013; &Weis, 2011. Williams et al. (2011; 2013; 2015) and Heinze et al. (2015) also reported that greater occurrence and severity of symptoms on the TRSC were related to lower HRQOL.

Secondary Purposes

1. Symptom Occurrence and Severity by Ethnicity- African-American vs. Caucasian

There is clear evidence in the literature that cancer therapy-related symptoms vary among different ethnic groups. Findings of the present study showed that there was a significant difference in symptom occurrence and severity between African-American and Caucasian patients. That is, African Americans reported higher TRSC scores compared to Caucasians. Results are consistent with those reported by Martinez, Snyder, Malin, & Dy (2014) that pain severity was higher for black patients and multiracial patients compared to white patients. Im (2007), also strongly supported ethnic differences in cancer pain experience. Im et al. (2013) conducted a study to cluster cancer patients who reported similar cancer pain experience, and to determine ethnic differences in the clusters. African Americans reported higher symptom scores than did whites.

2. Symptom Occurrence and Severity by Adolescent-young Adult (18-39 years) vs. Older Adults (40 years or older)

The present study did not find any significant difference in symptom occurrence and severity by age group (adolescent-young adult, 18-39 years) vs. older adults (40 years or older). Williams, K (2012) described adolescent and young adult oncology care as an "emerging specialty" and stated the need for age-appropriate services by oncology nurses. Adolescents experience multiple symptoms that are inter-related; clinicians should prioritize symptom management interventions with the adolescent's input to focus on the most distressing symptoms (Erickson et al., 2013). Chang et al. (2011) compared adolescent and young adult to a cancer patient cohort older than 40 years old by the severity of cancer, treatment status, symptom burden, symptom changes, and difficulty in caring for them. There were no significant differences in cancer stage, current treatment status and clinician's perception of difficulty in caring for adolescent and young adult cancer patients. The present study also supports findings reported by Chang et al. (2011). Since this is an emerging field of study, more research studies need to be conducted with adolescent and young adult cancer patients.

3. Self-care Methods Used to Alleviate Symptoms Reported by Ethnicity: African-American vs. Caucasian

In the present study, the most commonly used self- care strategy by both African-American and Caucasians was medications. The second most commonly used self- care strategy by Caucasians was lifestyle changes, and that of African-American was diet/ nutrition. There are various studies reported in literature about the common self- care strategies by cancer patients in general. Feeling sluggish was the top-ranked symptom with a maximum reported self-care strategies by Caucasians. Taste change was the top-ranked symptom with a maximum reported

self-care strategies by African- Americans. Twelve symptoms alleviation methods used by Caucasians and thirteen symptoms alleviation methods used by African- Americans were 100 % effective regardless of the method of self-care or the frequency with which it was performed. Most commonly used self-care methods by Caucasians in rank order were 1) medications, 2) lifestyle changes, and 3) diet/nutrition and that of African-Americans were 1) medications, 2)diet/nutrition, and 3) lifestyle changes. There were no studies reported the difference self-care methods used to alleviate symptoms by ethnicity: African-American vs. Caucasian. Therefore, more research studies need to be conducted to understand and compare self- care strategies used by various ethnic groups. Identification of common symptoms, self-care practices, and effectiveness of self-care strategies would help health care providers assist patients to manage their symptoms more effectively and efficiently.

4. Self-care Methods Used to Alleviate Symptoms Reported by Age group- Adolescent-Young Adult (18-39 years) vs. Older Adults (40 years or older)

Findings of the present study showed that there was similarities in self- care strategies by both adolescent-young adults (18-39 years) and older adults (40 years or older). Specifically, medications were the most commonly used self- care strategy by both adolescent-young adults (18-39 years) and older adults (40 years or older) for symptoms pain, nausea, constipation, and skin changes. Other commonly used strategies by both age groups were diet/ nutrition and lifestyle changes. Depression, difficulty concentrating, and difficulty sleeping were the three symptoms reported with least effective self-care strategies by adolescent-young adults. Taste change, skin changes, and numbness in fingers and/or toes were the three symptoms reported with least effective self-care strategies by older adults. Several studies have focused on the use of complementary or self-care methods to alleviate cancer therapy-related symptoms. The most

commonly used categories were diet/nutrition/lifestyle change and mind/body control as patients in the Midwest (Williams et al., 2006); Puerto Rico (Gonzalez et al.2011); Thai patients (Piamjiariyakul et al., 2010), Chinese patients in China (Williams et al., 2010a), and Filipino patients (Williams et al., 2010b). Findings of the present study support these findings, however, there was no study that reported the difference in self- care strategy by both Adolescent-young adult (18-39 years) and older adults (40 years or older). The literature clearly indicates that cancer patients use various self- care strategies. There is a need for further research into self-care strategies used by adolescent-young adult and older adults. This will help healthcare professionals to manage their patients'(adolescent-young adult and older adults) symptoms effectively.

Theoretical Relevance

The present study assumed that demographic variables (ethnicity, age, gender, marital status, education, economic status) and cancer-related characteristics (diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities), are associated with cancer therapy-related symptom occurrence and severity, and which in turn influences cancer patients' quality of life. Results from this study did not completely support all the assumed relationships showed in Conceptual model 1 (Figure 1). However, findings of this study showed gender, economic status, and cancer stage were significantly associated with symptom occurrence and severity. Significant associations were also found between HRQOL and economic status (annual income > $ 60,000), and ethnicity (African Americans and Asians & Hispanics). Moreover, there was a significant inverse relationship found between HRQOL and symptom occurrence/severity. That is patients with high TRSC total scores reported low HRQOL-LASA total score. Therefore, findings provide support for the relationship between two

(gender and economic status) of six selected demographic variables and symptom occurrence and severity and one (cancer stage) of five cancer-related characteristics and cancer therapy-related symptom occurrence and severity. Findings also support that symptom occurrence and severity was associated with quality of life of cancer patients. Economic status (annual income > $ 60,000), was the only variable that showed a significant relationship with both symptom occurrence and severity and HRQOL. More research studies need to be conducted using this conceptual model to better understand the relationships between variables.

Findings of the path analysis showed that there was a significant negative correlation between economic status and symptom severity. Significant positive correlation was found between disease stage and symptom severity. Ethnicity had a strong positive relationship with HRQOL. Positive relationship found between economic status and HRQOL. Economic status also showed a negative relationship with symptom severity. This indicates that patients from the high socio-economic group had lower symptom occurrence/severity and higher HRQOL. The significant inverse relationship found between symptom occurrence and severity and HRQOL. This indicates that participants with higher symptom occurrence and severity reported lower quality of life. It was clear from the analysis that selected demographic and disease-related variables contribute towards 23% variance in symptom occurrence and severity (TRSC scores) and 20% variance in HRQOL scores. Findings of path analysis partially support the model tested in this study that independent variables → symptom occurrence/ severity and HRQOL.

Conceptual model 2 (Figure 2, Chapter I), addressed the four secondary research questions. In this model, symptom occurrence and severity are assumed to be associated with ethnicity and age grouping, and will influence self-care activities. Findings of the study showed that there was a significant difference in symptom occurrence and severity between African-

American and Caucasian patients. However, there was no significant difference in symptom occurrence and severity by age grouping, adolescent-young adult (18-39 years) vs. older adults (40 years or older). Content analysis showed that most commonly used self-care strategies by Caucasians were medications and lifestyle changes and that of African- Americans were medications, and diet and nutrition. Twelve symptoms alleviation methods used by Caucasians were 100 % effective, and thirteen symptoms reported as 100 % effective by African-Americans. Adolescent-young adult (18-39 years) reported medications and diet/ nutrition as the most commonly used self-care strategies. Older adults reported medications, diet/nutrition, and lifestyle changes as commonly used self-care strategies. Thirteen symptoms alleviation methods used by adolescent-young adults were 100 % effective, and twelve symptoms reported as 100 % effective in older adults. Therefore, findings of this study partially support conceptual model 2 used for the present study.

Overall, findings of the present study partially support the theoretical models (model1 and 2) used in this study. Further study with larger sample size and more participants under age 40 years may provide more robust support for the selected conceptual models used in the present study.

Clinical Implications

The ultimate aim of cancer treatment is to ensure minimal suffering and maximum comfort to the patients. The findings of the present study support the need for ongoing assessment of cancer therapy related symptom occurrence and severity, HRQOL, and common useful self-care strategies used by cancer patients. A systematic tracking of patient-reported symptoms during treatment is essential to prioritize and manage their symptoms effectively (Williams et al., 2014). The result of the present study provides additional support for the use of

TRSC in oncology nursing practice. TRSC is a simple tool which can be utilized in clinical oncology setting to identify and track major symptoms experienced by suffering cancer patients. TRSC was successfully used in many clinical settings in various countries (Gonzalez et al., 2011; Heinze, 2012; 2014; Piamjiariyakul et al., 2010; Williams et al., 1997, 2001, 2006, 2010, 2011, 2013, 2014, 2015). TRSC also was used electronically in studies conducted by Heinze et al., 2015 and Heinze and Williams, 2014. Evidence from the present study clearly support the fact that cancer therapy-related symptom occurrence and severity (as measured by TRSC total scores) significantly influenced their QOL (as measured by HRQOL-LASA total scores). That is, patients with higher TRSC total scores reported lower HRQOL-LASA total scores. There is ample evidence in literature that cancer therapy related symptom occurrence/severity and HRQOL are influenced by demographic factors such as ethnicity, age, gender, marital status, education, economic status and disease-related variables such as diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities.

The Symptom Alleviation: Self- care Methods tool is based on the TRSC. In the present study, this tool was found very useful for patients to report their self-care methods in relation to their reported cancer therapy-related symptoms. The Symptom Alleviation: Self- care Methods tool is reported as a simple and easy tool used to identify the self-care measures used by patients to alleviate their reported symptoms (Heinze & Williams, 2014; Piamjariyakul et al. 2010; Williams et al., 2006, 2010a, b; 2011; 2014). Guiding and motivating patients and families toward self-care activities may reduce symptom burden and can enhance patients' cancer experience across the illness journey (McCorkle et al., 2011; Williams et al., 2011; 2013). Studies conducted by Heinze et al. (2015) and Heinze and Williams (2014) reported the successful use of Symptom Alleviation: Self- care Methods tool electronically. Hoffman (2007)

stressed the need for oncology nurses to incorporate assessment of symptoms into everyday practice to optimize symptom management and enhance the comfort level of cancer patients. In an evidence-based practice study, Williams et al. (2011) conducted an educational intervention study to manage patient-reported symptoms on the TRSC during cancer treatment. Findings showed that patient education, counseling, and follow-up by advanced practice nurses decreased patients' self-reported symptom severity, and improved health-related QOL. In another "intervention study", Williams et al. (2013) reported similar findings.

Knowing that cancer therapy-related symptoms are highly prevalent occurs at any stage of cancer treatment; nurses can tailor prevention and provide appropriate intervention strategies to optimize symptom management. Although further research is needed, many patients could benefit from more comprehensive evaluation and greater use of available symptom assessment and interventions for cancer therapy-related symptoms and HRQOL. Oncology nurses are in an influential position to educate, motivate, and support patients and families to manage their treatment-related symptoms effectively at home.

The importance of assessment of oncology patients' symptoms and HRQOL can be incorporated into the nursing curriculum so that emerging nurses will have a clear understanding of the need for symptom assessment and prompt treatment to improve HRQOL and minimize suffering. Nurse administrators/ educators can provide in-service to clinical nurses on tools like TRSC, Symptom Alleviation: Self- care Methods tool, HRQOL- LASA, EORTC QLQ-C 30 and the importance of routine assessment of cancer patients' symptom severity, occurrence, and HRQOL. Nurse administrators can revise policies related to patient assessment, symptom monitoring, and management in oncology units and clinics. Nurse researchers may take the initiative to conduct more researches related to cancer therapy related symptom occurrence and

severity, and HRQOL. Therefore, findings of the present study have implications for clinical practice, nursing education, nursing administration, and research.

Study Strengths and Limitations

The present study is a unique study conducted among three groups of cancer patients on treatments (chemotherapy alone, radiation therapy alone, and combined chemotherapy and radiation therapy) to find out both cancer therapy related symptom occurrence and severity, HRQOL, and self-care strategies. There were no previous studies with all three groups and three outcome variables (symptom occurrence and severity, HRQOL, and self- care strategies) in a single study, except ones by Williams et al. (2011; 2013) –described in Table 5. The present study also examined the difference in the cancer therapy related symptom occurrence and severity, and self- care strategies influenced by variables such as ethnicity (African-American vs. Caucasian patients), and age group, adolescent-young adult (18-39 years) vs. older adults (40 years or older). These are the major strengths of the present study. The study researcher personally met all participants and collected all data. This gave the opportunity to clarify participants' questions and minimized discrepancy in data gathering. This also reduced the amount of missing information. The researcher collected disease-related information from patients' medical records and this enhanced accuracy of information. Patients/ participants self-reported their symptom occurrence and severity, and HRQOL by themselves-- although this prevented interviewer bias, it also did not allow clarification of questions (e.g., on the data collection instruments) by some patients.

There are a number of limitations identified in the present study. The sample size was small (*N*= 110), and there were only 11 participants under 40 years of age. This limits analysis done on a comparison between adolescent-young adult (18-39 years) vs. older adults (40 years or

older). The study design used in the present study was a cross-sectional design. This limits the ability to make a causal inference, and since the data were collected only one time, there are chances that the results may be different if another time frame had been chosen. A convenience sampling method was used in the study, and that is another limitation. The present study was conducted in one health care system -- this limits the generalizability of study findings. A few patients had previous cancer treatments. Some of these patients informed the researcher that they had intense and varying symptoms with their previous chemotherapy treatments; however, in the present study, patients were instructed to report the current symptoms only. There may be some influence on their reported present symptoms from their experienced symptoms in the past.

Recommendations for Future Research

Future research with a larger diverse sample from more than one geographic area with various demographic and disease-related variables would provide an in-depth understanding of specific relationships and associations with cancer therapy-related symptoms and HRQOL. Samples from more than one hospital system will highlight the difference in symptoms and HRQOL between the hospital systems. Future research should concentrate on the equal proportion of sample subgroups for selected demographic characteristics and treatment type. For example, an equal number of sample in the treatment group receiving chemotherapy alone, radiation therapy alone, and combined chemotherapy and radiation therapy, equal participants under age 40 and older adults, equal Caucasians and African- Americans, etc. This will minimize variations in data while comparing the groups. The study may be replicated in a larger sample with different groups based on cancer diagnosis. This will help to compare symptoms and HRQOL based on various cancer diagnoses, and this will help physicians for proper management of their patients' symptoms.

Findings of this study showed that majority of cancer patients use various self- care strategies and were found helpful. Future research may be conducted to understand the common effective self-care strategies used by cancer patients and have good clinical application in future. Future intervention studies may be conducted to manage cancer patients' symptoms. Findings of effective intervention studies may be applied in oncology practice. More research studies also may be conducted to examine the role of caregivers in cancer patients' symptoms and to find interventions to support caregivers in managing cancer patients' symptoms effectively at home. Data collection tools in the present study may be used online in the future for reporting cancer patient's symptoms. This may enhance patient participation and may be more convenient for participants.

Conclusions

The study conclusions will be addressed using the primary research hypothesis and secondary research questions. Significant relationships were found between symptom occurrence/severity (as measured by TRSC total score) and gender, economic status (Annual income> $60,000), and disease stage. Female patients reported higher symptom occurrence and severity compared to male patients. African Americans had more severe symptoms compared to Caucasians. Also, participants from higher economic group reported lower symptom occurrence and severity. Further, participants diagnosed with stage three and four cancers reported higher symptom severity and occurrence. Age, education, ethnicity, marital status, cancer diagnosis, the length of time since treatments started, and a number of comorbidities were not associated with TRSC scores.

There was significant relationship found between economic status and HRQOL and ethnicity and HRQOL (as measured by HRQOL-LASA total score). Patients with higher

economic status (annual income >$60,000) reported higher HRQOL. In addition, African Americans and Asians/Hispanics reported higher HRQOL compared to Caucasians. There was significant inverse relationship found between symptom occurrence/severity and HRQOL. Patients with higher symptom occurrence and severity reported lower HRQOL.

Findings of the path analysis also supported these findings. Path analysis showed that there was a significant negative correlation between economic status (Annual income >$60,000) and symptom severity. This indicates that patients with high socioeconomic status reported lower symptom occurrence and severity. Significant positive correlations found between symptom severity and disease stage. This shows that patients diagnosed with stage 3 &4 cancers reported higher symptom occurrence and severity compared to cancer stages 0, 1, and 2. There was significant association found between HRQOL and economic status (annual income > $60,000), and ethnicity. There was also a significant inverse relationship between symptom occurrence/severity and HRQOL.

For the secondary research questions, findings showed that there was a significant difference in symptom occurrence and severity between African-American and Caucasian patients. However, there was no significant difference in symptom occurrence and severity by age grouping (adolescent-young adult, 18-39 years) vs. older adults (40 years or older). Content analysis showed that most commonly used self-care strategies by Caucasians were medications and lifestyle changes and that of African- Americans were medications, and diet and nutrition. Twelve symptoms alleviation methods used by Caucasians were 100 % effective, and thirteen symptoms were reported as 100 % effective in African- Americans. Adolescent-young adult (18-39 years) reported medications and diet/ nutrition as the most commonly used self-care strategies. Older adults reported medications, diet/nutrition, and lifestyle changes as commonly

used self-care strategies. Thirteen symptoms alleviation methods used by adolescent-young adults were 100 % effective, and twelve symptoms reported as 100 % effective in older adults.

Summary

The findings of the present study support the need for ongoing assessment of cancer therapy related symptom occurrence and severity, HRQOL, and common useful self-care strategies used by cancer patients. Future research may be conducted on a larger sample with varying demographic and disease-related characteristics. This will increase the generalizability of findings to a larger population. The present study findings have implications for oncology clinical practice, nursing education, administration, and nursing research. The study findings provide a basis for future research studies. More oncology research studies on monitoring or assessment of symptom occurrence and severity, HRQOL, patient engagement in self-care need to be conducted. This would enhance the discovery of effective self-care strategies. Applied in clinical practice to these findings would minimize suffering and enhance patients' overall HRQOL.

References

Aaronson, N.K., Ahmedzai ,S., Bergman, B., Bullinger, M., Cull, A., Duez, N.J., ...de Haes JC et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85,* 365–376

Adams, L. (2009). Managing side effects in radiation therapy patients. *Radiation Therapist, 18*(2), 109-123.

Alabbas, F. F., Al-Otaibi, S. M., Pasha, M. H., Alghamdi, A. M., Al-Hindi, H. M., Al-Ahwal, M. S., & El-Deek, B. S. (2015). Impact of Physiological Symptoms and Complications of Colorectal Cancer on the Quality of Life of Patients at King Abdulaziz University Hospital. *Journal of Cancer Education*. doi: 10.1007/s13187-015-0839-7

Alexiusdottir, K. K., Moller, P. H., Snaebjornsson, P., Jonasson, L., Olafsdottir, E. J., Bjornsson, E. S., . . . Jonasson, J. G. (2012). Association of symptoms of colon cancer patients with tumor location and TNM tumor stage. *Scandinavian Journal of Gastroenterology, 47*, 795-801. doi: 10.3109/00365521.2012.672589

Alsadius, D., Olsson, C., Pettersson, N., Tucker, S. L., Wilderang, U., & Steineck, G. (2013). Perception of body odor-an overlooked consequence of long-term gastrointestinal and urinary symptoms after radiation therapy for prostate cancer. *Journal of Cancer Survivorship, 7*, 652-658. doi: 10.1007/s11764-013-0304-8

Akin, S., Can, G., Durna, Z., & Aydiner, A. (2008). The quality of life and self-efficacy of Turkish breast cancer patients undergoing chemotherapy. *European Journal of Oncology Nursing, 12,* 449-456. doi: 10.1016/j.ejon.2008.07.006

Akin, S., Can, G., Aydiner, A., Ozdilli, K., & Durna, Z. (2010). Quality of life, symptom experience, and distress of lung cancer patients undergoing chemotherapy. *European Journal of Oncology Nursing, 14*, 400-409. doi: 10.1016/j.ejon.2010.01.003

Akin, S., & Durna, Z. (2013). A comparative descriptive study examining the perceptions of cancer patients, family caregivers, and nurses on patient symptom severity in Turkey. *European Journal of Oncology Nursing, 17,* 30-37. doi: 10.1016/j.ejon.2012.02.002

Alemi, F., Hesham, H., Williams, A.R., Williams, P.D., Donley, B., & Kheirbek, R.E. (2014). Computers that show recognition of patients' symptoms. In F Ortuño, I Rojas (Eds.), *Proceedings of IWBBIO, International Work-Conference on Bio-Informatics and Biomedical Engineering*. Vol 1. Granada, Spain: Copicentro Granada S.L., 2014: 321-329.

American Cancer Society. (2015). *Cancer Facts & Figures 2015*. Retrieved from http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2015/index

American Cancer Society. (2016). *Cancer Facts & Figures 2016*. Retrieved from http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2016/

Armes, J., Wagland, R., Finnegan-John, J., Richardson, A., Corner, J., & Griffiths, P. (2014). Development and testing of the patient-reported chemotherapy indicators of symptoms and experience: patient-reported outcome and process indicators sensitive to the quality of nursing care in ambulatory chemotherapy settings. *Cancer Nursing, 37*(3), E52-60. doi: 10.1097/NCC.0b013e3182980420

Armstrong, T. S. (2003). Symptom experience: A concept analysis. *Oncology Nursing Forum, 30,* 601-606.

Aumann, I., Kreis, K., Damm, K., Golpon, H., Welte, T., & Graf von der Schulenburg, J. M. (2015). Treatment-related experiences and preferences of patients with lung cancer: a qualitative analysis. *Health Expectations*. doi: 10.1111/hex.12417

Backman, M., Browall, M., Sundberg, C. J., & Wengstrom, Y. (2015). Experiencing health - Physical activity during adjuvant chemotherapy treatment for women with breast cancer. *European Journal of Oncology Nursing*. doi: 10.1016/j.ejon.2015.09.007

Bayram, Z., Durna, Z., & Akin, S. (2014). Quality of life during chemotherapy and satisfaction with nursing care in Turkish breast cancer patients. *European Journal of Cancer Care,* doi: 10.1111/ecc.12185

Basch, E. (2014). The Rationale for Collecting Patient-Reported Symptoms during Routine Chemotherapy. *American Society of Clinical Oncology educational book, 34,* 161-165. doi: 10.14694/EdBook_AM.2014.34.161

Bretscher, M, Rummans, T, Sloan,J. et al. (1999). Quality of life in hospice patients, a pilot study. *Psychosomatics, 40*, 309-313.

Brown, L. F., & Kroenke, K. (2009). Cancer-related fatigue and its associations with depression and anxiety: A systematic review. *Psychosomatics, 50*, 440-447. doi: 10.1176/appi.psy.50.5.440

Bruce, S. D. (2004). Radiation-induced xerostomia: how dry is your patient? *Clinical Journal of Oncology Nursing, 8,* 61–67

Brzozowska, A., Idziak, M., Burdan, F., & Mazurkiewicz, M. (2015). [Symptoms and treatment of radiation-induced reactions]. *Pol Merkur Lekarski, 38*(227), 283-287.

Budhrani, P. H., Lengacher, C. A., Kip, K. E., Tofthagen, C., & Jim, H. (2014). Minority Breast Cancer Survivors: The Association between Race/Ethnicity, Objective Sleep

Disturbances, and Physical and Psychological Symptoms. *Nursing Research and Practice*. doi: 10.1155/2014/858403

Carroll, J., Kohli, S., Mustian, K., Roscoe, J. & Morrow, G. (2007). Pharmacological treatment of cancer-related fatigue. *The Oncologist,12 (S1),*43-51.

Catlin, A., & Taylor-Ford, R. L. (2011). Investigation of Standard Care Versus Sham Reiki Placebo Versus Actual Reiki Therapy to Enhance Comfort and Well-Being in a Chemotherapy Infusion Center. *Oncology Nursing Forum, 38,* E212-E220.

Centers for Disease Control and Prevention. (2013). *Breast Cancer Statistics*. Retrieved from http://www.cdc.gov/cancer/breast/statistics/index.htm

Chang, V.T., Zhao, F., Wagner, L.I., Sanford, S.D., Salsman, J., & Fisch, M. (2011). Symptom burden and change among adolescent/young adult (AYA) patients with breast, lung, colorectal, or prostate cancer. *Journal of Clinical Oncology, 29.*

Cheung Y.T., Shwe M., Chui W.K., Chay W.Y., Ang S.F., Dent R.A., Yap Y.S., Lo S.K., Ng R.C. & Chan A. (2012). Effects of chemotherapy and psychosocial distress on perceived cognitive disturbances in Asian breast cancer patients. *Annals of Pharmacotherapy, 46,* 1645–1655

Choi, E. K., Kim, I. R., Chang, O., Kang, D., Nam, S. J., Lee, J. E., . . . Cho, J. (2014). Impact of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression in breast cancer patients. *Psycho-oncology*. doi: 10.1002/pon.3531

Cleeland, C. S., Zhao, F., Chang, V. T., Sloan, J. A., O'Mara, A. M., Gilman, P. B., . . . Fisch, M. J. (2013). The symptom burden of cancer: Evidence for a core set of cancer-related and treatment-related symptoms from the Eastern Cooperative Oncology Group

Symptom Outcomes and Practice Patterns Study. *Cancer, 119*, 4333-4340. doi: 10.1002/cncr.28376

Cleophas, T.J., & Zwilderman, A. H. (2012). *Statistics Applied to Clinical Research*. London: Springer.

Coolbrandt, A., Dierckx de Casterle, B., Wildiers, H., Aertgeerts, B., Van der Elst, E., van Achterberg, T., & Milisen, K. (2015). Dealing with chemotherapy-related symptoms at home: a qualitative study in adult patients with cancer. *European Journal of Cancer Care* (Engl). doi: 10.1111/ecc.12303

Cope, D. G. (2015). Cultural Competency in Nursing Research. *Oncology Nursing Forum, 42*(3), 305-307. doi: 10.1188/15.ONF.305-307

Cramarossa G., Chow E., Zhang L., Bedard G., Zeng L., Sahgal A., Vassiliou V., Satoh T., Foro P., Ma B.B., Chie W.C., Chen E., Lam H. & Bottomley A. (2013) Predictive factors for overall quality of life in patients with advanced cancer. *Supportive Care in Cancer, 21,* 1709– 1716.

Dalal, S, Bruera, E. (2012).Assessing cancer pain. *Current Pain and Headache Reports, 16*(3), 14-24.

DeSantis, C. E., Lin, C. C., Mariotto, A. B., Siegel, R. L., Stein, K. D., Kramer, J. L., . . . Jemal, A. (2014). Cancer treatment and survivorship statistics, 2014. *Cancer Journal for Clinicians, 64*(4), 252-271. doi: 10.3322/caac.21235

de Souza, B. F., de Moraes, J. A., Inocenti, A., dos Santos, M. A., Silva, A. E., & Miasso, A. I. (2014). Women with breast cancer taking chemotherapy: depression symptoms and treatment adherence. *Revista Latina-Americana de Enfermagem, 22*(5), 866-873.

Davis, M. P., & Goforth, H. W. (2014). Long-term and short-term effects of insomnia in cancer and effective interventions. *Cancer Journal, 20*(5), 330-344. doi: 10.1097/PPO.0000000000000071

Dodd, M., Janson, S ., Facione, N., Faucett, J ., Froelicher, E. S., Humphreys, J ., Lee, K., Miaskowski, C., Puntillo, K., Rankin, S., & Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*, 668-676.

Doorenbos, A., Given, B., Given, C., & Verbitsky, N. (2006). Physical functioning: effectof behavioral intervention for symptoms among individuals with cancer. *Nursing Research, 55,* 161–171.

Donovan, H. S., Ward, S. E., Sereika, S. M., Knapp, J. E., Sherwood, P. R., Bender, C. M., . . . Ingel, R. (2014). Web-based symptom management for women with recurrent ovarian cancer: a pilot randomized controlled trial of the WRITE Symptoms intervention. *Journal of Pain and Symptom Management, 47*(2), 218-230. doi: 10.1016/j.jpainsymman.2013.04.005

Drageset, J., Corbett, A., Selbaek, G., & Husebo, B. S. (2014). Cancer-related pain and symptoms among nursing home residents: a systematic review. *Journal of Pain and Symptom Management, 48*(4), 699-710 e691. doi: 10.1016/j.jpainsymman.2013.12.238

Erickson, J. M., Macpherson, C. F., Ameringer, S., Baggott, C., Linder, L., & Stegenga, K. (2013). Symptoms and symptom clusters in adolescents receiving cancer treatment: a review of the literature. *International Journal of Nursing Studies, 50*(6), 847-869. doi: 10.1016/j.ijnurstu.2012.10.011

Fingeret M.C., Nipomnick S.W., Crosby M.A. & Reece G.P. (2013). Developing a theoretical framework to illustrate associations among patient satisfaction, body image and quality of

life for women undergoing breast reconstruction. *Cancer Treatment Reviews, 39,* 673–681.

Garabeli Cavalli Kluthcovsky, A. C., Urbanetz, A. A., de Carvalho, D. S., Pereira Maluf, E. M., Schlickmann Sylvestre, G. C., & Bonatto Hatschbach, S. B. (2012). Fatigue after treatment in breast cancer survivors: prevalence, determinants, and impact on health-related quality of life. *Support Care Cancer, 20*(8), 1901-1909. doi: 10.1007/s00520-011-1293-7

George, M., Elias, A., & Shafiei, M. (2015). Insomnia in Cancer - Associations and Implications. *Asian Pacific Journal of Cancer Prevention, 16*(15), 6711-6714.

Golan-Vered, Y., & Pud, D. (2013). Chemotherapy-induced neuropathic pain and its relation to cluster symptoms in breast cancer patients treated with paclitaxel. *Pain Practice, 13,* 46- 52. doi: 10.1111/j.1533-2500.2012.00554.x

Gonzalez, V., Williams, P.D., Tirado, M., & Williams D.D. (2011, March). *Patient-reported symptoms, alleviation and self-care methods, daily activities, and health-related quality of life of adults during outpatient cancer treatments in Puerto Rico* (poster). Midwest Nursing Research Society Conference. Columbus, OH

Gray, P. S., Williamson, J.B., Karp, D.A., & Dalphin, J.R. (2007). *The research imagination: An introduction to qualitative and quantitative methods*. New York: Cambridge University Press.

Grenade, C., Phelps, M. A., & Villalona-Calero, M. A. (2014). Race and ethnicity in cancer therapy: what have we learned? *Clinical Pharmacology & Therapeutics, 95,* 403-412. doi: 10.1038/clpt.2014.5

Gussgard, A. M., Jokstad, A., Hope, A. J., Wood, R., & Tenenbaum, H. (2015). Radiation-Induced Mucositis in Patients with Head and Neck Cancer: Should the Signs or the Symptoms Be Measured? *Journal of Canadian Dental Association, 81*, f11.

Halyard, M. Y., & Ferrans, C. E. (2008). Quality-of-Life assessment for routine oncology clinical practice. *The Journal of Supportive Oncology, 6,* 221-229, 233.

Harrow, A., Dryden, R., McCowan, C., Radley, A., Parsons, M., Thompson, A. M., & Wells, M. (2014). A hard pill to swallow: a qualitative study of women's experiences of adjuvant endocrine therapy for breast cancer. *British Medical Journal- Open, 4*, e005285. doi: 10.1136/bmjopen-2014-005285.

Hartvig, P., Aulin, J., Hugerth, M., Wallenberg, S., & Wagenius, G. (2006). Fatigue in cancer patients treated with cytotoxic drugs. *Journal of Oncology Pharmacy Practice, 12,* 155-164. doi:http://dx.doi.org/10.1177/1078155206070774.

Hassan, B. A., & Yusoff, Z. B. (2010). Negative impact of chemotherapy on breast cancer patients QOL - utility of antiemetic treatment guidelines and the role of race. *Asian Pacific Journal of Cancer Prevention, 11,* 1523-1527.

Heinze, S, B. (2012). *Relationships Among Symptoms, Brain-Derived Neurotrophic Factor (BDNF), Daily Activities, Self-Care, and Quality of Life in Breast Cancer Survivors* (Doctoral dissertation). Retrieved from http://kuscholarworks.ku.edu/dspace/handle/1808/11445.

Heinze, S. B., & Williams, P. D. (2015). Symptom alleviation and self-care among breast cancer survivors after treatment completion. *Clinical Journal of Oncology Nursing, 19*(3), 343-349. doi: 10.1188/15.CJON.343-349.

Heinze, S., Williams, P.D, Bott, M. (2015). Ongoing Symptoms Reported by Breast Cancer Survivors. *Journal of Hospice & Palliative Nursing, 17* (2), 157-164.

Heinze, S., Williams, P.D., Pierce, J., Diaz, F.L., Kirschner, K.F. (2015). Brain-Derived Neurotrophic Factor (BDNF) VAL66MET Polymorphism and Symptoms in Breast Cancer Survivors. *Jacobs Journal of Cancer Science and Research,* 1(1):007.

Henry, D.H., Viswathan, H.N., Elkin, E.P., Traina, S., Wade, S., & Cella, D. (2008). Symptoms and treatment burden associated with cancer treatment: Results from a cross-sectional national survey in the U.S. *Supportive Care in Cancer, 16*, 791–801. doi: 10.1007/s00520-007-0380-2

Hickey, M., Peate, M., Saunders, C. M., & Friedlander, M. (2009). Breast cancer in young women and its impact on reproductive function. *Human Reproduction Update, 15,* 323-339. doi: 10.1093/humupd/dmn064

Ho, R. T., Fong, T. C., & Cheung, I. K. (2014). Cancer-related fatigue in breast cancer patients: factor mixture models with continuous non-normal distributions. *Quality of Life Research.* doi: 10.1007/s11136-014-0731-7

Hofman, M., Ryan, J. L., Figueroa-Moseley, C. D., Jean-Pierre, P., & Morrow, G. R. (2007). Cancer-related fatigue: the scale of the problem. *Oncologist, 12* Suppl 1, 4-10. doi: 10.1634/theoncologist.12-S1-4

Hofso, K., Rustoen, T., Cooper, B. A., Bjordal, K., & Miaskowski, C. (2013). Changes over time in occurrence, severity, and distress of common symptoms during and after radiation therapy for breast cancer. *Journal of Pain and Symptom Management, 45,* 980-1006. doi: 10.1016/j.jpainsymman.2012.06.003

Hsiao, C. P., Moore, I. M., Insel, K. C., & Merkle, C. J. (2014). Symptom self-management strategies in patients with non-metastatic prostate cancer. *Journal of Clinical Nursing, 23*(3-4), 440-449. doi: 10.1111/jocn.12178

Huang, S. M., Tai, C. J., Lin, K. C., Tai, C. J., Tseng, L. M., & Chien, L. Y. (2013). A comparative study of symptoms and quality of life among patients with breast cancer receiving target, chemotherapy, or combined therapy. *Cancer Nursing, 36,* 317-325. doi: 10.1097/NCC.0b013e318268f86d

Huebner, J., Ebel, M., Muenstedt, K., Micke, O., Prott, F. J., Muecke, R., & Hoppe, A. (2014). Lecture Program on Complementary and Alternative Medicine for Cancer Patients-Evaluation of the Pilot Phase. *Journal of Cancer Education*. doi: 10.1007/s13187-014-0706-y

Hughes, C., Fasaye, G.A., LaSalle, V.H., et al. (2003). Sociocultural influences on participation in genetic risk assessment and testing among African American women. *Patient Education and Counseing, 51*,107-114.

Husson, O., Mols, F., van de Poll-Franse L.V. (2011).The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Annals of Oncology, 22,* 761–772. doi: 10.1093/annonc/mdq413.

Hutter, N., Vogel, B., Alexander, T., Baumeister, H., Helmes, A., & Bengel, J. (2013). Are depression and anxiety determinants or indicators of quality of life in breast cancer patients? *Psychology, Health & Medicine, 18,* 412-419. doi: 10.1080/13548506.2012.736624

Hwang, S. Y., Chang, S. J., & Park, B. W. (2013). Does chemotherapy really affect the quality of life of women with breast cancer? *Journal of Breast Cancer, 16,* 229-235. doi: 10.4048/jbc.2013.16.2.229.

Hyland, M.E & Sodergren, S.C. (1996). Development of a new type of quality of life scale, and comparison and preference for 12 global scales. *Quality of Life Research, 5*, 469-480.

Im, E. (2007). Ethnic Differences in Cancer Pain Experience. *Nursing Research, 56*, 296-306.

Im, E. O., Ko, Y., & Chee, W. (2013). Symptom clusters among multiethnic groups of cancer patients with pain. *Palliative Support Care, 11*(4), 295-305. doi: 10.1017/S1478951512000314

Induru, R. R., & Walsh, D. (2014). Cancer-related insomnia. *American Journal of Hospital Palliative Care, 31*(7), 777-785. doi: 10.1177/1049909113508302

Janz, N. K., Mujahid, M. S., Hawley, S. T., Griggs, J. J., Alderman, A., Hamilton, A. S., . . . Katz, S. J. (2009). Racial/ethnic differences in quality of life after diagnosis of breast cancer. *Journal of Cancer Survivorship, 3*(4), 212-222. doi: 10.1007/s11764-009-0097-y

Jeste, N., Liu, L., Rissling, M., Trofimenko, V., Natarajan, L., Parker, B. A., & Ancoli-Israel, S. (2013). Prevention of quality-of-life deterioration with light therapy is associated with changes in fatigue in women with breast cancer undergoing chemotherapy. *Quality of Life Research, 22,* 1239-1244. doi: 10.1007/s11136-012-0243-2

Jimenez, A., Madero, R., Alonso, A., Martinez-Marin, V., Vilches, Y., Martinez, B., . . . Feliu, J. (2011). Symptom clusters in advanced cancer. *Journal of Pain and Symptom Management, 42,* 24-31. doi: 10.1016/j.jpainsymman.2010.10.266

Juarez, G., Mayorga, L., Hurria, A., & Ferrell, B. (2013). Survivorship education for Latina breast cancer survivors: Empowering Survivors through education. *Psicooncologia (Pozuelo de Alarcon), 10*, 57-68. doi: 10.5209/rev_PSIC.2013.v10.41947

Kagawa-Singer, M. (2011). Impact of culture on health outcomes. *Journal of Pediatric Hematology Oncology, 33,* S90-95. doi: 10.1097/MPH.0b013e318230dadb

Kayl, A.E., & Meyers, C.A. (2006). Side effects of chemotherapy and quality of life in ovarian and breast cancer patients. *Current Opinions in Obstetrics and Gynecology, 18,* 24–28. doi: 10.1097/01.gco.0000192996.20040.24

Keefe, D. M., Schubert, M. M., Elting, L. S., Sonis, S. T., Epstein, J. B., Raber- Durlacher, J. E., . . . the International Society for Oral, Oncology. (2007). Updated clinical practice guidelines for the prevention and treatment of mucositis. *Cancer, 109,* 820-831. doi: 10.1002/cncr.22484

Kenzik, K. M., Ganz, P. A., Martin, M. Y., Petersen, L., Hays, R. D., Arora, N., & Pisu, M. (2015). How much do cancer-related symptoms contribute to health-related quality of life in lung and colorectal cancer patients? A report from the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium. *Cancer, 121*(16), 2831-2839. doi: 10.1002/cncr.29415

Kennedy, F., Harcourt, D., Rumsey, N., White, P. (2010). The psychosocial impact of ductal carcinoma in situ (DCIS): a longitudinal prospective study. *Breast,19,* 382–387.

Kidwell, K. M., Harte, S. E., Hayes, D. F., Storniolo, A. M., Carpenter, J., Flockhart, D. A., . . . Henry, N. L. (2014). Patient-reported symptoms and discontinuation of adjuvant aromatase inhibitor therapy. *Cancer.* doi: 10.1002/cncr.28756

Kirchhoff, A.C., Spraker-Perlman, H.L., McFadden, M., Warner, E.L., Oeffinger, K.C., Wright , J., Kinney, A.Y. (2014). Sociodemographic Disparities in Quality of Life for Survivors of Adolescent and Young Adult Cancers in the Behavioral Risk Factor Surveillance System. *Journal of Adolescent and Young Adult Oncology, 3,* 66-74.

Kirchheiner, K., Nout, R. A., Czajka-Pepl, A., Ponocny-Seliger, E., Sturdza, A. E., Dimopoulos, J. C., . . Potter, R. (2015). Health related quality of life and patient reported symptoms before and during definitive radio(chemo)therapy using image-guided adaptive brachytherapy for locally advanced cervical cancer and early recovery - a mono-institutional prospective study. *Gynecologic Oncology, 136*(3), 415-423. doi: 10.1016/j.ygyno.2014.10.031

Krippendorff, K. (2005). *Content analysis: An introduction to its methodology*. Thousand Oaks: Sage Publications.

Kuo, C. Y., Liang, S. Y., Tsay, S. L., Wang, T. J., & Cheng, S. F. (2015). Symptom management tasks and behaviors related to chemotherapy in Taiwanese outpatients with breast cancer. Eur J Oncol Nurs. doi: 10.1016/j.ejon.2015.03.012

Kwak, M., Zebrack,B. J., Meeske, K.A., Embry, L., Aguilar, C., Block, R.,.....Cole, S. (2013). Trajectories of Psychological Distress in Adolescent and Young Adult Patients With Cancer: A 1-Year Longitudinal Study. *Journal of Clinical Oncology, 31,* 2160-66

Kwok, W., & Bhuvanakrishna, T. (2014). The relationship between ethnicity and the pain experience of cancer patients: a systematic review. Indian J Palliat Care, 20(3), 194-200. doi: 10.4103/0973-1075.138391

Langford, D. J., Paul, S. M., Cooper, B., Kober, K. M., Mastick, J., Melisko, M., . . . Miaskowski, C. (2015). Comparison of subgroups of breast cancer patients on pain and

co-occurring symptoms following chemotherapy. Support Care Cancer. doi: 10.1007/s00520-015-2819-1

Larson, P. J., Kohlman, V.C., Dodd, M.J., Douglas,M., Faucett,J.,.....Stotts, N.A. (1994). A model for symptom management. *Journal of Nursing Scholarship, 26,* 272- 276.

Lewis, P. E., Sheng, M., Rhodes, M. M., Jackson, K. E., & Schover, L. R. (2012). Psychosocial concerns of young African American breast cancer survivors. *Journal of Psychosocial Oncology, 30,* 168-184. doi: 10.1080/07347332.2011.651259

Lien, C. Y., Chen, S. H., Tsai, P. P., Chen, K. M., Hsieh, Y. I., & Liang, Y. (2010). The effectiveness of nursing instruction in reducing uncertainty, anxiety and self-care in breast cancer women undergoing initial chemotherapy. *Hu Li Za Zhi The Journal of Nursing, 57,* 51-60.

Likhacheva, A., Jhingran, A., Bodurka, D. C., Sun, C., Sam, M., & Eifel, P. J. (2013). Prospective study of symptom assessment among patients with cervical cancer during concurrent chemoradiotherapy with weekly cisplatin or every-3-week cisplatin and 5-fluorouracil. *International Journal of Gynecological Cancer, 23,* 1520-1527. doi: 10.1097/IGC.0b013e3182a0c0e5

Lis, C. G., Rodeghier, M., Grutsch, J. F., & Gupta, D. (2009). Distribution and determinants of patient satisfaction in oncology with a focus on health related quality of life. *BMC Health Services Research, 9*, 190. doi: 10.1186/1472-6963-9-190

McCabe, M. (2008). Cancer: Thinking beyond the disease. *Oncology, 22*, 11-11. Retrieved from http://search.proquest.com/docview/340386339?accountid=28920

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green. D., Schilling, L.S., Lorig, K., Wagner, E.H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *Cancer, 61,* 50-62.

McMillan, S.C., & Small, B.J. (2007). Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Oncology Nursing Forum, 34,* 313–321.

Mao, J. J., Armstrong, K., Bowman, M. A., Xie, S. X., Kadakia, R., & Farrar, J. T. (2007). Symptom burden among cancer survivors: impact of age and comorbidity. *Journal of the American Board of Family Medicine, 20,* 434-443. doi: 10.3122/jabfm.2007.05.060225

Martinez, K. A., Snyder, C. F., Malin, J. L., & Dy, S. M. (2014). Is race/ethnicity related to the presence or severity of pain in colorectal and lung cancer? *Journal of Pain and Symptom Management, 4*8(6), 1050-1059. doi: 10.1016/j.jpainsymman.2014.02.005

Masmoudi, A., Frikha, M., & Daoud, J. (2009). Feasibility of quality of life assessment in routine clinical oncology practice: a Tunisian study. *Eastern Mediterranean health journal, 15,* 362-368.

Mcquestion, M. (2011). Evidence-Based Skin Care Management in Radiation Therapy: Clinical Update. *Seminars in Oncology Nursing, 27,* e1-e17.

Miaskowski, C., Cooper, B.A., Paul, S.M., Dodd, M., Lee, K., Aouizerat, B.E., . . . Bank, A. (2006). Subgroups of patients with cancer with different symptom experiences and quality-of-life outcomes: A cluster analysis [Online exclusive]. *Oncology Nursing Forum, 33,* E79–E89.doi: 10.1188/06.ONF.E79-E89

Michelson, H., Bolund, C., Nilsson, B., & Brandberg, Y. (2000). Health-related Quality of Life Measured by the EORTC QLQ-C30 Reference Values From a Large Sample of the Swedish Population. *Acta Oncologica, 39,* 477–484.

Miltenburg, N C., & Boogerd, W. (2014). Chemotherapy-induced neuropathy: A comprehensive survey. *Cancer Treatment Reviews, 40,* 872–882.

Minton, O., Richardson, A., Sharpe, M., Hotopf, M., & Stone, P. C. (2011). Psychostimulants for the management of cancer-related fatigue: a systematic review and meta-analysis. *Journal of Pain and Symptom Management, 41,* 761-767. doi: 10.1016/j.jpainsymman.2010.06.020

Minton, O., Berger, A., Barsevick, A., Cramp, F., Goedendorp, M., Mitchell, S. A., & Stone, P. C. (2013). Cancer-related fatigue and its impact on functioning. *Cancer, 119 Suppl 11*, 2124-2130. doi: 10.1002/cncr.28058

Mitchell, S., & Berger, A. (2006). Cancer-related fatigue: the evidence base for assessment and management. *Cancer Journal, 12,* 374-387.

Mitchell, S., Beck, S., Hood, L., Moore, K., & Tanner, E. (2007). Putting evidence into practice: Evidence-based interventions for fatigue during and following cancer and its treatment. *Clinical Journal of Oncology Nursing, 11*, 99. doi:10.1188/07.CJON.99-113

Mohile, S.G., Heckler, C., Fan, L., Mustian, K., Jean-Pierre, P., Usuki, K., ...Morrow, G. (2011). Age-related Differences in Symptoms and Their Interference with Quality of Life in 903 Cancer Patients Undergoing Radiation Therapy. *Journal of Geriatric Oncology, 2,* 225-232.

Mols, F., Beijers, T., Vreugdenhil, G., & van de Poll-Franse, L. (2014). Chemotherapy-induced peripheral neuropathy and its association with quality of life: a systematic review. *Support Care Cancer.* doi: 10.1007/s00520-014-2255-7

Mooney, K. H., Beck, S. L., Friedman, R. H., Farzanfar, R., & Wong, B. (2014). Automated monitoring of symptoms during ambulatory chemotherapy and oncology providers' use of the information: a randomized controlled clinical trial. *Support Care Cancer, 22*(9), 2343-2350. doi: 10.1007/s00520-014-2216-1

Molassiotis, A., Sylt, P., & Diggins, H. (2007). The management of cancer-related fatigue after chemotherapy with acupuncture and acupressure: a randomised controlled trial. *Complementary Therapies in Medicine, 15,* 228-237. doi: 10.1016/j.ctim.2006.09.009

Morrow, G. R., Shelke, A. R., Roscoe, J. A., Hickok, J. T., & Mustian, K. (2005). Management of Cancer-Related Fatigue. *Cancer Investigation, 23,* 229-239. doi:10.1081/CNV-200055960

Morrow, G.R. (2007). Cancer-Related Fatigue: Causes, Consequences, and Management. *The Oncologist, 12,*1-3. doi: 10.1634/theoncologist.12-S1-1

Mota, D. D., Pimenta, C. A., & Caponero, R. (2012). Fatigue in colorectal cancer patients: Prevalence and associated factors. *Revista Latino-Americana de Enfermagem, 20,* 495-503.

Muehlbauer, P.M., Thorpe, D., Davis, A., Drabot, R., Rawlings, B. L., Kiker, E. (2009). Putting evidence into practice: evidence-based interventions to prevent, manage, and treat chemotherapy- and radiotherapy-induced diarrhea. *Clinical Journal of Oncology Nursing,13,* 336–341.

Munro, B. H. (2005). *Statistical Methods for Health Care Research*. Philadelphia: Lippincott Williams & Wilkins.

Mustian, K. M., Morrow, G. R., Carroll, J. K., Figueroa-Moseley, C. D., Jean-Pierre, P., & Williams, G. C. (2007). Integrative nonpharmacologic behavioral interventions for the management of cancer-related fatigue. *Oncologist, 12* Suppl 1, 52-67. doi: 10.1634/theoncologist.12-S1-52

Mustian, K. M., Janelsins, M., Peppone, L. J., & Kamen, C. (2014). Yoga for the Treatment of Insomnia among Cancer Patients: Evidence, Mechanisms of Action, and Clinical Recommendations. *Oncology & Hematology Review, 10*(2), 164-168.

Myers, J.S. (2012). Chemotherapy-related cognitive impairment: The breast cancer experience. *Oncology Nursing Forum, 39,* E 31-40.

Narayanan, V., & Koshy, C. (2009). Fatigue in cancer: A review of literature. *Indian Journal of Palliative Care, 15,* 19-25. doi:http://dx.doi.org/10.4103/0973-1075.53507

Naik, A. D., Uy, N., Anaya, D. A., & Moye, J. (2015). The effects of age, education, and treatment on physical, sexual and body concern symptoms among multimorbid, colorectal cancer survivors. *Journal of Geriatric Oncology, 6*(4), 299-306. doi: 10.1016/j.jgo.2015.04.001

National Cancer Institute. (2013). *Fatigue*. Retrived from http://www.cancer.gov/cancertopics/pdq/supportivecare/fatigue/Patient.

National Cancer Institute. (2015). Adolescents and Young Adults with Cancer. Retrieved from http://www.cancer.gov/types/aya#1

National Cancer Institute. (2015). Staging. Retrieved from http://www.cancer.gov/about-cancer/diagnosis-staging/staging.

Neuberger, G.B., Kasal, S., Smith, K.V., Hassanein, R., & Devinley, S. (1994). Determinants of exercise and aerobic fitness in outpatients with arthritis. *Nursing Research, 43,* 11-17.

Obeidat, R., & Khrais, H.I. (2014). Information needs and disclosure preferences among Jordanian women diagnosed with breast cancer. *Journal of Cancer Education,* doi:10.1007/s13187-014-0665-3

Ohaeri, B.M., Ofi. A.B., & Campbell, O.B. (2012). Relationship of knowledge of psychosocial issues about cancer with psychic distress and adjustment among breast cancer clinic attendees in a Nigerian teaching hospital. *Psycho-Oncology, 21,* 419-26.

Olobatuyi, M.E. (2006). *A User's Guide to Path Analysis*. Maryland: University press of America.

Orem, D.E. (2005). *Nursing concepts of practice* (5th ed.). St. Louis, MO: Mosby.

Parode, L. (2012). *Applied Regression Modeling*. New Jersey: John Wiley & Sons, Inc.

Park, H., & Yoon, H. G. (2013). Menopausal symptoms, sexual function, depression, and quality of life in Korean patients with breast cancer receiving chemotherapy. *Support Care Cancer, 21,* 2499-2507. doi: 10.1007/s00520-013-1815-6

Paul, M., Davey,B., Senf, B., Stoll, C., Muenstedt, K., Muecke, R., Micke, O., Prott, F.J., Buentzel, J., & Huebner ,J .(2013). Patients with advanced cancer and their usage of complementary and alternative medicine. *Journal of Cancer Research Clinical Oncology 130,* 1515–1522

Pettersson, G., Bertero, C., Unosson, M., & Borjeson, S. (2014). Symptom prevalence, frequency, severity, and distress during chemotherapy for patients with colorectal cancer. *Supportive Care in Cancer, 22,* 1171-1179. doi: 10.1007/s00520-013-2069-z

Piamjariyakul, U., Williams P.D., Prapakorn, S., Kim, M., Park, L., Rojjanasrirat, W., & Williams, A.R. (2010). Cancer therapy-related symptoms and self-care in Thailand. *European Journal of Oncology Nursing*, *14,* 387-394.

Pisu, M., Kenzik, K. M., Oster, R. A., Drentea, P., Ashing, K. T., Fouad, M., & Martin, M. Y. (2015). Economic hardship of minority and non-minority cancer survivors 1 year after diagnosis: another long-term effect of cancer*? Cancer, 121*(8), 1257-1264. doi: 10.1002/cncr.29206

Plichta, S.B., & Garrzon, L.S. (2009). *Statistics for Nursing and Allied Health*. Philadelphia : Lippincott Williams & Wilkins.

Polit, D.F., & Beck, C.T. (2008*). Nursing Research: Generating and assessing the evidence for nursing practice* (8th ed.). New York: Lippincott Williams & Wilkins.

Polit, D.F., & Beck, C.T. (2012*). Nursing Research: Generating and assessing the evidence for nursing practice* (9th ed.). New York: Lippincott Williams & Wilkins.

Prigozin,A., Uziely, B.,& Musgrave, C. F. (2010). The relationship between symptom severity and symptom inference, education, age, marital status, and type of chemotherapy treatment in Israeli women with early-stage breast cancer. *Oncology Nursing Forum, 37,* E411- 418.

Prue, G., Allen, J., Gracey, J., Rankin, J., & Cramp, F. (2010). Fatigue in gynaecological cancer patients during and after anticancer treatment. *Journal of Pain and Symptom Management, 39,* 197-210.

Pud, D., Har-Zahav, G., Laitman, Y., Rubinek, T., Yeheskel, A., Ben-Ami, S., . . . Wolf, I. (2014). Association between variants of 5-hydroxytryptamine receptor 3C (HTR3C) and chemotherapy-induced symptoms in women receiving adjuvant treatment for breast

cancer. *Breast Cancer Research and Treatment, 144,* 123-131. doi: 10.1007/s10549-014-2832-y

Rana, Z., Hong, R. L., Abugideiri, M., McRae, D., Cernica, G., Mordkin, R., . . . Nasr, N. M. (2015). Sexual, irritative, and voiding outcomes, following stereotactic body radiation therapy for prostate cancer. *Radiation Oncology, 10*, 182. doi: 10.1186/s13014-015-0488-3

Rauh-Hain, J. A., Buskwofie, A., Clemmer, J., Boruta, D. M., Schorge, J. O., & del Carmen, M. G. (2015). Racial disparities in treatment of high-grade endometrial cancer in the Medicare population. *Obstetrics & Gynecology, 125*(4), 843-851. doi: 10.1097/AOG.0000000000000605

Reyes-Gibby, C. C., Swartz, M. D., Yu, X., Wu, X., Yennurajalingam, S., Anderson, K. O., . . . Shete, S. (2013). Symptom clusters of pain, depressed mood, and fatigue in lung cancer: assessing the role of cytokine genes. *Support Care Cancer, 21*(11), 3117-3125. doi: 10.1007/s00520-013-1885-5

Savard, J., Ivers, H., Savard, M. H., & Morin, C. M. (2015). Cancer treatments and their side effects are associated with aggravation of insomnia: Results of a longitudinal study. *Cancer, 121*(10), 1703-1711. doi: 10.1002/cncr.29244

Samuels, N., Maimon, Y., & Zisk-Rony, R. Y. (2013). Effect of the Botanical Compound LCS101 on Chemotherapy-Induced Symptoms in Patients with Breast Cancer: A Case Series Report. *Integrative Medicine Insights, 8,* 1-8. doi: 10.4137/IMI.S10841

Sato, K., Shimizu, M., & Miyashita,M.(2014). Which quality of life instruments are preferred by cancer patients in Japan? Comparison of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 and the Functional Assessment

of Cancer Therapy-General. *Support Care Cancer,* DOI 10.1007/s00520-014-2287-z

Sbitti, Y., Kadiri, H., Essaidi, I., Fadoukhair, Z., Kharmoun, S., Slimani, K., . . . Errihani, H. (2011). Breast cancer treatment and sexual dysfunction: Moroccan women's perception. *BMC Womens Health, 11,* 29. doi: 10.1186/1472-6874-11-29

Schag, C.C., Heinrich, R.L., & Ganz, P.A. (1984). Karnofsky performance status revisited: reliability, validity, and guidelines. Journal of Clinical Oncology, 2(3), 187–193.

Schneider, B. P., Hershman, D. L., & Loprinzi, C. (2015). Symptoms: Chemotherapy-Induced Peripheral Neuropathy. *Advances in Experimental Medicine and Biology,* 862, 77-87. doi: 10.1007/978-3-319-16366-6_6

Schulmeister, L., & Gobel, B. H. (2008). Symptom management issues in oncology nursing. *The Nursing Clinics of North America, 43*(2), 205-220; v. doi: 10.1016/j.cnur.2008.02.004

Senf, B., Brandt, H., Dignass,A., et al. (2010). Psychosocial distress in acute cancer patients assessed with an expert rating scale. *Support Care Cancer, 18,* 957–965.

Sherman, D. W., Haber, J., Hoskins, C. N., Budin, W. C., Maislin, G., Shukla, S., . . . Roth, A. (2012). The effects of psychoeducation and telephone counseling on the adjustment of women with early-stage breast cancer. *Applied Nursing Research, 25,* 3-16. doi: 10.1016/j.apnr.2009.10.003

Sherwood,P., Given,B.A., Given,C.W.,Champion,V.L., Doorenbos, A.Z., Azzouz,F., Kozachik, S., Wagler-Ziner, K., & Monahan, P.O. (2005). A cognitive behavioral intervention for symptom management in patients with advanced cancer. *Oncology Nursing Forum, 32*, 1190–1198.

Siegel, R.L., Miller, K.D., & Jemal, A. (2015). Cancer Statistics, 2015. *CA: A Cancer Journal for Clinicians, 65*, 5-29.

Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. *Cancer Journal for Clinicians, 63,* 11-30. doi: 10.3322/caac.21166.

So, W. K., Choi, K. C., Chan, C. W., & Chair, S. Y. (2011). Age-related differences in the quality of life of Chinese women undergoing adjuvant therapy for breast cancer. *Research in Gerontological Nursing, 4,* 19-26. doi: 10.3928/19404921-20101201-01

Song, H. Y., Kwon, J. A., Choi, J. W., Kim, S. J., & Park, E. C. (2014). Gender differences in marital disruption among patients with cancer: results from the Korean National Health and Nutrition Examination Survey (KNHANES). *Asian Pacific Journal of Cancer Prevention, 15*(16), 6547-6552.

Stanton, A.L., Bernaards, C.A., & Ganz, P.A. (2005). The BCPT symptom scales: A measure of physical symptoms for women diagnosed with or at risk for breast cancer. *Journal of the National Cancer Institute, 97*, 448–456. doi: 10.1093/jnci/dji069

Stava, C.J., Lopez, A., & Vassilopoulou-Sellin, R. (2006). Health profiles of younger and older breast cancer survivors. *Cancer ,107,*1752-1759.

Stubbe, C. E., & Valero, M. (2013). Complementary strategies for the management of radiation therapy side effects. *Journal of the Advanced Practitioner in Oncology, 4,* 219-231.

Sun, V., Kim, J. Y., Williams, A. C., Raz, D. J., Sampath, S., & Ferrell, B. (2014). Quality of life and symptoms following stereotactic body radiotherapy in early-stage lung cancer patients. *Journal of Community and Supportive Oncology, 12*(11), 407-414.

Tariman, J.D., Doorenbos, A., Schepp, K.G., Becker, P., & Berry, D.L. (2014). Patient, physician and contextual factors are influential in the treatment decision making of older adults newly diagnosed with symptomatic myeloma. *Cancer Treatment Communications, 2*, 24–47. doi:10.1016/j.ctrc.2014.1008.1003.

Tariman, J. D., & Szubski, K. L. (2015). The Evolving Role of the Nurse During the Cancer Treatment Decision-Making Process: A Literature Review. *Clinical Journal of Oncology Nursing, 19*(5), 548-556. doi: 10.1188/15.CJON.548-556

Thomas, B. C., Waller, A., Malhi, R. L., Fung, T., Carlson, L. E., Groff, S. L., & Bultz, B. D. (2014). A longitudinal analysis of symptom clusters in cancer patients and their sociodemographic predictors. *Journal of Pain and Symptom Management, 47*(3), 566-578. doi: 10.1016/j.jpainsymman.2013.04.007

Van Rooyen, D., Le Roux, L., & Kotzé, ,W.J. (2008). The experiential world of the oncology nurse. *Health S A Gesondheid, 13,* 18-30. Retrieved from http://search.proquest.com/docview/195464006?accountid=28920

Verhaar, S., Vissers, P. A., Maas, H., van de Poll-Franse, L. V., van Erning, F. N., & Mols, F. (2015). Treatment-related differences in health related quality of life and disease specific symptoms among colon cancer survivors: results from the population-based PROFILES registry. *European Journal of Cancer, 51*(10), 1263-1273. doi: 10.1016/j.ejca.2015.04.004

Walling, A. M., Weeks, J. C., Kahn, K. L., Tisnado, D., Keating, N. L., Dy, S. M., . . . Malin, J. L. (2014). Symptom Prevalence in Lung and Colorectal Cancer Patients. *Journal of Pain and Symptom Management*. doi: 10.1016/j.jpainsymman.2014.06.003

Walsh, D., Donnelly, S., & Rybicki, L. (2000). The symptoms of advanced cancer: relationship to age, gender, and performance status in 1,000 patients. *Support Care Cancer, 8,* 175-179.

Weis, J. (2011). Cancer-related fatigue: Prevalence, assessment and treatment strategies. *Expert Review of Pharmacoeconomics & Outcomes Research, 11,* 441-446. doi:http://dx.doi.org/10.1586/erp.11.44.

Williams, K.A. (2012). Adolescent and young adult oncology: An emerging subspeciality. *Clinical Journal of Oncology Nursing, 17*, 292-296.

Williams, P.D., Balabagno, A,O., Manahan,L., Piamjariyakul, U., Ranallo, L., et al .(2010). Symptom monitoring and self-care practices among Filipino adults with cancer. *Cancer Nursing, 33*, 37-46.

Williams P.D., Ducey, K.A., Sears, A.M, Williams, A.R., Tobin- Rumelhart, S.E., & Bunde, P. (1997). A Therapy- Related Symptom Checklist (TRSC) for oncology patients: A self-report instrument. *Oncology Nursing Forum, 24,* 301.

Williams P.D., Ducey, K.A., Sears, A.M, Williams, A.R., Tobin- Rumelhart, S.E., & Bunde, P. (2001). Treatment type and symptom severity among oncology patients by self-report. *International Journal of Nursing Studies, 36*, 359-367.

Williams, P. D., Graham, K. M., Storlie, D. L., Pedace, T. M., Haeflinger, K. V., Williams, D. D., . . . Williams, A. R. (2013). Therapy-related symptom checklist use during treatments at a cancer center. *Cancer Nursing, 36,* 245-254. doi: 10.1097/NCC.0b013e3182595406

Williams, P.D., Graham, K., Storlie, D., Pedace, T., Otte, D., Haeflinger, K., . . . Williams, A.R. (2011, February). *Outcomes of checklist use during treatments at a cancer center: The*

TRSC:A clinical/ translational trial. Paper presented at the 11th National Conference on Cancer Nursing Research, Los Angeles, CA.

Williams P.D., Lopez ,V., Chair, S.Y., et al (2010). Symptom monitoring and self-care practices among oncology adults in China. *Cancer Nursing*, 33(3), 184-193.

Williams, P. D., Lantican, L. S., Bader, J. O., & Lerma, D. (2014). Symptom monitoring, alleviation, and self-care among Mexican Americans during cancer treatment. *Clinical Journal of Oncology Nursing, 18*(5), 547-554. doi: 10.1188/14.CJON.547-554

Williams, A. R., Mowlazadeh, B., Sisler, L., & Williams, P. D. (2015). Self-Reported Assessment of Symptoms and Self-Care Within a Cohort of U.S. Veterans During Outpatient Care for Cancer. *Clinical Journal of Oncology Nursing*, *19*(5), 595-602. doi: 10.1188/15.CJON.595-602

Williams, P. D., Piamjariyakul, U., Shanberg, R., & Williams, A. R. (2015). Monitoring and Alleviation of Symptom Occurrence and Severity Among Thai Children and Adolescents During Cancer Treatments. *Journal of Pediatric Oncology Nursing, 32*(6), 417-428. doi: 10.1177/1043454214563754

Williams, P.D., Piamjariyakul, U., Badura ,J., et al.(2006). Cancer treatment, symptom monitoring, and self-care in adults. *Cancer Nursing, 29*, 347-355.

Williams, P.D., Schmideskamp, J., Ridder, E.L., & Williams, A.R. (2006). Symptom monitoring and dependent care during cancer treatment in children: Pilot study. *Cancer Nursing, 29,* 188–197.doi:10.1097/00002820-200605000-00004

Williams, A.R., Williams, P.D., Ducey, K.A., Sears, A.M, & Tobin- Rumelhart, S.E. (2000). A Therapy- Related Symptom Checklist (TRSC) for oncology patients : A Self- Report Instrument Development. In Williams, P.D., Williams, A. R. (Eds.). *Individual, Familiy,*

and Community: Promoting and Restoring Health and Wellbeing. JMC Press: Quezon city, 85-100.

Williams, P.D., Williams, K, LaFaver-Roling, A., Johnson, R, & Williams, A. (2011). An Intervention to Manage Patient-Reported Symptoms During Cancer Treatment. *Clinical Journal of Oncology Nursing, 15*, 253-258. doi: 10.1188/11.CJON.253-258

Williams, P.D., Williams, D.D., Smith, J., Heinze, J., Greenfield, A., & Bryant, K. (2011, September). *Patient-reported symptoms, alleviation, and self-care methods, daily activities, and healthrelated quality of life during outpatient cancer treatments in the U.S.A.* [Poster]. Presented at the Fifth Pan-Pacific Nursing Conference and Seventh Nursing Symposium on Cancer Care. Hong Kong, China.

Williams, A.R., Williams, D.D., Williams, P.D., Alemi, F., et al. (2015). The development and application of an oncology Therapy-Related Symptom Checklist for Adults (TRSC) and Children (TRSC-C) and Bioinformatics Applications. *BioMedical Engineering OnLine; 14*(Suppl 2). doi: 10.1186/1475-925X-14-S2-S1

Wilson Van Voorhis, C. R. & Morgan, B. L. (2007). Understanding power and rules of thumb for determining sample sizes. *Tutorials in Quantitative Methods for Psychology*, *3*(2), 43-50.

World Health Organization. (2013). 10 facts about cancer. Retrieved from http://www.who.int/features/factfiles/cancer/en/

World Health Organization. (2015). Cancer. Retrieved from www.who.int/mediacentre/factsheets/fs297/en/

Worthington, H. V., Clarkson, J. E., Bryan, G., Furness, S., Glenny, A. M., Littlewood, A., . . . Khalid, T. (2011). Interventions for preventing oral mucositis for patients with cancer

receiving treatment. *Cochrane Database Systematic Reviews(4),* CD000978. doi: 10.1002/14651858.CD000978.pub5

Xiao, C., Hanlon, A., Zhang, Q., Ang, K., Rosenthal, D. I., Nguyen-Tan, P. F., . . . Bruner, D. W. (2013). Symptom clusters in patients with head and neck cancer receiving concurrent chemoradiotherapy. *Oral Oncology, 49*(4), 360-366. doi: 0.1016/j.oraloncology.2012.10.004

Yuen, H. K., Mitcham, M. D., & Morgan, L. I. (2006). Managing post-therapy fatigue for cancer survivors using energy conservation training. *Journal of Allied Health, 35,* 121E-139E. Retrieved from: http://search.proquest.com/docview/1034227586?accountid=28920

Youngblood, M., Williams, P., Eyles, H., Waring, J., & Runyon, S. (1994). A comparison of two methods of assessing cancer therapy-related symptoms. *Cancer Nursing*, 17(1), 37-44.

Appendix A

Selected Review of Literature (Tables 2 to 5)

Table 2

Selected Literature Review - Descriptive, Comparative, Correlational, Other Studies

Author, Year, Country	Objective	Methods	Findings
Alexiusdottir et al., 2012 Iceland	To examine colon cancer patients' symptoms at the time of diagnosis and their relationship with tumor TNM-stage.	Retrospective and population-based study. Information obtained from all colon cancer patients diagnosed in Iceland in 1995-2004. Information collected from patients' files on patients' symptoms and blood hemoglobin. N=768 patients (422 males, 346 females).	Median age was 73 years. 60% of patients had anemia at the time of diagnosis. 53% had visible blood in stools. 65% had changes in bowel habits. 84% of patients had visible blood in stools and/or anemia. Patients with right-sided tumors, 75% had anemia. Left-sided tumors were associated with blood in stools and changes in bowel habits. Findings indicated that a lower TNM-stage was strongly associated with blood in stools, and a higher TNM stage was strongly associated with Anemia.
Alsadius et al., 2013 Sweden	To examine the association of long-term gastrointestinal and urinary symptoms associated with perceived fecal or urine body odor after radiation therapy among prostate cancer and its effect on survivors' quality of life.	A study-specific questionnaire was used to measure the occurrence of long-term gastrointestinal and urinary symptoms, the perception of urine or fecal body odor, and QOL. Subjects were 2 to14 years after radiation therapy. The questionnaire was sent to eligible survivors (N=895) who reported symptom occurrence and QOL in the previous six months.	11/13 of the long-term gastrointestinal symptoms were associated with the perception of fecal body odor. 11/11 were associated with the perception of urine body odor for the long-term urinary symptoms. Males who perceived urine or fecal body odor reported a lower QOL, a lower physical health, and more frequent feelings of depression. Long-term urinary and gastrointestinal symptoms after prostate irradiation are associated with the perception of fecal or urine body odor leading to a reduced QOL

Table 2 (continued).

Author, Year, Country	**Objective**	**Methods**	**Findings**
Akin, et al., 2010 Turkey	To describe the QOL and symptom distress of lung cancer patients receiving chemotherap y. This study also aims and to investigate the relationships between demographic and treatment-related characteristic s and QOL.	The sample consisted of lung cancer patients (*N*= 154) receiving chemotherapy. The symptom experiences and QOL were evaluated using the Memorial Symptom Assessment Scale and Quality of Life Index - Cancer Version.	The lung cancer patients reported low QOL scores. Health and Functioning subscale scores were the lowest (20.33 ± 5.59), and that of the Family subscale were the highest (27.66 ± 2.77). The most common physical symptoms experienced patients were lack of appetite, coughing, lack of energy, pain, and nausea. Common psychological symptoms were worrying,difficulty sleeping, feeling nervous, feeling sad, and. A negative relationship found between the symptom distress and quality of life scores (r=-0.45; p<0.000). Greater symptom distress and performance status experienced were reported by females, and those with low-income levels.
Akin et al., 2013 Turkey	To describe the symptom severity of patients receiving chemotherap y. This study also aims to compare patients' self-reports of symptom severity with inferences made by nurses and family caregivers.	A descriptive, comparative study. 119 patients receiving chemotherapy that had a family caregiver and a nurse primarily responsible for their care were participated in this study. Edmonton Symptom Assessment System (ESAS) was used for symptom assessment. Symptoms were rated independently by the patient, caregiver, and nurse.	Major symptoms reported by patients were tiredness, depression, drowsiness, loss of well-being, anxiety, appetite changes, pain and nausea. The caregivers and patients showed a strong agreement of the patients' symptoms. Patients and nurses showed poor to the fair agreement of the symptoms of depression, pain, tiredness, nausea, drowsiness, poor appetite, loss of well-being, skin and nail changes, mouth sores, and hand numbness. The patients' mean scores of symptoms (anxiety, depression, pain, loss of well-being and drowsiness) were lower than those of the caregivers. The patients' mean scores of symptoms (shortness of breath, tiredness, mouth sores and skin and nail changes) were higher than those of the nurses.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Bayram et al., 2014 Turkey	To evaluate QOL for breast cancer patients receiving chemotherapy, and to evaluate their satisfaction with nursing care.	Descriptive, cross-sectional study. Functional Assessment of Cancer Therapy-General Scale, the Memorial Symptom Assessment Scale and the Newcastle Satisfaction with Nursing Scale were the tools used for data collection.	Most negatively affected area was emotional well-being, with patients reporting, feeling sad, being afraid of death and being worried about their health. Patients overall satisfaction with the nursing care was good. Positive correlation found between total scores on the Newcastle Satisfaction with Nursing Scale and social and family well-being scores. Breast cancer patients have concerns and fears about their health, and they need support for coping with negative changes in their emotional, physical and functional well-being during chemotherapy.
Cheung et al., 2012 Singapore	To compare the severity of perceived cognitive disturbance in Asian breast cancer patients receiving and not receiving chemotherapy. This study also aims to identify clinical characteristics associated with perceived cognitive disturbances.	A cross-sectional, observational study. Breast cancer patients receiving and not receiving chemotherapy completed the Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (QLQ-C30), and Beck Anxiety Inventory to assess their perceived cognitive functioning, health-related quality of life, and anxiety, respectively. Conducted multiple regressions to identify the factors associated with perceived cognitive disturbances. Breast cancer patients receiving chemotherapy (*n*=85) and 81 not receiving chemotherapy (*n*=81) were recruited.	Chemotherapy patients experienced more fatigue and moderate-to-severe anxiety compared to patients not receiving chemotherapy. Better perceived cognitive functioning was reported by patients not receiving chemotherapy, than those who received chemotherapy. Chemotherapy and endocrine therapy were strongly associated with perceived cognitive disturbances. Anxiety and fatigue was moderately associated with perceived cognitive disturbances ($\beta = -0.29$; $p = 0.037$).

Table 2 (continued).

Author, Year, Country	**Objective**	**Methods**	**Findings**
Choi et al., 2014 Korea	To evaluate the impact of chemotherapy-induced alopecia (CIA) distress on psychosocial well-being, body image, and depression among patients with breast cancer.	It was a cross-sectional survey (*N*=168). Study conducted at the breast cancer advocacy events held at 16 hospitals in Korea. Alopecia distress was assessed using the 'Chemotherapy-Induced Alopecia Distress Scale.' European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 and breast specific module (BR23) was used to measure body image and psychosocial well-being. Depression was measured using the Center for Epidemiological Studies Depression scale. Compared means of outcomes between low and high CIA distress groups. Univariable and multivariable linear regression models were used to analyze the relationship between the CIA distress and body image, psychosocial well-being, and depression.	The mean age of the participants was 48.4 (SD = 8.4) years. 55.3% of the patients experienced higher distress from alopecia. The high distress group was more likely to have a poorer body image than the low distress group (35.2 vs. 62.0; $p < 0.001$). Distressed patients were also more likely to report lower role (58.6 vs. 72.0; $p < 0.001$), emotional (55.3 vs. 76.9; $p < 0.001$), and social functioning (51.3 vs. 70.9; $p < 0.001$). The high distress group was also more likely to have depression compared with the low distress group (19.6 vs. 14.8; $p < 0.001$).

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Cleeland et al., 2013 USA	To assessed the effects of disease site and stage on the percentages of patients rating proposed symptoms as moderate to severe.	Large, multicenter, prospective study. The severity of 13 symptoms proposed to represent "core" oncology symptoms was rated regardless of disease stage or phase of care by ambulatory patients (N= 3106) with cancer of the breast, prostate, colon/rectum, or lung. 2801 patients (90%) repeated the assessment 4 to 5 weeks later.	33% of the patients reported ≥ 3 symptoms in the moderate-to-severe range at the time of the initial assessment. 11 of the 13 symptoms were rated as moderate to severe by at least 10% of all patients, and 6 were rated as moderate to severe by at least 20% of those patients receiving active treatment. Fatigue/tiredness was the most severe symptom. Disturbed sleep, pain, dry mouth, and numbness/tingling were other severe symptoms. Lung cancer patients and those receiving active treatments reported more moderate to severe symptoms. Symptomatic patients' percentages are increased by disease stage, less adequate response to therapy and declining Eastern Cooperative Oncology Group performance status.
Cramarossa et al., 2013 Europe	To identify which domains/symptoms from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) were predictive of overall quality of life (QOL) in patients with advanced cancer.	Patients with brain metastases or bone metastases (*N*= 447) from seven countries were enrolled. Regression analysis is used to determine the predictive value of the QLQ-C30 overall health (question 29), functional/symptom scores for patient-reported overall QOL (question 30), and the global health status domain (questions 29 and 30).	The most significant predictive factors for worse QOL were poor role functioning, social functioning, fatigue and financial problems. In the bone metastases patients (*n* = 400), role functioning, fatigue, and financial problems were the most significant predictors. In patients with brain metastases (*n* = 47), none of the EORTC domains significantly predicted worse QOL.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Garabeli Cavalli Kluthcovsky et al., 2012. Brazil	To examine the occurrence of fatigue in disease-free breast cancer survivors after treatment and to identify variables associated with fatigue. This study also aims to evaluate the impact of fatigue on HRQOL.	A cross-sectional study (N=202) was conducted in outpatient facilities of two large hospitals. Sample included women diagnosed with in situ to Stage III breast cancer attending, one year or more after diagnosis. Participants completed Piper Fatigue Scale-Revised and the European Organization for Research and Treatment of Cancer QLQ-C30. Multiple logistic regression models were used to identify predictive factors associated with fatigue. Compared EORTC QLQC-30 scores of fatigued survivors with non-fatigued survivors.	37.6% of the breast cancer survivors reported the prevalence of fatigue. Predictive factors for fatigue based on findings of multiple logistic regression analysis included 1)younger age (odds ratio [OR]=2.23, 95% confidence interval [CI]=1.11-4.45, p = 0.024), 2) presence of pain (OR = 3.87, 95% CI = 1.88-7.98, p = 0.000), 3) dyspnea (OR = 3.72, 95% CI = 1.46-9.50, p = 0.006), 4) insomnia (OR = 2.40, 95% CI = 1.19-4.86, p = 0.015); and 5) nausea and vomiting (OR = 12.25, 95% CI = 1.18-126.75, p = 0.036). Fatigued women had poorer HRQOL than non-fatigued women in all domains.
Golan- Vered, et al., 2013 Israel	To examine the relationship between symptom clusters and chemotherapy-induced neuropathic pain (CINP) among 40 breast cancer patients.	The study was based on 2 sessions conducted before and during paclitaxel treatment. In each session, neuropathic pain was assessed by the DN4 Questionnaire. In the second session, the General Sleep Disturbance Scale, the Center for Epidemiological Studies-Depression Scale and the Lee Fatigue Scale, were also administered. The worst pain intensity was assessed. 2 symptom	Patients in the High Cluster (37%) experienced a high level of all symptoms. Patients in the Low Cluster (63%) experienced a low level of all symptoms. Twenty patients (50%) were diagnosed with CINP. A subgroup of patients (23%) from the High Cluster was identified as having CINP; 35% were in the Low Cluster and free of CINP. A specific subgroup of patients with hypersensitive cancer needed greater attention to symptom management. Severe multiple symptoms of CINP can be prevented by early detection of symptoms, careful dose selection, and assessment of

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		clusters by cluster analysis were identified by the severity of the four symptoms scores.	early stages in the development of neuropathic pain.
Hassan et al., 2010. Malaysia	To determine the impact of chemotherapy-induced nausea and vomiting (CINV) on breast cancer patients' QOL and to identify opinions related with antiemetic guidelines used dependent on the three main races(Malay, Chinese, Indian) in Malaysia.	Longitudinal, prospective study. 158 breast cancer patients treated with chemotherapy were interviewed. Valid questionnaires (MANE and ONEM) were used to report the impact of CINV on their QOL within the first 24 hours and after 3 to 5 days of chemotherapy treatment.	Delayed CINV has an impact on QOL greater than acute CINV. The impact of nausea on CINV was reported higher than that of vomiting. Differences in race, i.e., genetic polymorphisms (pharmacogenomics) influenced the utility of antiemetic treatments and patients opinions.
Harrow et al., 2014 Scotland	To explore breast cancer patients' experiences of taking adjuvant endocrine therapy as a treatment and how their beliefs about the purpose, side effects and interactions with health professionals might influence adherence.	A qualitative study conducted using semi-structured, one-to-one interviews. 30 women with breast cancer included in this study. Participants were breast cancer patients who had been prescribed tamoxifen or aromatase inhibitors and had been taking this medication for 1-5 years.	Women clearly expressed the need to take their adjuvant endocrine therapy medication as prescribed and they believed that it offered protection against breast cancer recurrence. Some women missed their tablets and did not believe that this may reduce the efficacy of their treatment. Women did not perceive that their healthcare professionals were routinely monitoring their adherence. Side effects were common and impacted greatly on the women's QOL but did not always lead participants to stop taking their medication, or to seek professional advice to reduce their side effects.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Hartvig et al., 2006. Sweden	The aims of this study were to assess the frequency, severity, and the impact of fatigue in cancer outpatients receiving cytotoxic drugs.	A non-randomized, prospective design. Used an existing international fatigue scale applied for Swedish use. Once a week, 147 cancer patients filled out questionnaires containing 13 items from the Fatigue Symptom Inventory (FSI), and five additional questions.	Prevalence of fatigue was 92% in the week after all patients had received cytotoxic drugs. Patients were significantly more fatigued during treatment than before treatment. The degree of fatigue was highest during the week after treatment and declined over the following week. The depressed mood had a strong correlation with cancer and cytotoxic-induced fatigue. Lung and breast cancer patients experienced the highest degree of fatigue. Some cytotoxic drug regimens(cyclophosphamide or gemcitabine) were associated with high fatigue scores irrespective of the underlying cancer diagnosis.
Heinze S & Williams P.D. 2015a USA	To describe self-care strategies used to alleviate symptoms after completion of treatment, as reported by breast cancer survivors in one Mid-Atlantic state.	Phase 2 of a larger study recruited two groups of volunteer participants. Phase 1 subjects completed an online survey (included the TRSC, Therapy-Related Symptom Checklist, and other tools). In Phase 2, participants reported the occurrence & severity of symptoms at six months or more post-treatment Participants also reported their self-care strategies on the SA: SCM (Symptom Alleviation: Self-Care Methods) tool.	The post-treatment time duration (range = 6 months to 18 years) were significantly associated with TRSC total scores among the breast cancer survivors. Group 1 had low symptom occurrence/ severity [low TRSC scores, *n*= 26). Group 2 reported high TRSC total scores, *n*= 25). Williams' 6 self-care categories were used, based on the literature. Diet/nutrition/lifestyle change was the most often used self-care symptom alleviation method, and least used were herbs/ vitamins/ complementary therapies. The effectiveness of all self-care methods ranged from 25%–100%.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Heinze S et al., 2015b USA	To examine the relationship between TRSC total scores (symptom occurrence & severity) in breast cancer survivors after treatment completion, & the absence of BDNF (Brain-Derived Neurotrophic Factor) *Val66Met polymorphism*	A cross-sectional design with two phases: Phase 1- Used electronic survey to collect symptom occurrence and severity data, daily activities, and QOL. Instruments included TRSC, the Health Form, & the Demographic Form. Data collected on variables such as age, education, ethnicity, type of treatments received, and time length since treatment completion. Phase 2- Collection of saliva samples for genotyping. A convenience sampling method used. of Participants recruited from the database of a statewide breast cancer coalition of one Mid-Atlantic state(*N* = 195).	BDNF genotype did not show significant effect on total TRSC scores (OR = 0.27; 95% CI, [0.036, 1.98]; p = 0.196). Even though, the sample size was small (weak statistical power), the odds of reporting higher TRSC scores (OR=29.29; 95% CI [2.81, 305.10], p=.005) were found in patients who received chemotherapy treatment. Higher percent occurrence of 7 symptoms was reported by breast cancer survivors with absent BDNF SNP. Conclusions: Symptom occurrence and severity related to chemotherapy are long lasting (present after the completion of chemotherapy treatment), and a larger study on BDNF is needed.
Heinze S, Williams PD, Bott M, 2015c USA	To examine ongoing symptom occurrence and severity after completion of treatment by breast cancer survivors, as self-reported on the TRSC.	A cross-sectional design, a survey using an electronic form of the TRSC, HRQOL-LASA, Daily Activities Rating Scale (DARS), Demographic Form, and Health Form, other medical information. The independent	The time length since treatment completion was not significantly related to TRSC total scores. Higher total TRSC scores were related to higher DARS total scores and lower total HRQOL-LASA scores. The odds of reporting a low TRSC total score increased with higher education level and

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
	The quality of life, daily living activities, and related variables were also studied.	variables studied included age, education, treatment type, and time length since treatment completion. The dependent variables examined were symptom occurrence/ severity (Therapy-Related Symptom Checklist [TRSC] score), Quality of life (HRQOL-Linear Analogue Self-Assessment [LASA] score), and the DARS score). Correlations among study variables were examined.	increased age and the odds decreased with chemotherapy treatment. Implications: Monitoring of the occurrence and severity of breast cancer survivors' ongoing symptoms by skilled palliative nurses are necessary even after completion of their treatment. It is important to develop interventions for palliation of common symptoms related to cancer treatment.
Henry et al., 2008 USA	To examine the prevalence of chemotherapy-or radiotherapy-related side effects, treatment burden, and correlates of fatigue and missed work days among cancer patients	Conducted a cross-sectional survey (*N*=63,949) and used a dual sampling frame of cancer patients. 35,751 patients from an online panel, and remaining 28,198 from telephone listings. Patients included were ≥18 years receiving chemotherapy and/or radiotherapy at the time of the survey or during the previous 12 months. Collected data on variables such as cancer type, treatment side effects, visits, caregiver burden, missed working days, and socio-demographic characteristics. Data were presented only for patients receiving cancer treatment at the time of the survey.	The most common and severe side effects were fatigue (80%), pain (48%), and nausea/vomiting (48%). On average, patients spent 4.5 hours per visit to treat therapy-related side effects. 43% of the patients were employed, and among them, 78% were actively working. On average, employed patients missed about 18 workdays annually for side effect treatment. Younger and unemployed patients, females, and those with higher levels of anxiety and depression reported the experience of more fatigue. Patients with a higher number of side effects reported more missed workdays.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Ho et al., 2014 Hong Kong	To examine the breast cancer patients' potential population heterogeneity in fatigue symptoms using the innovative non-normal mixture modeling.	Breast cancer patients (*N*=197), completed the brief fatigue inventory and other measures on their cancer symptoms. Analysis and comparison of non-normal factor mixture were done using the normal, t, skew-normal, and skew-t distributions. The number of latent classes was based on the Bayesian information criterion (BIC). Validation of the identified classes was done by comparing their demographic profiles, clinical characteristics, and cancer symptoms. A stepwise distal outcome approach was used.	Findings of the t distribution mixture models showed the lowest BIC for the 2-class model. The restored class (52.5 %) showed moderate severity (item mean = 2.8-3.2) and low interference (item mean = 1.1-1.9). The exhausted class (47.5 %) showed high fatigue severity and interference (item mean = 5.8-6.6). The exhausted class reported significantly higher perceived stress, anxiety, depression, pain, sleep disturbance, and lower quality of life compared to the restored class.
Hofso et al., 2013 Norway	To evaluate the changes in and predictors of occurrence, severity, and distress of six common symp toms (lack of energy, worrying, difficulty sleeping, feeling drowsy, sweats, and pain) during radiation therapy for breast cancer.	188 breast cancer patients completed the Memorial Symptom Assessment Scale. Data collected before, during, and after the completion of radiation therapy, over a six-month period. Changes in symptom occurrence were examined using multilevel logistic regression analysis. Multilevel proportional odds ordinal logistic was used to evaluate changes in severity and distress scores.	For the six symptoms, the trajectories for occurrence, severity, and distress followed similar patterns. All three dimensions changed over time for three (lack of energy, feeling drowsy, and worrying) of the six symptoms. No changes over time occurred for the other three symptoms (difficulty sleeping, sweats, and pain), for any of the symptom dimensions. Symptom burden increased across all three dimensions due to the overall effect of the five covariates. This study provides a complete picture of breast cancer patients' symptom experience during radiation therapy.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Hughes et al., 2003. USA	To discuss the associations between cultural beliefs and values and participation in genetic risk assessment/testing among African American women at high risk of having a BRCA1 or BRCA2 gene alteration.	This was an observational study. High-risk women (N=28), who self-referred to a genetic counseling and testing research program. Study procedures included baseline telephone interview (about 40 minutes) and then mailed survey to assess cultural beliefs, genetic counseling, and genetic testing.	Test acceptors had higher mean levels of fatalistic beliefs about cancer and future temporal orientation compared to decliners. Test acceptance rate was not associated with their socio-demographic factors; however, women with greater perceptions of familial interdependence reported lower rates of test acceptance (41% versus 91%). This study suggests that among African American women, there is the influence of cultural beliefs and values in genetic testing decisions.
Hutter et al., 2013. Germany	To examine the relationship of depression and anxiety with QOL among breast cancer patients.	Depression, anxiety and QOL were assessed at baseline and six-month follow-up in breast cancer patients (*N*=118). Cross-lagged partial correlation analysis was used to examine the relationship between study variables.	Significant partial correlations found between depression and anxiety at baseline. Significant partial correlations found between physical functioning, emotional functioning and "global health and QOL" at six-month follow-up. Baseline "Global health and QOL" was significantly associated with depression and anxiety at follow-up. Cognitive functioning at baseline was significantly associated with anxiety at follow-up. Cross-lagged partial correlation analysis of two models (depression and anxiety determining QOL vs. QOL determining depression and anxiety) did not find significant results.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Hwang et al.,2013 Korea	To evaluate the effect of adjuvant chemotherapy on QOL among breast cancer patients according to the survival time from surgery.	Cross-sectional study. Data collected from 534 women with breast cancer. Reviewed socio-demographic and clinical characteristics. Major tools used dor data collection were Functional Assessment of Cancer Therapy-Breast Cancer instrument, global quality of life, Beck Depression Inventory. Statistical analyses conducted using descriptive statistics, t-tests, chi-square tests and multiple analysis of covariance while controlling for confounding variables.	Chemotherapy and no chemotherapy group had statistically significant differences between on depression, unmet sexuality needs, breast cancer specific concerns, physical well-being, and emotional well-being. Effects of chemotherapy varied according to survival time since surgery. Significant differences were found for group 1 (<1 year since surgery), on Beck Depression Inventory (p=0.042), breast cancer subscale (p=0.004), unmet sexuality needs (p=0.016), and physical well-being (p=0.016). For group 3 (>3 years since surgery) significant differences were found on depression (p=0.019) and physical well-being (p=0.028). No significant differences were found between chemotherapy and no chemotherapy group for group 2 (1-3 years since surgery).
Im, E. 2007 U.S.A	To examine ethnic differences in cancer pain experience of four ethnic groups in the United States.	A survey of a multi-ethnic sample (*N*=480) cancer patients. Samples were recruited using Internet and community settings. Questions were asked on socio-demographic characteristics and health and illness status. Tools used for data collection included three unidimensional cancer pain scales, two multi-dimensional cancer pain scales, the Functional Assessment of Cancer Therapy Scale, and the	The results showed that there were certain ethnic differences in types of pain and symptoms that patients experienced. Findings of this study also showed significant ethnic differences in cancer pain and functional status.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		Memorial Symptom Assessment Scale. The data analysis were done using descriptive and inferential statistics, which included ANOVA and hierarchical multiple regression analyses.	
Jimenez et al., 2011 Mexico	To examine symptom clusters(SCs) in advanced cancer, evaluate the characteristics associated with various clusters, and determine their relationship to cancer survival.	This study conducted on patients (*N*=406) in the palliative care program. The Edmonton Symptom Assessment System and a supplement including 13 other symptoms were used to identify symptoms. Principal component analysis was performed to identify symptom relationships and to compare symptom clusters with associated parameters.	The most common primary carcinomas were gastrointestinal (35%), lung (25%), genitourinary (8%), breast (5%), and head and neck (5%). Common symptom clusters identified were: neuropsychological (anxiety, depression, and insomnia), confusion (cognitive impairment, agitation, urinary incontinence), gastrointestinal (nausea and vomiting), and anorexia-cachexia (anorexia, weight loss, and tiredness). Survival rate was related to the number of symptom clusters present in a given patient: zero symptom cluster, 52days; one symptom cluster, 38 days; two symptom clusters, 23 days; and three to four symptom clusters, 19 days. Different symptom clusters can be identified in patients with advanced cancer. These symptom clusters are influenced by age, gender, primary cancer site, and Eastern Cooperative Oncology Group performance status.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Kennedy et al., 2010 UK	To examine psychosocial impact of ductal carcinoma in situ (DCIS)	A prospective longitudinal study. Newly diagnosed 50 women with ductal carcinoma in situ were followed over the first year after diagnosis.	This study found a significant reduction in anxiety and depression from baseline to 6 months. Body image distress was relatively stable. However, the distress was extensive for some women. Patients undergoing mastectomy with immediate reconstruction experienced significantly greater body image distress. DCIS patients can often experience transient psychosocial distress, but in some cases, it is extensive and prolonged.
Lewis et al., 2012. USA	To determine psychosocial fears and concerns of young African American breast cancer survivors.	African American breast cancer survivors (*N*=33) with age 45 or younger participated in this study. Data collected using semi-structured phone interviews. The interview items focused on the impact of cancer on women's employment, relationships, living situations, fertility, and sexuality.	Findings showed that 26% of participants believed that treatment interfered with employment. One-third informed the need for additional emotional support at and after diagnosis. One-half reported that cancer negatively influenced their romantic relationships. Forty-five percent wanted children at diagnosis, but one-half these women never received fertility information. One-third reported sexual problems. Fifty-two percent reported a lack of information about cancer-related sexual dysfunction and 73% never discussed sexuality with their providers. African American women's spirituality and strength may facilitate their cancer adjustment; however, cultural taboos influence their health issues and may interfere with successful coping.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Kidwell et al., 2014 USA	To examine and report the association of patient-reported symptoms before the initiation of an Aromatase inhibitors (AI) and treatment discontinuation within one year of starting the drug.	A prospective clinical trial. Postmenopausal women initiating Aromatase inhibitors therapy were enrolled in this study. Participants completed questionnaires at baseline to assess sleep, fatigue, mood, and pain. Women were randomized 1:1 to treatment with oral exemestane 25 mg daily or oral letrozole 2.5 mg daily. Enrolled patients completed questionnaires and underwent phlebotomy before initiation of treatment, and then after one month, three months, six months, 12 months, and 24 months of aromatase inhibitors therapy. Reasons were recorded for treatment discontinuation during the first year of treatment. Associations were identified using logistic regression between baseline patient-reported symptoms and treatment discontinuation because of toxicity.	Patients who had a greater number of symptoms before initiation of Aromatase inhibitors had higher odds of treatment discontinuation. Poor sleep quality at baseline was associated with early treatment discontinuation. Patients with presence of tired feeling and forgetfulness at baseline had similar odds for treatment discontinuation. An increasing number of total baseline symptoms was associated with an increased likelihood of discontinuation of treatment.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Likhacheva, et al., 2013 USA	To identify symptoms in patients with locally advanced cervical cancer undergoing concurrent chemoradiotherapy (CTRT) with either weekly Cisplatin or every -3- week cisplatin /5- fluorouracil.	Patients with stage IIB to stage IVA disease as per1994 International Federation of Gynecology and Obstetrics, biopsy-proven positive pelvic nodes, or gross tumor size greater than 5 cm were eligible for this study. Patients requiring para-aortic radiotherapy were excluded. Patients reported symptom severity three times per week on an 11-point scale during CTRT and at the first follow-up. Modified Edmonton Symptom Assessment Scale was used for data collection. Multilevel mixed-effects linear regression and the Wilcoxon rank sum test were used to assess the effect of chemotherapy regimen on symptoms.	Among the cancer patients included in the final analysis(*N*=52), 37 received cisplatin, 13 received cisplatin/5-fluorouracil, and 2 received one cycle of cisplatin/5- fluorouracil followed by cisplatin. Compliance with the completion of Edmonton Symptom Assessment Scale questionnaires was 75%. Significant differences were found in symptom scores for anorexia, well-being, diarrhea, fatigue, and stomatitis favoring the Cisplatin regimen. All reported symptoms except diarrhea were stable and of low severity in the Cisplatin group. Symptoms had a cyclical pattern in the cisplatin/5- fluorouracil group, with an initial rise followed by a gradual fall in symptoms during the 3-week period after chemotherapy. Scores for all symptoms improved to baseline levels, 4 to 6 weeks after treatment for the patients (N=29) who completed the follow-up surveys.
Masmoudi et al.,2009 Africa	To assess the feasibility of quality of life assessment in a cohort of Tunisian cancer patients	The EORTC QLQ-C30 questionnaire was used for data collection. The tool was administered to women with early breast cancer (*N*=23), who are treated with adjuvant chemotherapy on an outpatient basis. Data have collected twice: 1)at baseline and 2) during the 3rd cycle of chemotherapy.	A significant deterioration was found in physical functioning, cognitive functioning, and social functioning during chemotherapy treatment. This study identified a wide range of methodological and practical obstacles to routine evaluation of the quality of life was identified. Improvement of public education and cancer care infrastructure is needed before the reliable quality of life studies can be performed.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Miaskowski et al., 2006 USA	To identify subgroups of cancer outpatients based on their experiences with the symptoms of sleep disturbance, fatigue, depression, and pain. This study also aims to explore the difference in patients in the subgroups based on selected demographic, disease, and treatment characteristics; and to identify whether patients differed on two important patient outcomes: functional status and quality of life (QOL).	Descriptive correlational study. The sample included outpatients with cancer (*N*= 191) receiving active treatment. Patients completed a Karnofsky Performance Status scale, a demographic questionnaire, Center for Epidemiological Studies Depression Scale, Multidimensional Quality-of-Life Scale-Cancer, Lee Fatigue Scale, General Sleep Disturbance Scale, and a numeric rating scale of worst pain intensity. Disease and treatment information were collected from medical records. Cluster analysis was used to identify patient subgroups based on patients symptom experiences. Differences in demographic, disease, and treatment characteristics and outcomes were evaluated using ANOVA and chi-square analysis.	Four patient subgroups were identified based on patients' experiences with four highly prevalent and related symptoms. The subgroup of patients who had lower levels of all four symptoms reported the best functional status and quality of life.
Mota et al., 2012 Brazil	To determine the prevalence and predictors of fatigue in colorectal cancer (CRC) patients.	Cross-sectional study. Sample included 157 adult colorectal cancer outpatients. The Piper Fatigue Scale-revised was used for data collection. Data on socio-demographic, clinical, depression, performance status, pain	Fatigue was reported by 26.8% of colorectal cancer patients. Logistic regression identified three predictors: performance status (OR: 3.2; 95% CI 1.37-7.51), depression (OR: 4.2; 95% CI 1.68-10.39), and sleep disturbance (OR: 3.2; 95%CI 1.30-8.09). When all predictors were

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		and sleep disturbance was assessed. Associations were analyzed through logistic regression models.	present, the probability of experiencing fatigue was 80%, and when none were present, the probability was only 8%.
Myers, 2012 USA	To obtain an in-depth description of the experience of chemotherapy-related cognitive impairment (CRCI) for women with breast cancer. To identify related information that women would find useful prior to chemotherapy treatment and at the onset of cognitive changes.	Qualitative, descriptive design. Breast cancer survivors (*N*=18) within 6-12 months of chemotherapy completion, who self-reported changes in cognitive function. Data were collected through semi-structured interviews, a demographic questionnaire, and a focus group. Qualitative content analysis was performed.	Study themes were How I Changed, Life With Chemobrain, How I Cope, and How to Teach Me. Participants described difficulty with focusing, short-term memory, reading, word finding, and driving. Problems related to neuropathy, trouble sleeping, fatigue, balance, and coordination also were of concern. Coping strategies included writing things down, focusing on one task at a time, depending on others, and giving oneself permission to make mistakes. Exercise and getting enough rest were helpful and recommended activities for mind stimulation by participants. Participants wanted information/education about the potential for chemotherapy-related cognitive impairment prior to chemotherapy treatment.
Obeidat et al., 2014 Jordan	To examine Jordanian women's attitudes toward disclosure of breast cancer information and their information needs.	A comparative-descriptive research design. A convenience sample of 156 Jordanian women included in this study. Women who had a confirmed first-time diagnosis of breast cancer within 18 months before the study and had received treatment at three hospitals in Central and Northern Jordan was	The majority of patients wanted to know whether their diagnosis was breast cancer (92 %) and the stage of their cancer disease (78 %). Information about the spread of the disease (88%) and chances of cure (85 %) was of highest importance for the majority of the patients. Patients with younger age and higher education were expressed a preference for truthful disclosure of their breast

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		recruited for the study. Data collection was done using a modified version of the Information Needs Questionnaire (INQ).	cancer diagnosis.
Park et al., 2013 Korea	To describe the relationships among sexual function, menopausal symptoms, depression, and QOL in women with breast cancer receiving chemotherapy.	Cross-sectional study (*N*=200). Tools for data collection included: the Female Sexual Function Index (FSFI), Menopause Rating Scale (MRS), Beck Depression Inventory-II (BDI-II), and the Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B). Data were analyzed using descriptive statistics, ANOVA, Scheffe's test, t-tests and Pearson product moment correlations. SPSS v. 20 was used for data analysis.	Participants reported changes in menopausal symptoms and sexual function and were depressed with a decreased QOL. These factors also influenced satisfaction with sexual relationships ($p < 0.05$) and family support ($p < 0.05$). Nurses should provide education to breast cancer patients on their sexual issues and should encourage them to attend family support programs. Nurses should also include family members in education and encourage them to address menopausal and depressive symptoms of breast cancer patients to enhance their sexual functioning and QOL.
Paul et al., 2013 Germany	To gather data on complementary and alternative medicine (CAM) use and their reasons to use CAM of patients with advanced cancer stage and being admitted for residential palliative care and their relatives.	Structured interviews were conducted with a sample of 25 patients and 25 relatives of those patients. The study setting was a German comprehensive cancer center. Data collected based on a standardized questionnaire of the working group Prevention and Integrative Oncology of the German Cancer Society.	The median age of cancer patients was 64.5 years, and that of relatives was 53.5 years. 15 patients were males, and ten patients were females (relatives: 7 and 18) respectively. 40 % of all patients in this study used some CAM method at the time of the study, and supplements and prayer were the most frequent used method. Main reasons for using CAM were to sustain one's strength and to be able to do something by oneself. Main sources of information were television/radio and family/friends. Relatives also used the Internet.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Pettersson et al., 2014 Sweden	To describe the frequency, prevalence, and severity of symptoms and the distress during the early treatment of patients with colorectal cancer (CRC) undergoing chemotherapy.	Outpatients were asked to rate their symptoms during cycle 2 or 3 of their chemotherapy. The Memorial Symptom Assessment Scale was used for data collection. A total of 104 CRC patients (58 men & 46 women) evaluated their symptoms of the previous week at one point during the cancer treatment.	The mean number of symptoms was 10.3 (SD, 7.7). Highly prevalent symptoms reported were numbness/tingling in the hands/feet (64 %), lack of energy (62 %), feeling drowsy (49 %), and nausea (45 %). Symptoms with the highest scores for severity, frequency and distress were a lack of energy. Other severe symptoms were difficulty in sleeping and numbness in the hands/feet. Lack of energy was reported as occurring almost constantly by 26 % of patients and was rated as being severe/very severe by 12% and as quite distressing/very distressing by 15 %.
Piamjariyakul et al., 2010 Thailand	To identify patient-reported symptoms and self-care strategies in Thai cancer patients.	This study used a cross-sectional, descriptive design and carried out at the National Cancer Institute, Thailand. Patients (*N*= 202) undergoing CT alone, n=103; or RT alone, n=47; or combined radiotherapy and chemotherapy (RT-CT), n=52 participated in this study. Data was collected with the use of a 25-item Therapy-Related Symptom Checklist, TRSC (Thai); the Karnofsky Scale; a Self-Care Method scale; and a Health Data form.	Patients on combined RT-CT reported more severe symptoms on the TRSC than those receiving RT or CT alone and lower Karnofsky score. Karnofsky and TRSC scores were inversely correlated. Most common self-care methods used were grouped into six categories: (1) Diet, nutrition, and lifestyle changes (e.g. modify food) to relieve Eating and Fatigue symptoms; (2) Mind/Body Control to manage Fatigue and other symptoms; (3) Biologic treatment (e.g. vitamins) for eating difficulties; (4) Herbal treatments for hair loss; (5) Other methods, and (6) taking prescribed medicines to control pain and other symptoms. Some patients reported "doing nothing" as a method of coping.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Prigozin et al., 2010 USA	To examine the association of symptom severity to age, education, marital status, symptom interference, and type of chemotherapy treatment in Israeli women diagnosed with stage I or II breast cancer.	The sample included 51 women with breast cancer (stage I or II) who were receiving an adjuvant chemotherapy protocol with doxorubicin. Data collection was done using a modified version of the Breast Cancer Prevention Trial Hot Flashes Subscale (BCPT-HFS), M.D. Anderson Symptom Inventory (MDASI), and a demographic and treatment questionnaire to assess their symptoms toward the end of their treatment.	The most frequent and severe symptoms reported were fatigue, sleep disturbance, and drowsiness. The Symptom severity (MDASI total scores) was positively correlated with total scores of interference with activities of daily life. Most of the individual symptoms scores were significantly associated with the total interference scores. The strongest relationships were found with fatigue, sadness, and distress. The inverse relationship was found between education and the MDASI general symptom severity total scores. The inverse relationship was found between age and the BCPT-HFS total scores. Breast cancer patients who received doxorubicin, cyclophosphamide, plus fluorouracil or doxorubicin plus cyclophosphamide reported greater symptom severity than patients who received doxorubicin plus cyclophosphamide.
Pud et al., 2014 Israel	To examine the association between polymorphisms in candidate genes and chemotherapy-induced symptoms.	Women who completed, at least, two cycles of adjuvant doxorubicin and cyclophosphamide, with or without paclitaxel for early breast cancer (n = 105) were included in this study. Data were collected using the memorial symptom assessment scale, and sample of blood for genotyping. DNA was extracted	Genotyping of HTR3C showed a significant association between the presence of rs6766410 and rs6807362 SNPs and increased severity of symptoms. Multiple regressions revealed that rs6766410 and rs6807362, but not age or stage at diagnosis, predicted the severity of symptoms and explained 12 % of the variance in each regression model. No association was found between the genetic variants of CGH1 or COMT and symptom

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		from peripheral blood leukocytes.	score. An association found between variants of HTR3C and severity of chemotherapy-induced symptoms. Findings indicate that patients are at increased risk for chemotherapy-induced symptoms and targeting the serotonin pathway may serve as a novel symptom management strategy for these patients.
Sbitti et al., 2011 Algeria	To evaluate women's responses to questions related to changes in their body image and sexual functioning since their breast cancer diagnosis to treatment.	A questionnaire concerning body image and sexual problems experienced after cancer diagnosis and treatment was completed by120 women with breast cancer. The study setting was the outpatient clinic of hospital's medical oncology division. Subjects who were sexually active and had confirmed histology proven breast cancer were included in the study. Participants also had to have received treatment for breast cancer.	100% of participants have never spoken about body image and sexual functioning with their doctor. 84% of the patients continued their sexual activity after treatment. There was an increase in the incidence of problems related to sexual functioning. Sexual problems resulted in a slight reduction in their quality of sex lives. 65% of the women experienced dyspareunia. 54% of the women experienced lubrication difficulties. The absence/reduction of sexual desire (48% and 64%, respectively) while 37% had lack of satisfaction.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
			Female orgasmic disorder(40%) and brief intercourse and arousal were reported by 38% of the subjects. 91.5% subjects reported the absence of the sexual dysfunctions before diagnosis and management of breast cancer, and of these subjects 100% complained of a deterioration of their symptomatology after the various treatments for cancer. 90% of the dysfunctions were experienced after chemotherapy, 9% after surgery and 3% after radiotherapy. None of the subjects indicated the onset of dysfunctions associated with hormonotherapy. 100% of subjects reported that they did not receive sufficient information about how the disease and treatment might affect their sexual life.
Senf et al., 2010 Germany	To apply and evaluate a short expert rating scale for the assessment of distress during the acute cancer treatment phase and to determine potential socio-demographic and disease-related predictors.	Cancer patients (*N*=478) were assessed with the short form of the psycho-oncological basis documentation and its breast-cancer-specific version. Patients also completed a self-rating questionnaire on stress in cancer patients. The researcher recorded sociodemographic and disease-related variables and assessed their predictive value for psychosocial distress.	The majority (56.3%) of patients were rated distressed. According to a patient self-rating, only 31.3% of patients were classified as distressed. Finding of both approaches showed a good degree of concurrence and a consistent classification of 69% of patients. Higher distress levels were associated with younger age, current psychotropic medication, and past psychological treatment. Patients diagnosed with metastases and those with a poorer functional status were also more distressed. Patients having an operation reported a better psychological well-being.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Stanton et al., 2005. USA	To evaluate the psychometric properties of the Breast Cancer Prevention Trial (BCPT) Symptom Checklist across four relevant samples of women with breast cancer.	The sample included four different patient populations (*N* = 2208) who were diagnosed with breast cancer or were at risk for the disease. BCPT Symptom Checklist include a list of 42 physical and psychological symptoms that are relevant to women in cancer treatment or chemoprevention trials. Conducted exploratory and confirmatory factor analyses using data from the BCPT Symptom Checklist. Participants completed a mailed questionnaire packet that included the BCPT Symptom Checklist.	Findings of this study revealed eight problems related to physical symptoms associated with cancer treatment, chemoprevention, normal aging, and menopause. Common problems included nausea, bladder control, hot flashes, musculoskeletal pain, weight problems, vaginal problems, cognitive problems, and arm problems. Breast cancer women reported higher mean scores on scales for pain, hot flashes, and weight problems compared to scores on scales for the other symptoms. Cancer-related and demographic variables accounted for up to 15% of the variance in how participants responded to the symptom scales. The most common and consistent predictors for greater symptoms included the previous receipt of chemotherapy and lower education level.
So et al., 2011 China	To examine the difference in the quality of life (QOL) of younger (<60) and older (≥60) Chinese women receiving adjuvant therapy for breast cancer.	Secondary data analysis using cross-sectional descriptive design. Participants (*N*=261) completed a self-report survey on their demographic and clinical characteristics. Another tool used for data collection was a Chinese version of the Functional Assessment of Cancer Therapy for Breast Cancer and the Medical Outcomes Study Social Support Survey. Stepwise regression used	Significant differences found between the two groups (younger vs. older women) in their total score ($p = 0.049$), the physical well-being ($p = 0.048$), emotional well-being ($p = 0.014$), and breast cancer subscales ($p < 0.001$) after adjustment for potential confounding variables. The older group had, the better overall QOL, physical and emotional well-being, and higher breast cancer subscale scores compared to the younger group.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
		for data analysis.	
Van Rooyen et al., 2008. South Africa	To describe the lived experiences of the participating oncology nurses.	Qualitative, exploratory and descriptive design. Participants were selected for this study using a non-probability, purposive sampling method. The sample included 4 registered nurses, and two enrolled nurses work in the oncology unit. Data collected by unstructured interviews.	Findings show that the oncology nurse, taking care of the cancer patients and their family, experiences different nurse-patient relationship. Oncology nurses also reported very challenging interpersonal relationships with members of the multi-professional team and the management.
Walsh et al., 2000. USA.	To describe the influence of age, gender, and performance status on symptom profile.	A comprehensive prospective symptom analysis was conducted. Participants were 1,000 patients on their initial referral to the Palliative Medicine Program at the Cleveland Clinic. The study tool included an eight-page form on which detailed medical information are entered. It is an empirically derived clinical assessment based on conventional medical history taking. Clinical assessment included details of 38 specific symptoms affecting the respiratory, cardiovascular, skin, gastrointestinal, musculoskeletal, central and peripheral nervous systems, and a detailed pain and performance status assessment.	The median number of symptoms recorded per patient was 11 (range 1-27). The ten most prevalent symptoms were a pain, lack of energy, fatigue, constipation, weakness, anorexia, dry mouth, early satiety, dyspnea, and weight loss greater than 10%. The prevalence of common symptoms ranged from 50% - 84%. 11 symptoms were associated with younger age: pain, nausea, blackout, headache, vomiting, sedation, sleep problems, bloating, anxiety, constipation, and depression. Gender was associated with eight symptoms. Males reported more hoarseness, dysphagia, greater than10% weight loss and sleep problems. Females had more nausea, early satiety, vomiting, and anxiety. Performance status was associated with 14 symptoms. Advanced cancer patients are found to be polysymptomatic. Prevalence of 24 symptoms differs with age, or gender, or performance status.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Williams et al., 1997 USA	To develop a tool (TRSC) on symptom occurrence/severity in adult cancer patients on treatments.	192 oncology patients receiving chemotherapy, radiation therapy or combination therapy of both chemo and radiation included. Study site state University Medical Center in the southeastern USA. Patients with all cancer diagnoses included in this study.	TRSC is a 25-item checklist for patients to self-report symptoms experienced during cancer treatments, either chemotherapy and/or radiation therapies. The TRSC has 14 subscales (symptom clusters). Six subscales have multiple items while eight are single-item subscales (bleeding, hair loss, pain, numbness in fingers and/or toes, skin changes, constipation, soreness in vein, and decreased interest in sexual activity). Items in the Fatigue subscale are depression, feeling sluggish, difficulty concentrating, and difficulty sleeping. The Eating subscale includes loss of appetite, taste change, weight loss, and difficulty swallowing. The Oropharyngeal subscale has three items (sore mouth, sore throat, and jaw pain). Nausea subscale (nausea and vomiting), Fever subscale (fever and bruising), and Respiratory subscale (cough and shortness of breath) include two items each. Participants reported their symptom occurrence and rate the severity on a 5-point scale: 0 (none), 1 (mild), 2 (moderate), 3 (severe), or 4 (very severe). Space was given to write in, and rate other symptoms were provided. The ratings on the 25 items are summed (range 0 – 100) Higher scores (total score) on the TRSC indicates greater frequency (occurrence) and greater symptom severity.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Williams et al., 2001 USA	To describe and compare symptom severity by two treatment types (chemotherapy versus radiation therapy)	Oncology patients receiving chemotherapy (*n*=109) and radiation therapy RT (*n*=161). TRSC used to collect patient reported symptoms. This was a secondary analysis study. Self-reports of the two treatment groups was compared using the Mann-Whitney U Test.	RT patients reported the significantly greater severity of five symptoms ($p<0.05$) Chemotherapy patients reported the significantly greater severity of eight symptoms. The Therapy-Related Symptom Checklist is an easy and useful checklist. TRSC can be used in the clinical oncology setting to assess major symptoms associated with cancer treatments.
Williams et al., 2006 USA	To examine self-reported symptoms and self-care by adults receiving chemotherapy or radiation therapy using the Therapy-Related Symptom Checklist (TRSC).	37 adult cancer patients receiving chemotherapy primarily for lymphomas, leukemia, or breast cancer or radiation therapy for head and neck or lung cancers were participated in this study. A descriptive study was conducted on patient-reported symptoms and self-care. The Therapy-Related Symptom Checklist (TRSC) and demographic and interview forms on self-care for identified symptoms were used for data collection.	Severe symptoms on the TRSC subscales reported by patients on chemotherapy are eating, pain, nausea, fatigue, hair loss, numbness in fingers/toes, and constipation were. Patients on radiation therapy reported severe symptoms on the fatigue, eating, skin changes, oropharynx, and constipation subscales. Self-care strategies were grouped in the following categories: Diet,nutrition, and lifestyle change (eg, modifications of food and of eating habits; taking naps, sleep, and rest); biologic treatments (use of vitamins); herbal treatments (drinking green mint tea); mind/body control (eg, prayer, music,relaxation methods,); and ethnomedicine (lime juice and garlic). Diet/nutrition/lifestyle change was the common self-care method used by patients in both treatment types. Medications were prescribed also to control therapy- related symptoms (e.g., pain and nausea).

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Williams et al., 2010 (a) Philippines	To examine patient-reported symptoms and self-care methods used during cancer treatments, using selected checklists.	A descriptive study conducted at the Cancer Institute of a national medical center in Manila. Cancer patients (*N*=100) receiving chemotherapy alone (*n* = 63), or combined radiotherapy and chemotherapy (*n* = 37) were participated in this study. Instruments used for data collection were (a) Therapy-Related Symptoms Checklist (TRSC) - Philippine version (b) Self-care Methods tool, (c) Karnofsky Scale, (d) Demographic form, and (e) Health form. Cronbach's alpha of the TRSC (Philippine version) was .83.	Patients who received combined chemotherapy and radiotherapy reported more severe symptoms on several TRSC subscales compared with those receiving chemotherapy alone. Most common self-care methods used were in 2 categories. (1) Diet/nutrition/lifestyle change (e.g., eat vegetables and fruits (papaya); use nutritional supplements; modify food/eating habits; have rest, naps, sleep). Diet/nutrition/lifestyle change was used to manage eating, oropharynx, nausea, and fatigue subscale symptoms. (2) Mind/body control (e.g., prayer, music) to relieve symptoms of fatigue subscale, and other symptoms.
Williams et al., 2010 (b) Mainland China and Hong Kong	To describe patient-reported symptoms and self-care strategies of Chinese adults receiving cancer treatments.	A cross-sectional, descriptive study (N=222). Patients undergoing chemotherapy alone (*n* = 63), radiation therapy alone (*n* = 82), or combined chemotherapy and radiation therapy (*n* = 73) were included from cancer centers in Hong Kong and China. Data were collected using (1) Therapy-Related Symptom Checklist (TRSC) - Chinese version, (2) Symptom Alleviation: Self-care Methods tool, (3) Karnofsky Scale and Health Form, and (4) a demographic form.	The TRSC-Chinese version has good reliability and validity. Patients on combined chemotherapy and radiation therapy reported more severe symptoms than patients receiving either chemotherapy or radiation therapy alone ($F = 3.08$, $P < .05$). Patients on all treatment types reported symptoms with greater severity on TRSC subscales pain, nausea, oropharynx, eating, and fatigue. Most commonly used complementary/self-care categories were diet/nutrition/lifestyle change, mind/body control, and biologic treatments.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
Williams, et al., 2014 USA	To examine symptom occurrence and severity among Mexican American adults undergoing cancer treatments and their self-care strategies.	Mexican American cancer patients (*N*=67) receiving outpatient oncology treatments participated. The study setting was in the southwestern United States. Instruments for data collection included patient-report Therapy-Related Symptom Checklist (TRSC), the Symptom Alleviation: Self-Care Methods tool, and a demographic and health information form.	40% or more of cancer patients reported the occurrence of 12 symptoms with greater severity: nausea, hair loss, feeling sluggish, loss of appetite, taste change, difficulty sleeping, depression, weight loss, difficulty concentrating, skin changes, constipation, and numb fingers/toes. More than a third of patients also reported pain, decreased interest in sexual activity, vomiting, cough, and sore throat. The helpful self-care strategies reported included lifestyle changes, diet and nutrition changes; and mind, body control, and spiritual activities. Patient report of cancer therapy-related symptoms was facilitated by the use of the TRSC. Patients reported use and effectiveness symptom alleviation strategies to relieve their cancer therapy-related symptoms.
Williams, et al., 2015 USA	To describe symptom occurrence and severity by U.S. Veterans at a cancer clinic as self- reported on the TRSC. To examine symptom alleviation strategies and self-care use, and the relationship between TRSC total scores and functional status (Karnofsky) and quality of life	A cross-sectional, descriptive design. Convenience sampling method was used. Study included 100 U.S. Veterans receiving chemotherapy for their cancer diagnosis at one Florida VA Med Center. Tools used were the TRSC, the SA: SCM (Symptom Alleviation: Self-Care Methods) tool, a Demographic tool, a Health Form, the Karnofsky Performance Status scale, and the	Thirteen symptoms were reported by more than 35% of participants. Top-ranked symptoms by percentage occurrence and severity as self-reported by participants was feeling sluggish, taste changes, nausea, pain, constipation, loss of appetite, numbness of fingers/toes, difficulty sleeping, weight loss, hair loss, difficulty concentrating, shortness of breath, and decreased interest in sexual activity. Symptom occurrence and severity had significant negative correlations with functional status and with the overall QOL.

Table 2 (continued).

Author, Year, Country	Objective	Methods	Findings
	(HRQOL).	HRQOL-LASA (a quality of life tool). All scales had good psychometric properties.	Self-care strategies successfully used for symptom alleviation were medicines, diet and nutrition, and lifestyle change. Checklist use (TRSC) facilitated patient-report of symptoms, and self-care strategies helped to relieve therapy-related symptoms.
Youngblood, Williams, et al., 1994 USA	To compare the symptoms reported on a self-report tool with symptoms documented in the patient's medical record. To correlate total scores and quality of life (QOL).	Ninety-one oncology patients from three outpatient cancer clinics participated in the study. Self-report instruments, The Oncology Treatment Toxicity Assessment Tool (OTTAT) with 37 items and the Quality of Life Index (QLI) with 18 items were used for data collection. The OTTAT is the precursor of the TRSC in instrument development.	The mean number of therapy-related symptoms reported by patients on the OTTAT was significantly higher than the number of symptoms documented in the medical record. Higher scores on the OTTAT were significantly related to lower scores on the Quality of Life Index (QLI).

Appendix A (continued).

Table 3

Selected Literature - Symptom Occurrence and Severity by Age Grouping

Author, Year, Country	**Objective**	**Methods**	**Findings**
Chang et al., 2011 USA	To compare adolescent and young adult (AYA) to cancer patients greater than 40 years old in a cohort by the severity of cancer, symptom burden, treatment status, symptom changes, and difficulty in caring for them.	Patients with invasive cancer of the breast, lung, prostate, or colon/rectum were enrolled from multiple community sites (*n*=32) and academic sites *(n*=6) and). Patients rated their symptoms at study enrollment and 4-5 weeks later on a 0-10 numerical rating scale with the MDASI-ECOG. Descriptive statistics, logistic regression models, and Fisher's exact test were used to summarize the findings.	168 (5.4%) of the 3106 evaluable patients were 40 years old or younger and were more likely to be female, and Hispanic. There were 114 pts with breast cancer (mean age 37.5 yrs), 44 colon cancer (mean age 36.2 yrs), nine patients with lung cancer, and 1 with prostate cancer. African-American patients were more likely to have advanced cancer stage at baseline. Multivariate logistic regression analysis showed that adolescent and young adult cancer patients were more likely to suffer moderate/severe distress, hair loss, fatigue, drowsiness and cognitive difficulties. While the number of symptoms was similar, AYA cancer patients reported more severe interference with a function for mood and relations with others. Symptoms were less likely to improve in adolescent and young adult patients, and this reached significance for distress. There were no significant differences in cancer stage, current treatment status and clinician's perception of difficulty in taking care of adolescent and young adult cancer patients.

Table 3 (continued).

Author, Year, Country	Objective	Methods	Findings
Mao et al., 2007 USA.	To examine the prevalence of ongoing symptom burden among cancer survivors and compare it with the general population without cancer	A population-based survey study. The study population was selected from all of the adults who participated in the 2002 National Health Interview Survey (NHIS). The sample consisted of cancer survivors (*n*=1,904), and general population controls (*n*=29,092). The survey was conducted both in English and Spanish. Main outcome measures included self-reported insomnia, ongoing pain, and psychological distress. Data analysis was conducted using logistic regression and bivariate analysis.	The rates of ongoing pain, psychological distress, and insomnia reported by cancer survivors were 34%, 26%, and 30%, respectively. Compared with control groups in the same age groups, younger survivors (younger than 50) were more likely to report ongoing symptoms compared to older survivors (older than 64); adjusted odds ratios for pain in the respective age groups were 2.96 and 1.36 (P<.001). Comorbidities contribute to a marked increase in reports of ongoing symptom burden and also found to interact with cancer status among cancer survivors. The Greater number of comorbidities contributes to the greater degree of symptom burden.
Kirchhoff et al., 2014 USA	To evaluate QOL outcomes for adolescent and young adult (AYA) cancer sur vivors relative to a non-cancer comparison group by age, gender, and race/ethnicity.	The 2009 Behavioral Risk Factor Surveillance System (BRFSS) data was used to identify sample for this study. Participants included 8375 individuals aged 15-39 years diagnosed with cancer and 334,759 controls. Participants included were currently ≥20 years of age. QOL was measured by four items from the Center for Disease Control's Healthy Days Measure (general health, the number of days of poor mental and	Survivors were more likely to report fair/poor general health than controls. QOL limitations existed by gender and race/ethnicity for survivors. Approximately 30% of cancer survivors who are currently in their 40s, 50s, and early 60s were in poor health, compared to less than 20% of same-aged controls (both p<0.001). 41.0% of survivors with two or more cancers reported poor health compared to 26.2% with one cancer (p<0.001).

Table 3 (continued).

Author, Year, Country	Objective	Methods	Findings
		physical health, and activity limitation days). The analysis was conducted using multivariable regressions.	
Kwak et al., 2013 USA	To examine prevalence and changes in psychological distress symptoms over one year after initial cancer diagnosis in adolescent and young adult (AYA) patients. Sociodemographic and clinical factors that may predict changes in distress were also examined.	Multisite, longitudinal, prospective study. Ethnically diverse patients (N=215) with age 14 to 39 years were assessed for psychological distress within the first four months of cancer diagnosis and again 6 and 12 months later. Psychological distress was measured by the Brief Symptom Inventory-18 (BSI-18). Linear mixed models and random intercept and slope were used to estimate changes in psychological distress.	60 respondents (28%) had BSI-18 scores indicating caseness for psychological distress within the first four months of cancer diagnosis. Psychological distress symptoms exceeded population norms at the time of diagnosis, decreased at the 6-month follow-up, but increased at the 12-month follow-up to a level exceeding population norms. A statistically significant decline was observed in psychological distress over one year; however, the gradient of change was not clinically significant. Multivariate analyses revealed that the decrease in psychological distress over time was primarily the result of being off cancer treatment and involved in school or work. Psychological distress was not associated with cancer type or severity.
Mohile et al., 2011. USA	To evaluate the relationship of age to symptoms and interference with daily function and quality of life (QOL) during radiation therapy (RT).	A prospective observational study conducted at a university-based radiation oncology department. Participants (*N*=903) included cancer patients who received radiation therapy (RT) for their cancer diagnosis. Data was collected using symptom inventory pre- and post- radiation therapy.	The mean age was 61 years (18–92), and 41% of participants were ≥65 years old. Older and younger patients reported that their symptoms worsened during radiation therapy. There were no significant differences in the change in total symptom burden and interference with quality of life between older and younger patients during radiation therapy. Younger patients reported significantly worse pain,

Table 3 (continued).

Author, Year, Country	Objective	Methods	Findings
		Patients reported ten symptoms and their interference with daily function and quality of life on a Likert scale from 0 to 10.	sleep disturbance, and nausea after radiation therapy. Older patients reported more severe symptom interference with walking. Mixed modeling showed that time of the survey, older age, and age time interaction increased the likelihood of reporting their symptoms interfered with walking.
Stava et al., 2006 USA	To collect more information concerning the consequences of surviving breast cancer patients who had been treated for their cancer disease.	Conducted a descriptive analysis of information obtained from cancer survivors. Medical and psychosocial responses of cancer survivors were analyzed and compared with those of age-matched responders in a national survey.	695 breast cancer women who participated in this study were <45 years old, 580 women were 46 -54 years old, and 655 women were age > 55 years at the time of their cancer diagnosis. Younger breast cancer survivors reported that they received chemotherapy more often than older survivors. Younger breast cancer survivors who received chemotherapy were more likely to report memory loss and reported that cancer affected their overall health adversely. Several other differences also identified in physiologic and psychosocial characteristics, such as interpersonal relationships.

Table 3 (continued).

Author, Year, Country	Objective	Methods	Findings
Williams et al., 2015 Thailand	To evaluate the use of the Therapy-Related Symptom Checklist for Children (TRSC-C; Thai version) for reported Symptom occurrence, severity, and management of treatment-related symptoms within a cohort of Thai pediatric oncology Patients and their parents	A cross-sectional, descriptive study. A convenience sample of 100 parents and children aged five months to 17 years receiving chemotherapy at the outpatient clinic and the inpatient unit of a pediatric national children's hospital and cancer center in Bangkok, Thailand, were enrolled. Parents reported children's symptom occurrence and severity on the TRSC-C; and complementary care methods and their symptom alleviation methods on the Symptom Alleviation: Self-Care Methods. All tools had good psychometric properties.	Symptom occurrence reported by parents on the checklist was high. 18 symptoms were occurred in 42% - 95% of children. Mean symptom severity was between 1 and 2. Children with age 5-month to 11-year had higher(worse) TRSC-C total scores. Complementary care was used and reported. The TRSC-C is found to be an appropriate and useful symptom checklist to monitor oncology symptoms, and his will help in management of pediatric patients in Thailand.

Appendix A (continued).

Table 4

Selected Literature - Review Articles

Author, Year, Country	**Objective**	**Findings**
Basch, 2014 USA	To discuss the rationale for collecting patient-reported symptoms during chemotherapy.	There is increasing interest to integrate patient-reported outcomes (PROs) into routine clinical practice, for example during chemotherapy or after surgery. Patient self-reporting improves symptom detection, patient-clinic communication, and symptom control. Patient-reported data also may be useful for quality assessment. Combined patient-reported data can be informative for comparative-effectiveness research (CER). An electronic collection of outcomes as self-reported by cancer patients alerts clinicians for important patient symptoms. Various systems are developed and used with these characteristics in oncology for patients' symptom collection.
Brown et al., 2009 USA	To examine evidence regarding associations of cancer-related fatigue with depression and anxiety.	Database searches yielded 59 studies reporting correlation coefficients or odds ratios. The combined sample size was 12,103. Almost all studies showed a correlation of cancer-related fatigue with depression and with anxiety. 31 different instruments were used to assess fatigue, suggesting a lack of consensus on measurement.
Bruce, 2004 USA	To review normal salivary function, effects of radiation on oral mucosa, the impact of xerostomia on quality of life (QOL), and current treatment strategies used to manage xerostomia.	Most patients receiving radiation therapy to the head and neck region will experience some type of oral complication. Xerostomia is one of the most severe, devastating symptoms reported by patients receiving radiation therapy and most of the time this may become a lifelong problem. Xerostomia affects multiple domains including QOL. Oncology nurses have a significant impact on patient outcomes through proper symptom assessment and education to manage their symptoms.
Carroll et al., 2007 USA	To conduct a literature review of clinical trials that assessed pharmacologic agents used for the treatment of cancer-related fatigue (CRF).	CRF is the most commonly reported cancer-related symptom, with a prevalence of over 60%. Pharmacologic agents used in the treatment of cancer-related fatigue (CRF) include psychostimulants, hematopoietic (for anemia), and corticosteroids. Other therapeutic agents that are not well studied, but are currently the focus of clinical trials include bupropion, l-carnitine, modafinil, and selective serotonin reuptake inhibitors such as paroxetine.

Table 4 (continued).

Author, Year, Country	Objective	Findings
Fingeret et al.,2013 USA	To identify key findings in the area of patient-reported outcomes related to breast reconstruction and introduce a theoretical framework for advancing research related to this field.	Researchers developed a theoretical framework illustrating core patient-reported outcomes and factors associated with these outcomes. This model identifies variables (disease and treatment-related factors, historical and premorbid influences) that influence patient-reported outcomes. The theoretical model highlights distinguishing features and domains of body image, patient satisfaction, and QOL for women with breast reconstruction. This study also examined the association between patient-reported outcomes and evaluation of breast reconstruction.
Grenade et al., 2014 USA	To describe influential biological factors, such as racial and ethnic differences in the pathogenesis and natural history of common malignancies.	Cancer disproportionately affects various racial and ethnic groups who are not well represented in experimental/clinical trials and post-marketing studies within the U.S. Pathogenesis of common cancers and outcomes from treatment are influenced by racial and ethnic differences and are a major concern. These disparities are caused by differences in genetics, environment, lifestyle, and tumor biology.
Hickey et al., 2009 Australia	To describe the current management of breast cancer in young women and the impact of treatment on reproductive function and subsequent management.	Chemotherapy for breast cancer negatively impacts patients' reproductive function. A number of interventions are available to increase the chance of successful future pregnancy; however, the safety of these interventions is not well studied. Women who do conceive following breast cancer, there is no good evidence that pregnancy is detrimental to survival. Current treatment modalities and its effects on reproductive function; preservation of fertility; contraception; pregnancy; breastfeeding and management of menopausal symptoms following breast cancer are reviewed in detail in this study.
Hofman et al., 2007 USA	To examine the prevalence of cancer-related fatigue (CRF) and to explore the impact of this distressing symptom on patients' functioning and the quality of life (QOL).	Cancer-related fatigue is reported by as many as 40% of patients at diagnosis and is an early symptom of the malignant disease. Almost all patients expect fatigue from cancer therapy. Up to 90% of patients treated with radiation therapy and up to 80% of patients treated with chemotherapy experience fatigue. The impact of CRF on a patient's QOL, specifically in relation to physical functioning and the activities of daily living, is found to be both pervasive and profound.

Table 4 (continued).

Author, Year, Country	Objective	Findings
		CRF may last for several months and even years after completion of the treatment. CRF is associated with psychological distress and may impose a significant financial burden due to patient's inability to work.
Kayle et al., 2006 USA	To highlight research on side effects of chemotherapy and the quality of life (QOL) concerns of women with breast and ovarian cancer.	Adjuvant chemotherapy has demonstrated successful management of ovarian and breast cancers. Women receiving chemotherapy will experience significant cognitive dysfunction and physical side effects, and this may negatively influence their QOL. Variables including disease response, treatment indication and patient's social support will also influence QOL ratings.
Keefe et al., 2007 Australia	To review the biomedical literature on mucositis published in English between January 2002 and May 2005 and to reach a consensus based on the criteria used by American Society of Clinical Oncology.	Changes in the guidelines include recommendations for the use of amifostine for radiation proctitis, palifermin for oral mucositis associated with stem cell transplantation, and cryotherapy for mucositis caused by high-dose melphalan. Recommendations against specific practices were introduced: Antimicrobial lozenges and sucralfate and were not useful for radiation-induced oral mucositis, and systemic glutamine was not recommended for the prevention of gastrointestinal mucositis, and. New guidelines suggested that in the transplantation population, granulocyte-macrophage-colony stimulating factor mouthwashes should not be used for prevention of oral mucositis. Advances in mucositis treatment have been achieved by an increased rate of publication on mucosal injury in cancer patients receiving treatments.
McQuestion, 2011 Canada	To report a clinical update on the available evidence for the prevention and management of radiation skin reactions (radiodermatitis).	Techniques used in radiation treatment are the most promising intervention in reducing the degree of skin reaction. Appropriate use of calendula cream may reduce the incidence of grade 2 or 3 reactions in breast cancer women. Even though deodorant use as part of routine hygiene is recommended now for practice, the disagreement related to the deodorant use in the radiation treatment field still continues in clinical settings.
Miltenburg et al., 2014 Netherlands	To describe the different drug-related characteristics of CIPN, pharmacogenomic	Chemotherapy-induced peripheral neuropathy (CIPN) is a potentially dose-limiting side effects of commonly used chemotherapeutic agents like vinca-alkaloids, taxanes, platinum compounds, bortezomib, and thalidomide. The exact pathophysiology is not clear.

Table 4 (continued).

Author, Year, Country	Objective	Findings
	studies, neuro-physiological findings, treatment and outcome, and neuroprotective strategies.	Different mechanisms of action have been proposed for various anti-cancer drugs. Pain, numbness, and tingling are most common sensory symptoms, but autonomic dysfunction, motor weakness, and cranial nerve involvement may occur. CIPN can be painful and disabling, and may lead to significant functional disabilities and decrease QOL. This lead to reductions in medication dose, discontinuation of treatment and may affect cancer survival. Schedule of cancer treatment, dose per cycle, duration of chemotherapy infusion, cumulative dose, administration of other chemotherapeutic agents, pre-existing peripheral neuropathy, and comorbidity, are the common risk factors for the CIPN.
Minton et al., 2011 United Kingdom	To examine and summarize the increasing evidence for the use of psychostimulants, particularly methylphenidate, in the treatment of cancer-related fatigue.	A systematic review was conducted from inception to the start of October 2009. Cross-referencing of cited abstracts and hand searching of relevant cancer journals were also conducted. A meta-analysis was conducted on five psycho-stimulant trials (n=426 participants). Several trials failed to determine any benefit over placebo. There were no significant differences in the frequency of adverse events between methylphenidate and placebo.
Minton et al., 2013 United Kingdom	To describe the contrasting European and American perspectives on cancer-related fatigue (CRF) and its impact on functioning in cancer survivors.	This study findings suggest the need for international consensus regarding the defining features of CRF in cancer survivors. This helps to identify phenotypes, a harmonized measurement of CRF outcomes using instruments that have demonstrated good measurement equivalence across cultures and languages, and interventions (including psychoeducational, exercise, and rehabilitation). Coordinated intercontinental efforts would increase understanding of the biological, psychological, and social mechanisms underlying cancer-related fatigue and assist in revisions to clinical guidelines and design future intervention studies.
Mitchell et al., 2006. USA	To review the etiology and evaluation of cancer-related fatigue (CRF) and to analyze current evidence supporting pharmacologic and non-pharmacologic techniques for its management.	Primary research reports and meta-analyses of quantitative studies of interventions for fatigue published in English were identified using Systematic database searches and were critically examined. Pharmacologic and non-pharmacologic techniques to manage CRF have been studied. Most of the evidence are from pilot studies with small sample sizes, rather than from adequately powered, multicenter, randomized controlled trials.

Table 4 (continued).

Author, Year, Country	Objective	Findings
Mols et al., 2014 Netherlands	To systematically review available literature concerning chemotherapy-induced peripheral neuropathy (CIPN) and quality of life (QOL) among cancer patients.	A computerized literature search was performed in December 2013. Articles were included if the study investigated CIPN and quality of life among cancer patients. The included studies differed by 1)patient population (ovarian, endometrial, cervical or breast cancer, lung, colorectal, acute lymphoblastic leukemia, lymphoma, or a mixed population), 2) the study design (19 prospective studies, five cross-sectional, one both prospective and cross-sectional), 3) number of patients in the study(ranging from 14 to 1643), and 4)ways to assess CIPN (subjectively, objectively, or both). 25 articles were selected and were subjected to a 13-item quality checklist conducted by two investigators. Of the 25 studies included, 11 assessed the association of CIPN on patients' QOL and CIPN is likely to associate negatively with QOL.
Morrow et al., 2005 USA	To examine the etiology, epidemiology, assessment, and management of Cancer-related fatigue (CRF).	Fatigue is one of the most commonly reported symptoms of cancer patients, with a prevalence rate of 60% or more in many studies. Cancer-related fatigue is a distressing symptom which causes a disturbance in patients' QOL and ability to carry out normal function on a daily basis. Any definition of cancer-related fatigue should include its important elements such as its persistence, pervasiveness, the effect on QOL, and its inability to be relieved by sleep or rest. All cancer patients should be assessed for fatigue, and individualized treatment options should be considered for patients experiencing excessive levels of fatigue. Treatment should be determined based on the underlying pathology when a specific cause has been identified (e.g., sleep disorder, anemia, depression, or metabolic disorder). Nonspecific therapies also may be useful in short- and long-term CRF management in many patients.
Muehlkbauer et al., 2009 USA	To discuss recommendations for management of chemotherapy- and radiotherapy-induced diarrhea.	Evidence supports pharmacologic interventions (loperamide and octreotide) and probiotics as recommendations for practice. Soluble fiber supplements are found to be effective for treatment of chemotherapy or radiotherapy induced diarrhea; however, additional research is needed as the type and dose of soluble fiber in treating and preventing these types of diarrhea are unknown.

Table 4 (continued).

Author, Year, Country	Objective	Findings
		Evidence supports pharmacologic interventions (loperamide and octreotide) and probiotics as recommendations for practice.
Mustian et al., 2007 USA	To provide an insight of current research on the relative merits of integrative non-pharmacologic behavioral interventions for the effective clinical management of cancer-related fatigue (CRF) and makes recommendations for future research.	Cancer-related fatigue (CRF) is a multi-faceted, debilitating, biopsychosocial symptom reported by the majority of cancer survivors during and after treatment. CRF begins after diagnosis and frequently even after treatments is finished, and during cancer remission. The etiological pathopsychophysiology underlying CRF is multi-factorial and not well defined. Mechanisms of development of CRF may include irregularities in neuromuscular function, abnormal accumulation of muscle metabolites, dysregulation of the homeostatic status of cytokines and serotonin, abnormal gene expression, inadequate ATP synthesis, abnormal vagal afferent nerve activation. Psychosocial mechanisms include expectancy, coping, self-efficacy, causal attributions, and social support. An important first step in the management of CRF is the identification and specific treatment of associated comorbidities, such as anemia, pain, hypothyroidism, emotional distress, malnutrition, insomnia, and other comorbidities.
Narayanan et al., 2009 India	To examine the etiopathogenesis and management strategies of fatigue in cancer	Fatigue is a common symptom of advanced cancer limiting one's activities of daily living and affecting the quality of life. Fatigue is a complex symptom with subjective and objective components, and its definition and assessment seem incomplete, and elusive. Components of fatigue often merge with comorbidities such as anemia, depression and so on, and it is difficult to Assess separately. Association of fatigue with treatment modalities like chemotherapy, radiotherapy along with the primary disease process makes it seemingly ubiquitous in many cancer cases.
Stubbe et al., 2013 USA	To discuss complementary strategies for the management of radiation therapy-related side effects.	Dose-limiting side effects of radiation therapy include mucositis, skin toxicity, diarrhea, and xerostomia. Cancer- and treatment-related fatigue is a common side effect that is not necessarily dose-limiting but considerably troublesome, and long lasting is. The CAM therapies that helps to relieve some of the radiation therapy-related side effects include psyllium, probiotics, melatonin, honey, acupuncture, exercise, and calendula.

Table 4 (continued).

Author, Year, Country	Objective	Findings
		Therapies that require more research or have been shown to be ineffective include aloe vera, glutamine, and deglycyrrhizinated licorice.
Weis, 2011 Germany	To discuss the concept of CRF, its assessment, pathogenesis, and treatment strategies.	One of the most distressing symptoms reported by the majority of patients is cancer-related fatigue (CRF), and its prevalence rates range from 59 to nearly 100% depending on the clinical status of cancer CRF is defined as the feeling of extraordinary weakness associated with a high level of distress, that is disproportionate to the patients' activity, and is not relieved by sleep or rest. The mechanisms for CRF are not yet completely understood, except that for chemotherapy-induced anemia. CRF may be influenced by multiple physiological and psycho-social factors. CRF has been shown as either a short-term side effect or a chronic long-term late effect. CRF is more distressing compared with other symptoms, such as pain or nausea, and often long lasting, with a strong negative impact on daily living and quality of life.
Worthington et al., 2011 United Kingdom	To examine the effectiveness of prophylactic agents for oral mucositis in cancer patients receiving treatments, compared with placebo, other potentially active interventions, or no treatment.	A total of 131 studies with 10,514 randomized participants is included. Ten interventions with more than one trial in the meta-analysis, showed some statistically significant evidence of a benefit for either preventing or reducing the severity of mucositis, compared to either a placebo or no treatment. These ten interventions were: aloe vera, granulocyte-colony stimulating factor (G-CSF), amifostine, cryotherapy, intravenous glutamine, keratinocyte growth factor, honey, laser, polymixin/tobramycin/amphotericin (PTA) antibiotic pastille/paste and sucralfate.

Appendix A (continued).

Table 5

Selected Literature Review: Interventions for Cancer Symptom Management

Author, Year, Country	**Objective**	**Methods**	**Findings**
Catlin, A., & Taylor-Ford, R. L. 2011. USA	To determine whether the provision of Reiki therapy during outpatient chemotherapy is associated with increased comfort and well-being.	Participants (N= 189) were randomized to actual Reiki, sham Reiki placebo, or standard care. Double-blind, randomized clinical controlled trial. Randomly assigned patients receiving chemotherapy into one of three groups. Patients' demographic information was collected using a demographic tool. Data was collected by pre-test and post-tests conducted before and after chemotherapy infusion.	Although Reiki therapy was statistically significant in raising the comfort and well-being of patients post-therapy, the sham Reiki placebo also was statistically significant. Patients in the standard care group did not experience changes in comfort and well-being during their infusion session.
Doorenbos et al., 2006 USA	To determine if age, sex, chronic health conditions (comorbidity), cancer stage, site of cancer, depressive symptomatology, and symptom limitations moderate the effects of the cognitive behavioral intervention on physical function. To determine if symptom limitations mediate the effect of the intervention on physical functioning.	This study was a 10-contact, 18-week randomized control trial. Two hundred thirty-seven individuals with solid tumor cancer (118 experimental and 119 control group) participated in this study. Data collection occurred by trained telephone interviewers using a computer-assisted telephone interviewing system. Interviews occurred at baseline and 10, 20, and 32 weeks. The experimental group received cognitive behavioral theory guided the nurse-delivered problem-solving experimental intervention. The control group received	Women with breast cancer had significantly higher physical functioning than lung cancer women. Symptom limitation, chronic health conditions, and depressive symptomatology at baseline were found to moderate the influence of the intervention on patients' physical function. The effect of the intervention on physical function was not found to be mediated by symptom limitation. The intervention was found to affect physical function trajectories differently based on individual patient's personal and health characteristics.

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
		conventional care. Interviews were conducted at baseline and 10, 20, and 32 weeks.	
Huebner, 2014 Germany	To evaluate the pilot phase of a lecture program on complementary and alternative medicine (CAM) for cancer patients.	The study included a lecture program for patients, followed by evidence-based recommendations on counseling on CAM. Samples consist of 460 patients and relatives. Participants received a standardized questionnaire and to collect data on demographic information, participants' experience with CAM, their satisfaction with CAM lecture, and needs for further information on CAM. Seven lectures on CAM were given in several German states in cooperation with regional branches of the German Cancer Society.	Forty-eight percent of participants formerly had used CAM. Most often named sources of information on CAM were print media (48 %) and the Internet (37 %). Most participants rated additional written information valuable. About one-third reported their interest to have an individual consultation about CAM. A standardized presentation of evidence on most often used CAM methods, along with recommendations on the self-care methods on symptom management, is highly appreciated. The concept of a highly interactive lecture presented in lay terminology is feasible and adequate.
Jeste et al., 2012 USA	To examine whether increased light exposure would have a positive effect on QOL of breast cancer patients during chemotherapy.	Women with stage I-III breast cancer (*N*=39) scheduled to receive ≥ 4 cycles of chemotherapy were randomly assigned to two treatment groups [dim red light (DRL, n = 16), or bright white light (BWL, n = 23)]. Light was administered via a light box. Data were collected at baseline and during cycles 1 and 4 of chemotherapy. Instruments used to assess QOL was the Functional Assessment of Cancer Therapy-Breast (FACT-B)	The DRL group had a significant decline in QOL during the treatment weeks of both cycles, whereas the bright white light group had no significant decline compared with baseline data. Mixed model analysis revealed that there was a group-by-time interaction for FOSQ at the fourth cycle treatment week, and was mediated by fatigue.

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
		and the Functional Outcomes of Sleep Questionnaire (FOSQ).	
Juarez et al., 2013 USA	Nueva Luz is a quality of life (QOL) intervention developed in English, and Spanish to identify the Latina breast cancer survivors' educational needs and to provide strategies to assist them in their transition into survivorship	A qualitative approach was utilized to evaluate the educational intervention (Nueva Luz). A purposive sample of eight Latina breast cancer survivors included in this study. The sample was selected from the group who received the intervention to participate in a digitally recorded interview. Data analysis was conducted using thematic analysis.	Findings showed that the one-on-one tailored approach is an acceptable and feasible method to provide a bilingual psychosocial intervention. Use of printed information (bilingual) in addition to the verbal education from a culturally competent bilingual healthcare provider can be effective in Latina breast cancer survivor's successful transition into survivorship. This also improves the patient outcomes and their quality of life.
McMillan, & Small, 2007 USA	To test an intervention designed for hospice caregivers to help them better manage symptoms experienced by patients with cancer.	Hospice home care cancer patients and their caregivers (*N*=329) were assigned randomly into three groups. 1) control group consisted of 109 patients receiving only standard care 2) a group (*n* = 111) receiving standard care plus the creativity, optimism, planning, expert (COPE) information intervention 3) group *(n* = 109) receiving standard care plus friendly visits. Caregivers received training in the COPE intervention over nine days to assist with symptom management.	No decrease was noted for symptom intensity for three target symptoms. However, symptom distress was significantly improved (p = 0.009) in the COPE intervention group compared with other two groups. No significant difference was found in QOL.

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
Molassiotis et al., 2007 United Kingdom	To assess the effects of acupressure and acupuncture in managing cancer-related fatigue and the feasibility of running a randomized trial with these two therapies in preparation for a large trial.	A randomized controlled trial. Cancer patients (*N*=47) who experienced moderate to severe fatigue were assigned randomly to an acupressure group (n=16), an acupuncture group (n=15), or a sham acupressure group (n=16). The acupuncture group received six 20-min sessions over two weeks. The patients in the acupressure groups were taught to massage or press the points, and they did it daily for two weeks on their own. Study instrument used for data collection was the Multidimensional Fatigue Inventory. Data collected at three different times (before randomization, at the end of the 2-week intervention and again about two weeks after the end of the intervention).	Significant improvements were found with regards to General fatigue (P<0.001), Activity (p=0.004), Physical fatigue (P=0.016), and Motivation (P=0.024). In the acupuncture group, there was a 36% improvement in fatigue levels at the end of the intervention, and the improvements were 19% for the acupressure group and 0.6% for the sham acupressure group. Lower improvements (22%, 15%, 7%, respectively) were noticed even two weeks after treatments. Acupuncture was a more effective method compared to acupressure or sham acupressure. The trial was methodologically feasible. Subjects needed a longer treatment period to obtain sustained results.
Sherman et al., 2012 USA	To evaluate the physical, emotional, and social adjustment of early-stage breast cancer women who received telephone counseling, psychoeducation by videotapes, or psychoeducation plus telephone counseling as	Randomized controlled clinical trial (*N*=249). Randomized patients either to the control group receiving usual care or to one of the three intervention groups. The interventions were administered at the diagnostic, post surgery, adjuvant therapy, and ongoing recovery phases. Mixed model analysis of variance was used for data analysis. Physical adjustment was measured by the incidence	Patients in all groups showed improvement over time in overall health, psychological well-being, and social adjustment. No significant group differences were found in physical adjustment, as measured by side effect incidence, severity, or overall health. Poorer emotional adjustment over time was found in the control group as compared to the intervention groups on the measure of side effect distress. There was a marked decline in psychological well-being for the telephone counseling group, from

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
	interventions that address women's needs during the diagnostic, post surgery, adjuvant therapy, and ongoing recovery phases of breast cancer.	of side effects and severity subscales of the Breast Cancer Treatment Response Inventory (BCTRI) and the Self-Rated Health Subscale of the Multilevel Assessment Instrument for the overall health status score. The emotional adjustment was measured by the psychological well-being subscale of the Profile of Adaptation to Life Clinical Scale, and the side effect distress subscale of BCTRI. Social adjustment was measured by the vocational, domestic, and social environments subscales of the Psychosocial Adjustment to Illness Scale.	the adjuvant therapy phase through the ongoing recovery phase. No significant group differences found in the social adjustment dimensions.
Sherwood et al., 2005 USA	To determine the effectiveness of a cognitive behavioral intervention in decreasing symptom severity in advanced cancer patients receiving chemotherapy.	A prospective randomized clinical trial based on cognitive behavioral theory. 124 patients 21 years of age or older were recruited. Newly diagnosed cognitively intact cancer patients receiving chemotherapy for stage III, stage IV, or recurrent cancer (solid tumor or non-Hodgkin lymphoma), and able to read and speak English were recruited in this study. Data collection was done by telephone interviews at baseline and 10 and 20 weeks after randomization. Experienced oncology nurses delivered a five-contact, eight-week intervention aimed at teaching patients problem-solving techniques to affect	Patients with lower baseline symptom severity and those in the experimental group had significantly lower symptom severity at 10 and 20 weeks. Findings showed that the symptom difference in the experimental group at 20 weeks occurred primarily in patients 60 years of age and younger. Depressive symptoms at baseline predicted symptom severity at 20 weeks. Age, gender, and site of cancer did not affect symptom severity at either time point.

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
		symptom severity.	
Williams et al., 2011 USA	To find the effect of a nursing intervention on cancer patients' symptom management.	A two-group repeated measure design used. The sample included 20 cancer patients (10 in the treatment group and 10 in the control group). Therapy-related symptom checklist (TRSC), Health-related quality of life linear analog self-assessment (HRQOL-LASA), Karnofsky performance status scale, and health form used for data collection. Teaching intervention provided and its effectiveness evaluated in post-test.	Patient education and nurse follow-up were associated with decreased patient self- reported symptom severity and possible improvement in health-related quality of life (HRQOL).
Williams et al., 2013 USA	To assess whether the use of a Therapy-Related Symptom Checklist (TRSC) in oncology outpatients increases the number of documented and managed symptoms and whether this help to improve patients' health-related quality of life (HRQOL).	This was a sequential cohort trial. Group 1 (G1) - Oncology outpatients (*n*=55) in treatment received standard of care. Group 2 (G2) - Another group of patients (n=58) received standard of care at the same clinic, and additionally answered the TRSC immediately before each consultation. Their TRSC results were shared with clinicians. Repeated measures (2-11 visits) were obtained of the patient-reported number of symptoms documented. Data included symptoms documented in medical records for G1 and TRSC for G2, HRQOL, and Karnofsky scores. Total 696 observations (328	Patients in group-2 had a 7.2% higher population averaged covariate-adjusted HRQOL than that of group1 patients. One hundred sixteen percent more covariate- and non-covariate-adjusted symptoms were documented and managed in group-2 by using TRSC than group-1 (6.14 symptoms vs. 2.84, P < .0001). The TRSC, HRQOL, and Karnofsky scores correlated r > 0.40.

Table 5 (continued).

Author, Year, Country	Objective	Methods	Findings
		G1 and 368 G2).The number of reported symptoms and HRQOL was covariate-adjusted using population-averaged generalized estimating equations.	
Yuen et al., 2006. USA	To evaluate the effectiveness of energy conservation training to help post-therapy cancer survivors in managing their fatigue.	Post-therapy cancer survivors (*N*=12) were randomly assigned to an energy conservation training (*n*=6) or usual care control (*n*=6). Participants in the intervention group received individual, face-to-face energy conservation training (1-2 hours) from an occupational therapist, and followed by once-a-week telephone monitoring sessions in the subsequent three weeks. Participants in the control group received standard care from their oncologist. Piper Fatigue Scale (PFS) was used for data collection.	Analysis of pre- and post-training data from the Piper Fatigue Scale (PFS) revealed significant reduction only in the sensory subscale of the PFS (Z = 2.21; p = 0.027) for the intervention group. There was no significant reduction in the four subscale or total scores of the PFS for the control group. Energy conservation training found to be a viable strategy for managing cancer-related fatigue. Findings demonstrate partial support for the effectiveness of energy conservation training in helping post-therapy cancer survivors manage their fatigue. Incorporating specific energy restoration strategies such as meditation and relaxation for future research may help advance the symptom management knowledge for post-therapy cancer survivors.

Appendix B

Subject Recruitment "Flyer"

Needed: Study Participants

My name is Jaimol Sreedhar, RN, at 1Pavilion, Lankenau Medical Center. I am conducting a research study on oncology adult patients as part of my Ph.D. in Nursing program.

- **Purpose** - To study cancer patient-reported symptoms during treatments, their quality of life, and the methods used to relieve the symptoms.
- **Procedure** – The data collector (myself) will explain the study before you are asked to sign a consent form. Then you will be asked to complete four checklists to report symptoms you experienced, your quality of life, and methods you used to alleviate the symptoms. You also will be asked some demographic information such as age and so forth. Some information from your medical record will be obtained also, such as type of treatment and date it was started, and so forth. All information kept securely, and are used only for the study.
- **Duration** - Completing the checklists will take about 30 minutes.
- **With the study results, we hope to be better able to help patients with cancer.**

Please contact RN/other clinical staff if interested (and for more information), or call me at phone # 484-535-1555.

Thank you for your kind assistance
Sincerely
Jaimol Sreedhar, RN, OCN, MA, MSN
Registered Nurse
1 Pavilion
Lankenau Medical Center.

Appendix C

Informed Consent

Study title: "Symptom occurrence, severity and quality of life as predicted by variables related to the cancer condition and selected demographic variables"

You are being asked to join a research study. You are being asked to take part in this study because you are currently receiving treatment for cancer at Mainline health system (MLH). This research study will take place at Mainline health system; the study is part of a course in the Ph.D. program of the School of Nursing at the Kansas University Medical Center (KUMC). The researcher is an oncology nurse at Lankenau Medical Center, Mrs. Jaimol Sreedhar, RN, MA, MSN, OCN, a graduate student at KUMC: her faculty advisor is Dr. Phoebe D. Williams, Ph.D., RN. About 110 persons at MLH will participate in the study.

You do not have to participate in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate. Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at MLH.

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research. You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

BACKGROUND

Cancer is a major public health problem in the United States. Patients during treatments for cancer often experience symptoms. Proper assessment of symptom occurrence and severity is key to proper treatment. Nurses play a critical role in assessing patients' symptoms to identify changes in occurrence and severity of symptoms, and quality of life over time. In this study, participants will use a checklist to self-report their symptoms, quality of life, and the self-care strategies used to manage the reported symptoms.

WHY IS THIS STUDY BEING DONE?

The major purpose of this study is to examine the relationships among selected demographic factors (or patient characteristics) and disease-related factors and the symptom occurrence and severity and quality of life as reported by participants. This study also aims to find out the self-care strategies used by participants to manage their symptoms. Study findings will help health care professionals to better assess and manage cancer patients' self-reported symptoms and thereby improve their quality of life.

WHO MAY TAKE PART IN THIS STUDY?

Men and women receiving chemotherapy only, radiation therapy only, or a combination of chemotherapy and radiation therapy for cancer treatments.

Appendix C (continued)

PROCEDURES

If you choose to participate in this study, you will be asked to complete questionnaires that report the symptoms you have experienced during your cancer treatment, and your quality of life. You will be asked also to fill out a form about your age, gender, marital status, education and ethnic background. The researcher, using the medical record, also will collect information about your diagnosis, cancer stage, other medical conditions, type of treatments and date treatment started, types of chemotherapy drugs, and dose, and so forth. You will also be asked to describe the self-care strategies you use to manage your reported symptoms. Your participation may take approximately 25-30 minutes. The usual care provided to oncology patients at Main line health system will be provided to you.

WHAT ARE THE RISKS ASSOCIATED WITH THIS STUDY?

There are minimal risks associated with filling out the questionnaires. You may find completing the questionnaires tiring, you may rest as needed and continue. If at any point you are not comfortable with any question, you may skip that question; or, you may stop participating altogether. You are free to give only the information you choose to, and all information will be maintained confidentially by the researcher.

ARE THERE ANY BENEFITS FOR ME IF I PARTICIPATE IN THIS STUDY?

You will not receive any direct benefit from completing the questionnaires. Future patients may benefit from proper symptom management during cancer treatments. Findings of this study may also help health care professionals to provide appropriate patient education and treatment to alleviate cancer therapy-related symptoms.

NEW FINDINGS STATEMENT

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

WHAT ARE MY ALTERNATIVES IF I DO NOT PARTICIPATE IN THIS STUDY?

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at Main line health system.

WILL THERE BE ANY COSTS TO ME TO TAKE PART IN THIS STUDY?

There is no cost for being in the study.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

There is no payment for participation.

Appendix C (continued)

IN THE EVENT OF INJURY

There is no risk of injury in joining the study as it only involves answering questionnaires/ questions.

INSTITUTIONAL DISCLAIMER STATEMENT

If you think you have been harmed as a result of participating in research at LMC you may contact Albert Keshgegian, MD, Ph.D., Chairman, Main Line Hospitals IRB at 484-476-3552, or Anne Marie Hobson, Director, Office of Regulatory Affairs at 484-476-2692.

CONFIDENTIALITY AND PRIVACY AUTHORIZATION

Every effort to preserve the confidentiality of information will be made. **There is a slight risk of loss of confidentiality.** Codes will be used for your name and the only persons having access to those codes will be the investigators. All information collected for the study will be kept in locked cabinet accessible only to the principal investigator. Data collected from the surveys will be available to the Principal Investigators, Main Line Health Institutional Review Board, any regulatory agency as required by law, and will be used (as aggregated data only) for publication, and presentation as applicable.

Your health information is protected by a federal privacy law called HIPAA. By signing this consent form, you are giving permission for Mainline health system to use and share your health information. If you decide not to sign the form, you cannot be in the study. The researchers will only use and share information that is needed for the study. To do the study, they will collect health information from the study activities and from your medical record. You may be identified by information such as name, address, phone, or other identifiers.

Your health information will be used at Mainline health system by Jaimol Sreedhar, the institutional review board at Mainline health system, the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies. Study records might be reviewed by government officials who oversee research if a regulatory review takes place.

All study information that is sent outside Mainline health system will have your name and other identifying characteristics removed so that your identity will not be known. Because identifiers will be removed, your health information will not be re-disclosed by outside persons or groups and will not lose its federal privacy protection. Your permission to use and share your health information remains in effect until the study is complete and the results are analyzed. After that time, researchers will remove personal information from study records.

QUESTIONS

Before you sign this form, Jaimol Sreedhar, RN, should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call Main Line Hospitals IRB at 484-476-3552.

Appendix C (continued)

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at Mainline health system. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

You have the right to cancel your permission for researchers to use your health information. If you want to cancel your permission, please write to Jaimol Sreedhar, RN. The mailing address is Lankenau Medical Center, 100 E. Lancaster Ave, Wynnewood, PA, 19096. If you cancel permission to use your health information, you will be withdrawn from the study. The research team will stop collecting any additional information about you. The research team may use and share information that was gathered before they received your cancelation.

CONSENT

Jaimol Sreedhar, RN, has given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

By signing this form, you say that you freely and voluntarily consent to participate in this research study. You have read the information and had your questions answered.

You will be given a signed copy of the consent form to keep for your records.

_____

Print Participant's Name

_____ _____

Participant's signature Date Time

_____

Print Name of Person Obtaining Consent

_____ _____

Signature of Person Obtaining Consent Date Time

Appendix D

MAIN LINE HOSPITALS
Authorization Form for Use and Disclosure of
Protected Health Information for Research

I authorize the use and/or disclosure of my individually identifiable private health information as described below. I understand that this authorization is voluntary and that if the organization authorized to receive this information is not a health plan or healthcare provider, the release of such information may no longer be protected by federal privacy regulations. I also understand that once this information is used and/or disclosed as stated in this authorization it may be subject to re-disclosure by the recipient(s) and may no longer be protected by federal privacy regulations.

Subject's Name _____

Title of Research: Symptom occurrence, severity and quality of life as predicted by variables related to the cancer condition and selected demographic variables

Principal Investigator: Jaimol Sreedhar RN, OCN, MA, MSN

MLH IRB File Number: _____

Person(s) or class of persons authorized to use and/or disclose the information:

Jaimol Sreedhar and Dr. Phoebe Williams, PhD Dissertation Advisor

Person(s) or class of persons authorized to receive the information:

Jaimol Sreedhar, and Dr. Phoebe Williams, PhD Dissertation Advisor

Description of the information that may be used and/or disclosed: (*please state clearly*)

1. Demographic data of participants include age, sex, ethnic background, education, and marital status.
2. Health information includes primary cancer diagnosis, number of co-morbidities, date treatment started, and treatment modalities
3. Patient reported symptoms as per Therapy Related Symptom Checklist (TRSC)
4. Quality of life of patients as measured by the Health- Related Quality of Life Linear Analogue Self Assessment (HRQOL-LASA) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C- 30 (EORTC QLQ-C30) tools.
4. Patient reported self-care strategies as per Symptom Alleviation: Self-care method (SA: SCM) tool.

The information will be used and/or disclosed for the following purpose(s*):*

Research Project as part of PhD program in University of Kansas School of Nursing.

Description of any information to be submitted to the health insurance plan of the research subject for reimbursement of costs of care associated with the study protocol.

N/A

Appendix D (continued)

MAIN LINE HOSPITALS
Authorization Form for Use and Disclosure of
Protected Health Information for Research

There is no expiration date for the use and/or disclosure of your protected health information.

I understand that I may revoke this authorization at any time in writing by completing the Main Line Hospitals Revocation of Authorization for Use and Disclosure of Protected Health Information Created for Research (MLHHPA Form 007). I understand that the disclosures made in good faith may have already occurred in reliance with this authorization and that a revocation cannot apply retroactively to such disclosures. I understand that if I revoke this authorization, I will no longer be eligible to participate in the study. I also understand that in the event I do revoke this authorization, it will not have any effect on my present or future medical care at Main Line Hospitals.

Uses and/or disclosures of protected health information may be made if (1) required by law, (2) the use and/or disclosure is necessary to prevent or lessen a serious and imminent threat to the health or safety of a person or the public, and (3) the disclosure is made to a person or persons reasonably able to prevent or lessen the threat, including the target of the threat to the health or safety of a person or the public.

I have the right to see and copy my personal health information related to this study. However, to ensure the scientific integrity of the research, I agree to wait until the conclusion of the study before exercising this right.

I authorize the use and/or disclosure of my individually identifiable private health information as described above. I will receive a copy of this signed authorization form.

Signature of Research Subject	Signature of Principal Investigator or person obtaining authorization
Date	Date

Leave Blank for Approval Stamp

APPROVED BY
MAIN LINE HOSPITALS
INSTITUTIONAL REVIEW BOARD
APPROVAL DATE

JAN 23 2015

Appendix E

THERAPY-RELATED SYMPTOMS CHECKLIST (TRSC)

ID# _____ Date: _____

DIRECTIONS: PLEASE **CHECK THE PROBLEMS** YOU HAVE HAD IMMEDIATELY AFTER AND SINCE YOUR LAST TREATMENT. PLEASE **CIRCLE HOW SEVERE** IT WAS ACCORDING TO THE FOLLOWING SCALE:

0=NONE 1=MILD 2=MODERATE 3=SEVERE 4=VERY SEVERE

EXAMPLE	**Degree of severity**				
Pain	0	1	2	3	4

Taste change	0	1	2	3	4
Loss of appetite	0	1	2	3	4
Nausea	0	1	2	3	4
Vomiting	0	1	2	3	4
Weight loss	0	1	2	3	4
Sore mouth	0	1	2	3	4
Cough	0	1	2	3	4
Sore throat	0	1	2	3	4
Difficulty swallowing	0	1	2	3	4
Jaw pain	0	1	2	3	4
Shortness of breath	0	1	2	3	4
Numbness in fingers and/or toes	0	1	2	3	4
Feeling sluggish	0	1	2	3	4
Depression	0	1	2	3	4
Difficulty concentrati	0	1	2	3	4
Fever	0	1	2	3	4
Bruising	0	1	2	3	4

Appendix E (continued)

Bleeding	0	1	2	3	4
Hair loss	0	1	2	3	4
Skin changes	0	1	2	3	4
Soreness in vein where chemotherapy was given	0	1	2	3	4
Difficulty sleeping	0	1	2	3	4
Pain	0	1	2	3	4
Decreased interest sexual activity	0	1	2	3	4
Constipation	0	1	2	3	4
Other problems (please list)					
----------	0	1	2	3	4
----------	0	1	2	3	4
----------	0	1	2	3	4
----------	0	1	2	3	4

Appendix F

Health-Related Quality of Life (HRQOL), Linear Analogue Self Assessment (LASA)

ID #: Date:

Directions: Please **circle the number (0-10)** best reflecting your response to the following that describes your feelings **during the last week, including today.**

A. How would you describe:

1. your overall Quality of Life?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

2. your overall mental (intellectual) well being?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

3. your overall physical well being?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

4. your overall emotional well being?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

5. your level of social activity?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

6. your overall spiritual well being?

0 1 2 3 4 5 6 7 8 9 10

As bad as it can be As good as it can be

Appendix G

PORTEC-3 Quality of life questionnaire PORTEC-3 trial number: |__|__|__|

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your first initial: |___|
Your birth date (Day, Month, Year): |__|__||__|__||__|__|__|__|
Today's date (Day, Month, Year): |__|__||__|__||__|__|__|__|

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Please go on to the next page

Appendix G (continued)

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you:

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

Appendix H

Symptom Alleviation: Self-Care Methods (SA: SCM) tool

ID# _____ Date: _____
Name: _____ Data Collector: _____

DIRECTIONS: PLEASE DESCRIBE THE **ALLEVIATION METHODS** USED FOR **EACH REPORTED PROBLEM**

	ALLEVIATION METHODS DONE *OR* USED (Please list below)	***How often Done?** 4, Very Often Done; 3, Often Done; 2, Done Occasionally; 1, Seldom Done;	**Did it Help?** (Yes/No)
Taste Change			
Loss of appetite			
Nausea			
Vomiting			
Weight loss			
Sore mouth			
Cough			
Sore throat			
Difficulty swallowing			
Jaw pain			
Shortness of breath			
Numbness in fingers and/or toes			
Feeling sluggish			

Appendix H (continued)

	ALLEVIATION METHODS DONE *OR* USED (Please list below)	***How often Done?** 4, Very Often Done; 3, Often Done; 2, Done Occasionally; 1, Seldom Done;	**Did it Help?** (Yes/No)
Difficulty concentrating			
Fever			
Bruising			
Bleeding			
Hair loss			
Skin changes			
Soreness in vein where chemotherapy given			
Difficulty sleeping			
Pain			
Decreased interest in sexual activity			
Constipation			
Other problems (please list below)			

***Rate *each alleviation method* used—then, each reported symptom would have a *mean* alleviation rating**

Appendix I

Demographic Data Form

ID #

1. Age: years

2. Gender:

- ☐ Male (1)
- ☐ Female (2)

3. Ethnic Background:

- ☐ White (1)
- ☐ African American/Black (2)
- ☐ Asian (3)
- ☐ Hispanic (4)
- ☐ Native American (5)
- ☐ Other (6)

4. Education:

- ☐ Elementary (1)
- ☐ High school diploma (2)
- ☐ College Degree (3)
- ☐ Post College Degree (4)

5. Marital Status:

- ☐ Married (1)
- ☐ Single (2)
- ☐ Widowed (3)
- ☐ Divorced (4)
- ☐ Other (5)

Appendix I (continued)

6. Economic Status

Annual Income

- ☐ < $ 30,000 (1)
- ☐ $ 30,000- $60,000 (2)
- ☐ $ 61,000- $90,000 (3)
- ☐ $91,000- $ 120,000 (4)
- ☐ >$ 120,000 (5)

Appendix J

Health Form, Karnofsky performance/Functional Status, and Medication Profile

ID #: Date:

1. Primary Cancer Diagnosis:

2. Stage of Disease (Circle): None---- I---- II---- III---- IV----

3. Comorbid Conditions: 1----------2----------3----------

4. Date treatment started:

Chemotherapy (1):

Radiation (2) :

Treatment Modality (Meds, Doses):

(1) Chemotherapy (Drugs/dosage):

(2) Radiation Dose (cGy):

(3) RT + Chemo (Drugs and Doses)

(4) Other (Specify):

Karnofsky Performance Status = _____

Appendix J (continued)

Karnofsky Performance Status Scale

Condition	Percentage	Comments
Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

Appendix K

IRB Approval Letter

LANKENAU INSTITUTE FOR MEDICAL RESEARCH

www.limr.org

100 E. Lancaster Avenue • Wynnewood, PA 19096 • p: 484.476.8400 • f: 484.476.8533

January 23, 2015

Jaimol Sreedhar, RN
Lankenau Medical Center
100 Lancaster Ave.
Wynnewood, PA 19096

RE: F/N-R15-3489BLP – Symptom occurrence, severity and quality of life as predicted by variables related to the cancer condition and selected demographic variables

Dear Ms. Sreedhar:

A research proposal to examine the relationship between cancer therapy-related symptom occurrence and severity and health-related quality of life and selected variables related to the cancer condition [diagnosis/stage, type of treatments, length of time since start of treatment, number of co-morbidities], and selected demographic variables [ethnicity, age, gender, marital status, education, economic status] was reviewed and approved by the Main Line Hospitals Institutional Review Board (MLH IRB) by expedited procedures in accordance with 45 CFR 46.110 (b)(1); Research Category 5 and 7 for a period of one year.

Please note the following information:

Unanticipated Problems: If any unanticipated problems involving risks to subjects or others occur during the consent if this study, you are required to notify the Main Line Hospitals Institutional Review Board via the Office of Research Affairs as soon as possible and in all cases, within 10 working days. When a death is unforeseen and indicated subjects or others are at and increased risk of harm, report 24 hours of knowledge of the event.

Amendments: If you wish to change any aspect of this study, e.g. procedures, consent forms, or an investigator(s), please submit the requested change on the appropriate forms to the Office of Research Affairs. Forms for requesting such changes are available at the Office of Research Affairs or at www.limr.org/ora. Please be aware that no change to an approved protocol can be implemented prior to Main Line Hospitals Institutional Review Board (MLH IRB) review/approval unless it is in the best interest of the subject.

Continuing Review: It is the investigators responsibility to apply for continuing review of ongoing research at least annually or more often if required by the sponsor or the MLH IRB. Forms for Continuing Review are available at the Office of Research Affairs or at www.limr.org/ora.

Completion of Study (Final Report): It is the investigators responsibility to notify the Main Line Hospitals Institutional Review Board via the Office of Research Affairs of the completion of the approved study following the appropriate submission procedures on the appropriate forms available from the Office of Research Affairs or at www.limr.org/ora.

Approval for this study will expire January 22, 2016. It is recommended that a Request for Continuing Review be submitted to the Office of Research Affairs by December 1, 2015 to avoid a delay in re-approval. A copy of the informed consent and HIPAA Authorization form with the approval stamp affixed are enclosed for use in the study.

As a reminder, the Main Line Hospitals Procedures for Compliance with Federal Regulations for the Protection of Human Subjects is available at the Office of Research Affairs or at www.limr.org/ora. If you change the experimental design of the research described above, please inform the Office of Research Affairs so a determination can be made if the change requires MLH IRB review.

This expedited action will be reported at the next meeting of the Main Line Hospitals Institutional Review Board IRB. Thank you for your continued cooperation. If you have any questions, please contact the Office of Research Affairs at 484-476-2678.

Sincerely,

Albert A. Keshgegian, M.D, PhD,
Chairman, Main Line Hospitals Institutional Review Board

"In Medicine, Hope Springs from Research"