2016

# Young Adults Adherence to Cancer Treatment as Compared to Older Adults

Laurie Ann Cox
*Walden University*

# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Laurie Cox

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Maria van Tilburg, Committee Chairperson, Psychology Faculty
Dr. Peggy Gallaher, Committee Member, Psychology Faculty
Dr. Rachel Piferi, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Abstract

# Young Adults Adherence to Cancer Treatment as Compared to Older Adults

by

Laurie Cox

MS, Illinois State University, 1998, 2000

BS, Illinois State University, 1992

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

PhD Health Psychology

Walden University

August 2016

# Abstract

As compared to pediatric and older adult cancer patients, young adults are the only oncology group that has not demonstrated an increase in survival rates. Low treatment adherence rates have been one explanation for this discrepancy, although this hypothesis has not been explored specifically. Guided by the biopsychosocial model of health and wellness, this study compared the treatment adherence rates of 46 young adult cancer patients (ages 18-39 years) to 46 older adult cancer patients (ages 40 years and older). Adherence was measured by a dichotomized variable, as yes/no, adhering to radiation treatment and follow-up appointments recommended by the physician, 95% of the time. Additionally, gender and race were explored in relationship to adherence to radiation treatment and follow-up appointments. Demographic data were first extracted from the Cancer Registry of a Midwestern Hospital. Then radiation appointments and follow-up appointments were examined for each patient, in paper and/or computerized charts, to determine adherence rates. McNemar's test was used to compare young adults and older adult oncology patients' adherence rates, and Chi-square analysis was used to explore gender and race in relationship to adherence. Results indicated a lower adherence rate to follow-up appointments for younger adults as compared to older adults, with older adults adhering 3 ½ times more than younger adults. Gender was also related to follow-up appointment adherence, with males adhering better than females. This study contributes to positive social change by increasing the knowledge base of healthcare providers on adherence rates of young adult patients and reducing the dollars spent on treatment for reoccurrences.

# Young Adults Adherence to Cancer Treatment as Compared to Older Adults

by

Laurie Cox

MS, Illinois State University, 2000

MS, Illinois State University, 1998

BS, Illinois State University, 1992

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
PhD Health Psychology

Walden University
August 2016

# Dedication

This paper is dedicated to my parents, William and Marilyn Cox, who died much too young from cancer. Their deaths at very early ages changed the course of my life, taking me on an unimaginable journey. I would also like to dedicate this paper to the many cancer patients who have accepted my help along their own journeys.

# Acknowledgments

I would like to thank my family and friends who have provided encouragement and support, and tolerated my frustrations during the course of writing this paper. I would also like to extend a thank you to my committee members at Walden University, Dr. Miranda Van Tilburg and Dr. Peggy Gallaher. Also a special thanks to the Institutional Review Board, Cancer Registry, and Commission on Cancer Committee of my research site.

Table of Contents

# List of Tables

_Toc456976440

# Chapter 1: Introduction to the Study

## Introduction

Young adulthood, or what is also referred to as early adulthood, is the period of development spanning from the 20s to the 30s, and it is characterized by peak physical strength (Wood, Green-Wood, & Boyd, 2011). During this time, individuals are working on achieving independence and assuming many new roles and responsibilities related to careers and family (Wood et al., 2011). It is a time of transition where educational goals are typically achieved, intimate relationships have developed, and individuals transition to parenthood. Whereas issues related to choosing a career, geographic relocations, and decisions about long-term commitments and childbearing are common development concerns (Hockenbury & Hockenbury, 2012), coping with a major health crisis, such as a cancer diagnosis, is not consistent with the developmental milestones of this stage. Although a young adult may still be influenced by parental input, their recent independence in the early years of young adulthood renders them responsible for their own decision making regarding many important issues in their lives, including those related to physical well-being.

According to data collected between 1975-2000 on the incidence rates of 3,224 invasive cancer cases per year per million of the U.S. population, for individuals aged 15-39 years, the incidence rates are higher for males than for females in the young adult group. Additionally, non-Hispanic Whites in this age range has the highest incidence rates, and African Americans/Blacks have the highest mortality rates for the under 40 age group (National Cancer Institute, 2006). The young adult population is the only group of cancer patients that has not shown improvements in survival rates over the past 2 decades, as compared to older adults and pediatric patients (National Cancer Institute, 2004). These numbers seem contradictory, given young adults are in peak physical shape at this stage.

The purpose of this study was to explore the relationship between age of cancer patients and their adherence to radiation treatments and follow-up. More specifically, I measured adherence rates to radiation treatments and follow-up appointments for young adult cancer patients, age 18-39 years, as compared to cancer patients, age 40 years and older. This study is relevant in that young adult cancer patients have not experienced the same increases in survival rates over the past 20 years as pediatric and older cancer patients (National Cancer Institute, 2004). Although there may be other factors that contribute to reduced survival rates for the young adult population, treatment adherence was the focus of this study due to the wide variation in adherence rates among young adults and the minimal studies exploring adherence in the young adult cancer population.

The social change implications of the study include an increase in the knowledge base on the behavioral factors that impact the lack of increased longevity for younger adult cancer patients, as compared to pediatric and older oncology patients. Furthermore, increased longevity in younger adult cancer patients would be expected to also have a positive impact on future generations (i.e., the offspring of cancer survivors), in addition to saving dollars in health care, insurance, and promoting further scientific inquiry.

In this chapter, I will present a background on the issue of medical adherence, the problem studied, the purpose of the study, and the research questions. The biopsychosocial model of wellness, which was the theoretical framework for the study, will also be discussed, in addition to the rationale for a quantitative design. Subsequent subsections of this chapter will include assumptions and limitations of the study and further explanation of the significance and social change implications of measuring adherence in young adult cancer patients.

## Background

Cancer is a diagnosis that can affect any person at any age. According to the American Cancer Society (2012), it was estimated that there will be at least 1,638,910 new cancer cases diagnosed in the United States alone. Although the risk of cancer increases with age, according to the National Cancer Institute (2004), there are 70,000 adolescents and young adults (ages 15-39 years of age) diagnosed with cancer each year. The 5-year survival rate for all cancers has increased to 67% between 2001-2007 with childhood cancer mortality rates decreasing by 66% over the past 40 years (American Cancer Society, 2012). However, whereas mortality rates have decreased for pediatric cancer patients and older adult oncology patients, adolescent and young adults (ages 15-39 years) have shown minimal improvement in survival over the past 20 years. In fact, the age range of 25-35 years has shown no evidence of improvement in survival. Additionally, although the 5-year survival for 15-29-year olds has increased overall 11% between 1975 and 1997, the average annual percent change in 5-year survival for the following age groups were as follows: 15-20 year age group (.90%), 20-25 year age group (.59%), 25-30 year age group (.03%), 30-35 years age group (.-18%), and 35-40 year age group (.23); (Bleyer, O'Leary, Barr, & Ries, 2006; National Cancer Institute, 2004). The lack of increased survival for the young adult population presented an opportunity for further exploration of this topic.

There have been several reasons cited for the lack of increased survival rates for the young adult cancer population. Martin et al. (2007) cited health insurance status and delays in diagnosis as explanations for this discrepancy in survival rates between age groups. Additionally, the National Cancer Institute (2004) cited several other reasons for the lack of increased survival rates in adolescent and young adult patients: (a) physician inconsistency in treatment and follow-up recommendations, (b) a lack of knowledge regarding the biological and etiologic differences in young adult cancer patients, (c) poor data collection on survival rates by cancer reporting agencies, (d) low participation in clinical trials for this age group, and (e) a lack of focus on prevention and early detection. Another factor that contributes to the lower survival rates for young adults is that certain cancers may be more aggressive in the young adult population (Bleyer, 2007). Furthermore, delays in treatment, coupled with delays in diagnosis, could account for the lack of improvements in survival rates for young adult cancer patients. Age differences may affect prompt treatment decisions. Meyer, Talbot, and Ranalli (2007) found that older males were more likely to make immediate treatment decisions than younger males when diagnosed with prostate cancer. Similarly, older female breast cancer patients are also more likely to make immediate treatment decisions (Meyer, Russo, & Talbot, 1995). Woodhead, Lynch, and Edelstein (2011) found that younger adults were more likely to use data-driven strategies for decision making in a hypothetical lung cancer scenario, whereas older adults were more likely to use an experience-based approach to decision making. Young adults may be using different decision-making strategies than older adults, thereby influencing adherence to treatments, which could affect survival rates.

Treatment adherence could also explain the lack of increased survival for the young adult population. The issue of medical adherence has been studied for some time. However, studies on young adulthood cancer treatment nonadherence rates are few and have found rates ranging from 1% (Mitchell et al., 2004) to 47% (Tebbi et al., 1986). According to Brannon and Feist (2004), adherence has been measured in six general ways in the literature: gathering information from the physician, self-report of the patient, collecting information from others, counting medications, examining biochemical substances, or a combination of the various measures. There are advantages and disadvantages to these adherence measuring strategies. For example, physician reports and self-reports are both subjective and have validity issues. Patient self-report measures may be prone to validity issues for several reasons (e.g., the patient does not want to appear noncompliant, memory issues). Medication counting can also be inaccurate (e.g., the patient may remove part of the medication to appear adherent). Biochemistry, on the other hand, can provide a more objective way of measuring adherence. However, not all treatments can be measured in this manner. Although all approaches have their disadvantages, the least valid approach is physician report.

In spite of the extensive study of medical adherence, I could not find any studies on radiation treatment adherence rates in young adult cancer patients as compared to older cancer patients. Radiation treatment adherence is important to survival rates of patients because patients must receive a specific dosage of radiation within a certain time frame in order to get the most benefit from the treatment. Any missed appointments potentially reduce the effectiveness of the treatment. The recommended adherence cutoff is typically 95% of the recommended dosage of radiation treatment, so that patients receive an appropriate amount of radiation in order to decrease tumor growth, improve prognosis, and thereby potentially increase survival (International Commission on Radiation Units and Measurement, 2014; Radiation Therapy Oncology Group, 2011).

## Theoretical Framework for the Study

The biopsychosocial model of health and wellness was the theory of inquiry for this study. According to the biopsychosocial approach, there is a complex interaction between biological, psychological, and social/cultural factors that can contribute to, or impede, health and wellness (Engel, 1977). According to this model, multiple factors, such as genetics, decision-making skills, self-efficacy, lifestyle factors, coping skills, group belongingness, access to health care, and stress management can help promote or impede health and wellness (Engel, 1992).

There are many biological, psychological, and social factors that could contribute to treatment adherence. For example, biological factors, such as stage of disease, might impact the follow through of patients. Furthermore, social factors, such as support system, and religious beliefs may also impact treatment adherence, whereas psychological factors, such as anxiety and depression, may also play a role (Brannon & Feist, 2004). Young adulthood is a stage of development spanning the years of 18-39. Individuals at this stage of development are different biologically, financially, socially, emotionally, and cognitively, as compared to older adults. Most young adults are in good to excellent physical health, but this age group is also more likely to engage in unhealthy lifestyle behaviors (such as smoking, drinking, other drug usage), which can have long-standing consequences (Dolinoy & Jirtle, 2008). In the early years of young adulthood, individuals are beginning to live independently, are more likely to live in poverty, and are less likely to have access to health insurance (Park, Mulye, Adams, Brindis, & Irwin, 2006). The brain also continues to develop into the early 20s. Mature thinking, characterized by being able to see gray areas, not just think in terms of black and white, gradually develops over young adulthood and middle age. Young adults are also more likely to blame themselves when a conflict arises (Blanchard-Fields & Norris, 1994). These biological, psychological, and social factors all have the potential to impact and interact with a young adult's decision making in following treatment recommendations and on their coping skills in dealing with an illness (Mor, Allen, & Malin, 1994; Stava, Lopez, & Vassilopoulou-Sellen, 2006). Therefore, measuring a behavior, such as treatment adherence, can have an impact on mortality, which is a biological factor. Hence, the biopsychosocial model of health and wellness was chosen as the framework for exploring adherence to radiation treatment and follow-ups to help explain the differences in survival rates for young adults as compared to older cancer patients.

## Problem Statement

Young adults have been the only population to not demonstrate an increase in survival rates for cancer over the past 2 decades, in spite of increases in survival for both pediatric and older oncology patients (American Cancer Society, 2012). Although several reasons have been cited as possible explanations for the low survival rates in young adults, the issue of treatment adherence has not been addressed in relationship to oncology patients in the young adult age group, and therefore, is a gap in the literature to consider. Additionally, in the studies that do exist on the young adult population, treatment adherence rates vary considerably from 53% (Tebbi et al., 1986) to 99% (Mitchell et al., 2004). Furthermore, many scholars have used small samples. Young adults are different in terms of health insurance status, financial stability, cognitive skills, and attitudes towards a healthy lifestyle compared to other age groups (Papalia, Duskin-Feldman, & Martorell, 2012). All of these factors may impact the young adult's ability to adhere to medical recommendations, which subsequently could affect survival rates. Race and gender are also linked to survival rates and may be related to other factors, such as socioeconomic status in the case of race, and financial stability in the case of gender. Therefore, adherence rates were explored in relationship to age, and gender and race was also investigated in relationship to treatment adherence.

## Purpose of the Study

The purpose of this study was to explore young adults (ages 18-39 years of age) adherence to cancer treatment, as compared to older cancer patients. Failure to adhere to treatment and follow-up appointment recommendations may help explain the lack of improved longevity rates for the young adult group, which appears to be an area that is understudied in the literature. The study was quantitative in nature, with the independent variable being age range (18-39 years vs. 40 years and older) and the dependent variables being adherence to radiation treatments and follow-up appointments. Gender and race were also be explored in relationship to treatment adherence. These variables were explored due to the established differences in survival rates for males and females and Blacks as compared to other groups (National Cancer Institute, 2004).

## Research Questions and Hypotheses

The biopsychosocial model of wellness was the foundation of the study. In this study, I explored the relationship between age range of the cancer patient and adherence to cancer radiation treatment recommendations and physician recommended follow-up appointments. The method for measuring adherence was determining whether patients adhered at least 95% of the time to the radiation treatment and follow-up appointments recommended by the physician. Several scholars have used similar approaches to measuring adherence (Cooper, Schultz, Simpkins, and Lafata, 2007; Stensvold et al., 2011; Weggelaar, Aben, Warle, Strobbe, & van Spronsen, 2011; Winkeljohn, 2010). However, researchers have not compared young adult cancer patients to older adult cancer patients in relationship to adherence to radiation and follow-up appointments. Measuring adherence rates of young adult cancer patients is important to increase the knowledge base of survival rates for young adults with cancer. Additionally, a better understanding of treatment adherence rates could lead to further studies on the reasons for the discrepancy and ways to improve adherence rates.

The following are the research questions and hypotheses for the study:

1. Is there a significant difference in radiation treatment adherence for young adult patients as compared to older adult oncology patients?

$H_0$1: Young adult oncology patients do not adhere to radiation treatment less than older adult oncology patients.

$H_1$1: Young adult oncology patients do adhere to radiation treatment less than older adult oncology patients.

2. Is there a difference between young adult cancer patients and older adult cancer patients, in terms of adherence to follow-up appointment recommendations?

$H_0$2: Young adult oncology patients do not adhere to follow-up appointments less than older adult oncology patients.

$H_1$2: Young adult oncology patients do adhere to follow-up appointments less than older adult oncology patients.

3. Does gender impact adherence to radiation treatment?

$H_0$3: There is no association between gender and radiation treatment adherence.

$H_1$3: There is an association between gender and radiation treatment adherence.

4. Does gender impact adherence to follow-up appointments?

$H_0$4: There is no association between gender and adherence to follow-up appointments.

$H_1$4: There is an association between gender and adherence to follow-up appointments.

5. Does race impact adherence rates to radiation treatment appointments?

$H_0$5: There is no association between race and radiation treatment adherence.

$H_1$5: There is an association between race and radiation treatment adherence.

6. Does race impact adherence to follow-up appointments?

$H_0$6: There is no association between race and adherence to follow-up appointments.

$H_1$6: There is an association between race and adherence to follow-up appointments.

The independent variable was age group (i.e., 18-39 years vs. 40 years and older), and the dependent variables were adherence to radiation treatments and follow-up appointments (i.e., operationally defined as either yes or no, the patient completed 95% of the radiation treatments and follow-up appointments on time as recommended by the physician). Race and gender were also explored in relationship to adherence to radiation and follow-up appointments.

## Nature of the Study

The research was quantitative and involved the secondary analysis of previously gathered data in order to measure the adherence of cancer patients. The data gathered included demographic information (i.e., age, gender, race) and treatment-related information (i.e., number of radiation treatments and follow-up appointments recommended by the physician, and number completed as recommended in order to determine if patient adhered at least 95% of the time).

The data were extracted from the Cancer Registry database of a Midwestern Hospital, with the assistance of the Cancer Registrar. The Cancer Registry gathers data from past and current oncology patients, both inpatient and outpatient, and the information is submitted to a national data base that cancer centers in the United States report to on a regular basis. Additionally, information was extracted from the patient charts, which lists radiation treatment and follow-up appointment recommendations and whether or not and when the patient followed through with the appointment and/or treatment recommendations.

Two groups of patients were requested from the registry data base. One group was between the ages of 18-39 and the other were 40 years of age and older. Patients were from a variety of ethnic backgrounds, with the expectancy that there would be a larger than national average Hispanic population due to the location of the hospital.

The cancer registrar selected the 46 available cases from the young adult age group and then matched 46 older adult oncology patients on race, gender, and diagnosis. Because the software does not have the capability to randomly select a single matched case, when there were multiple options in the older adult group, one case was randomly selected from those available. Forty-six cases were chosen due to the limited number of young adult cases available. This number still represented over sampling to account for missed data which could have required cases be eliminated from the study. Patient charts were then reviewed to determine how many radiation treatments were recommended by the physician and how many were completed as recommended by the physician. Additionally, data regarding the recommended follow-up dates and the number completed on time by the patient, as compared to how many were cancelled or postponed by the patient was collected.

The age of 39 years was chosen as a cut-off age because major organizations, such as the National Cancer Institute, use this as the cut-off for the classification of young adult cancer patients (National Cancer Institute, 2004). The following are a description of the main variables which were explored: (a) treatment recommendations: number of radiation treatment recommended vs. number of radiation treatments completed. Radiation treatment appointments were selected as the variable because of the set number of consecutive appointments each patient is prescribed at the onset of treatment and the clear documentation of attendance in the patient files. Chemotherapy adherence, on the other hand, would be much more difficult to monitor due to the length of time the patient may receive treatment and the increased likelihood of other variables that may contribute to postponed treatments (e.g., side effects, low blood counts, changes in chemotherapy agents). Adherence to radiation treatment was considered as yes if the patient completed 95% of the appointments as recommended; (b) frequency of follow-ups: number of follow-up appointments recommended by physician and number of radiation treatment follow-up appointments completed and number missed or postponed by patient. Adherence was considered as yes if the patient completed 95% of their follow-up appointments as recommended; (c) gender: categorized as either male or female; (d) race: categorized as minority or White/Non-Hispanic

Only those patients who had started radiation treatment, not those who had refused treatment, were included in the study. This is because those who refused treatment would have qualified as 100% nonadherent and thus would be outliers. In the event that there were participants who were selected for the sample and refused to follow through with treatment, they were labeled as outliers and were not included in the data analysis.

## Scope and Delimitations

In this study, I explored treatment adherence rates of young adult oncology patients as an explanation for the lack of increase in survival rates for this population, as compared to pediatric and older adult oncology patients. Adherence was chosen as the focus of the study after I observed what appeared to be a significant difference in the young adult population's compliance with radiation treatment and follow-up appointments. However, there were delimitations in the study. I only looked at adherence to radiation treatment as an explanation for the lack of increased survival in the young adult population, and I did not include adherence to other types of treatment (e.g., chemotherapy, surgery).

The biopsychosocial model was chosen as the foundation of the study because it is a more inclusive model for exploring health-related issues, examining biological, psychological, and social factors in explaining disease outcome. For example, the model could predict whether behavioral factors (e.g., nonadherent behavior) affected biological factors (such as cancer outcome or death). The method and dataset were chosen because a quantitative study is a more accurate reflection of adherence rates as opposed to a qualitative study. Additionally, by using de-identified existing data, I removed subject burden and the potential for revealing of identity.

## Assumptions and Limitations

This study was based on the assumption that the demographic data and treatment attendance were entered correctly into the patient's electronic and paper chart files. Given that humans are not infallible, there is always the possibility of errors in the data collection, and because some of the data were not directly collected by me, there was no way of knowing this. Additionally, the data were secondary in nature and were not gathered for the purpose of this study; therefore, it may not be collected in a way that is best for the purposes of this study. In addition, missing data was also a potential issue.

One limitation of this particular study relates to generalizability. This study cannot be generalized to the U.S. population as a whole, as the community sample is likely not representative of the United States in terms of ethnicity, socioeconomic status, or educational level. Another limitation of this study was that I only addressed radiation treatment adherence, as opposed to other treatments, such as chemotherapy and surgery. Radiation treatments were chosen as a measure of adherence, due to the ability to quantify the attendance and completion of treatment sessions more easily, than chemotherapy appointments. This is due to the nature of the documentation in the charts (i.e., they are recorded more as an attendance record) and because radiation treatments are typically done consecutively, 5 days a week, as opposed to chemotherapy treatments, which may have weeks between treatments, and the potential for postponing due to other issues (e.g., low blood counts, side effects, changes in chemotherapy agents).

Another limitation of the study was that adherence was only measured at one hospital. Therefore, it was unclear as to whether or not individuals who dropped out of treatment, and were considered nonadherent, possibly continued treatment at another facility. However, the number of participants for which this latter issue might apply was likely minimal, and every attempt was made to clarify if this was the case.

## Significance

Whereas health insurance status, the lack of immediacy in making treatment decisions, and other factors have been explored as explanations for the lack of increased survival for younger adults, consistency and follow through in treatment does not appear to have been explored in relationship to this issue with younger cancer patients. As an oncology counselor/art therapist for the past 6 years, I have noticed that the younger patients do not follow through with treatment recommendations and follow-ups as consistently as the older patients. Therefore, I was interested in exploring the differences between younger adult cancer patients (ages 18-39) and older adult cancer patients (ages 40 and older) and their adherence to treatment recommendations and follow-up appointments to help determine if what I was seeing anecdotally was supported by scientific inquiry. Identification of a difference could have an impact on future studies, in that it would make cancer treatment adherence a focus of future studies in terms of exploring why adherence rates are low and identifying ways to increase treatment adherence.

The results of this study could provide additional knowledge on the behavioral factors that impact the lack of increased longevity for younger adult cancer patients, as compared to pediatric and older oncology patients. Furthermore, increased longevity in younger adult cancer patients would be expected to also have a positive impact on future generations (i.e., longer survival rates for young adult cancer patients could have positive benefits for the offspring of the patient, in that children are not having to deal with the loss of a parent before they are developmentally ready to cope with such a loss).

Additionally, a better understanding of adherence rates for young adults has implications for future scientific inquiry which could focus on understanding the reasons for low adherence rates and ways to increase adherence. This, in turn, has practical applications of improving the adherence rates of this population, thereby improving health by reducing the chance of disease reoccurrences or metastatic disease, which could lead to disabling effects, and saving money for not only insurance vendors, but also patients and their families.

## Summary

Young adulthood is a stage of development typically characterized by many changes, both occupationally and relationally. It is also a stage of peak physical strength. However, it is not a stage where individuals typically prepare themselves to deal with a major health crisis, such as a cancer diagnosis. There have been several explanations as to why young adults have been the only age group over the past 2 decades that have not shown an improvement in cancer survival rates (National Cancer Institute, 2004). Insurance status, poor data collection by agencies reporting cancer statistics, inconsistent treatment and follow-up recommendations, limited knowledge regarding the biological and etiologic differences in young adult cancer patients, poor clinical trial participation, and a lack of focus on prevention and early detection are just some of the areas that have been cited as reasons for this discrepancy (National Cancer Institute, 2004).

In this study, however, I focused on significantly lower adherence rates to radiation treatment and follow-up appointments as a potential explanation for the limited change in survival rates for young adult cancer patients over the past 20 years. I used the biopsychosocial model of health and wellness as a foundation for comparing the radiation treatment and follow-up appointment adherence rates of young adult cancer patients (ages 18-39 years) to older cancer patients' (ages 40 and above) adherence rates. Quantitative data were gathered from the Cancer Registry database and patient charts of a Midwestern community hospital cancer care center. The study was retrospective in nature. The demographic variables of race and gender were also explored in relationship to the adherence rates.

Chapter 2 provides a synopsis of the most recent literature related the developmental stage of young adulthood, the young adult cancer research, treatment adherence, in addition to gender and race in relationship to survival rates. Additionally, studies related to coping styles and decision-making strategies in relationship to age and the diagnosis of cancer are reviewed. Furthermore, the biopsychosocial model of health and wellness is discussed in more detail.

# Chapter 2: Literature Review

## Introduction

Cancer, which is a leading cause of death, affects individuals of all ages. In the United States alone, it was estimated that there will be at least 1,638,910 new cancer cases diagnosed each year (American Cancer Society, 2012). Of these newly diagnosed cases, 70,000 (approximately 4%) will be adolescents and young adults between the ages 15-39 years (National Cancer Institute, 2004). Survival rates are of great interest when discussing cancer and are continually being reported for the cancer population. Whereas the 5-year survival rate for all cancers has increased from 49% in 1975-1977 to 67% (2001-2007), and childhood cancer mortality rates have decreased by 66% over the past 40 years, adolescent and young adults (ages 15-39 years) have shown minimal improvement in survival over the past 20 years (American Cancer Society, 2012). The age range of 25-35 years has shown no evidence of improvement in survival (National Cancer Institute, 2004). Additionally, a study conducted in England showed limited improvements in survival rates for some diagnostic groups in the 13-24 year age cancer population (Geraci et al., 2009). However, this increase appears to vary according to region and did not appear to be related to socioeconomic status. Furthermore, the overall 5-year survival rate for the young adult cancer population in England during the time of the study was 55%, which was considerably less than the survival rate of pediatric patients, which was 83% (Geraci, et al., 2009). Survival rates for young adults are not only a concern in North America, but also in England.

Scholars who examine factors related to survival are plentiful. According to Miller, To, Baines, and Wall (2002), the success in improving survival rates for some age groups, has been credited to improvements in screening, particularly mammography, adjuvant chemotherapy and hormonal therapy advancements, in addition to treatment guidelines for early stage cancers. Improved diagnostic and treatment guidelines, particularly, at the early stages of diagnosis, could potentially improve prognosis and survival rates.

Although several variables have been explored to explain the lack of improvement in survival rates for the young adult age range, there appears to be a gap in the literature in regards to exploring adherence rates for different young adult age ranges. The purpose of this chapter is to provide a review of the most recent literature related to cancer survival and to demonstrate a gap in the literature as it relates to comparing young adulthood age groups and cancer treatment adherence. Initially, survival as it relates to gender and race will be discussed, followed by a description of the biopsychosocial model of health and wellness as compared to the biomedical model. Subsequently, there will be a discussion of the developmental milestones of young adulthood, followed by a literature review of young adults with cancer as it relates to the lack of increased survival rates in young adult cancer patients. Additionally, a discussion of the most common cancer diagnoses in the young adult population, in addition to risk factors and cancer staging, will be discussed. Treatment adherence as it relates to the biopsychosocial model of health and wellness will be discussed, followed by a review of the treatment adherence literature. In the final section, strategies for increasing treatment adherence will be discussed.

## Literature Search Strategy

A literature search was conducted electronically in the psychology and medical databases such as PsycARTICLES, PsycInfo, MEDLINE, and CINAHL through the Walden University and Elgin Community College EbscoHost library databases. Search terms included the following: *treatment adherence and cancer*, *cancer treatment adherence and young adults*, *treatment adherence and young adults*, *adherence and young adults*, *young adulthood and treatment adherence*, *young adults and cancer*, *biological factors and treatment adherence*, *psychological factors and treatment adherence*, *sociological factors and treatment adherence*, *survival rates in young adulthood*, and the *biomedical and biopsychosocial models of health and wellness*. Additionally, other sources were reviewed, such as data from the National Cancer Institute, the American Cancer Society, and the National Comprehensive Cancer Network. Google Scholar and PubMed databases were also accessed for articles. Additionally, articles of relevance that were referenced in the primary sources were also accessed and reviewed.

## Theoretical Foundation/Conceptual Framework

According to the biopsychosocial model (Engel, 1992), health and wellness is not only related to biological factors, but also can be attributed to psychological and social factors. Psychological factors include such personality traits as locus of control, coping skills, defense mechanisms, self-efficacy, decision making, and adherence to medical advice, while sociological factors include such variables as socioeconomic status, ethnicity, and group belongingness (Engel, 1992). According to the theory, these psychological and sociological factors interact with biological factors (e.g., genetics, age, vulnerability to stress, nutrition, exercise, brain maturation) to produce health or disease (Brannon & Feist, 2004; Green & Shellenberger, 1990).

Engel (1992) is the person most closely associated with the biopsychosocial model. The biopsychosocial model is an inclusive model for explaining disease. Whereas biological factors may account for the onset of the disease, psychological and social factors impact when the person actually begins to feel ill, when he or she accepts him or herself as being ill, and when he or she enters the health care system. The patient and the social context in which he or she lives, and the role of the physician and the entire health care system, should be taken into consideration when treating illness and disease (Engel, 1997). Additionally, according to Engel (2005), any information communicated, either verbally or nonverbally by the patient to the physician, qualifies as psychosocial. Furthermore, Engel (2005) believed that a successful biopsychosocial approach requires the physician to understand how the symptoms are integrated into the content of the patient's life.

The biopsychosocial model's roots are the biomedical model, a model that had dominated research, education, and modern medicine for over a century. The biomedical model is a scientific model with molecular biology roots and focuses on a more uni-linear concept of etiology (Engel, 1992). Proponents of this view see disease as being solely due to biological variables and believe that the disease must be, therefore, treated biologically (Engel, 1992). The model gives autonomous power to the physician as the primary care provider. The biomedical model is also reductionistic (i.e., there is a single primary explanation for disease) and dualistic in nature (i.e., the mind and body are separates entities). The biomedical model is also exclusionistic in that it implies that any issue that cannot be explained in terms of biochemistry should be excluded from the category of disease (Engel, 1992). However, the exclusion of psychosocial factors in explaining disease not only distorts what qualifies as disease, but also interferes with patient care (Engel, 1992). Therefore, a biopsychosocial model is a more inclusive model for examining illness and disease.

Regardless of a person's developmental stage in the lifespan, there are biological, psychological, and sociological factors that may impede or improve health and wellness. The stage of young adulthood, which will be the primary focus of this chapter, will be discussed next.

## Young Adulthood

Young adulthood is a stage characterized by many changes in career, work, relationships, and childbearing. Young adults are transitioning into careers and the workforce, making decisions about a long-term partnership with a significant other, in addition to starting families. Throughout the entire stage of young adulthood, which spans 18-39 years of age, a person can have more than one career, give birth to children, and begin the process of helping their own children establish their own identity and choose a career. However, some young adults are waiting longer to leave their family of origin and start their own careers and families (Benson, Kirkpatrick Johnson, & Elder, 2011). Typically, it is a stage characterized by growth, not coping with major illnesses.

Young adults present with their own set of physiological, psychological, and sociological characteristics. In addition to being in a stage of transition, early young adulthood, along with adolescence, has been described as a stage of risk taking behavior. Risky behaviors during these stages can lead to social, economic, and public health issues (Romer, 2003). Adolescents and young adults are responsible for a larger proportion of crime, more deadly vehicular crashes, and more newly diagnosed cases of HIV-Aids (Romer, 2003). Furthermore, this population is more likely to engage in unhealthy habits, such as smoking cigarettes, drinking alcohol, using drugs, and having a poor diet, which have an impact on longevity in later adulthood (Romer, 2003). Reyna et al. (2011) found that the 18-21-year-old age group is especially prone to sensation seeking behaviors. However, this is due to feelings of being invulnerable or being unconcerned about potential risks (Steinberg, 2007), but due to poor impulse control and emotional regulation and the inability to resist peer pressure and delay gratification; these characteristics appear to be tied to neurobiological maturation, particularly the limbic system and prefrontal cortex (Steinberg, 2007). These two areas gradually mature over the course of adolescence and early young adulthood (Steinberg, 2007). Additionally, a reduction in parental monitoring and increased peer contact also may play a role in early young adulthood health risk behaviors (Fisher & Feldman, 1998). Therefore, young adults may find themselves engaging in unhealthy behaviors which may contribute to, or exacerbate, a major illness or injury.

## Young Adults with Cancer

Although the main causal factor for death in young adults is accidental, cancer is the most common natural cause of death among this population (Albritton & Bleyer, 2003). Therefore, it is important to have an understanding of young adults with cancer. Haase and Phillips (2004) described adolescents/young adults with cancer as an invisible population for three reasons: (a) adolescents/young adults are not distinguished from children and older adults in the literature, (b) this age group rarely receives care in an appropriate setting (i.e., they are treated in pediatric or adult oncology treatment centers), and (c) there is a lack of understanding regarding adolescents/young adults lack of commitment to treatment. Additionally, although developmental theories are often applied to understanding cancer, the discussion does not include the possibility of a serious illness during the developmental stage of young adulthood (Sunmi, 2001), which could potentially contribute to late diagnosis.

The cancer spectrum is much different for the adolescent/young adult population as compared to the pediatric and middle aged/older adult population. The most commonly diagnosed malignancies in adolescent and young adult cancer patients, aged 15-39 years of age, are lymphomas, genitourinary and gastrointestinal carcinomas, leukemias, and melanomas (Holland, 2009). Whereas embryonal tumors are more common in children younger than 15 year of age, adults, 40 years of age and older, are primarily diagnosed with lung, prostate, breast, and colorectal cancers (Bleyer et al., 2008). Some of the cancers more likely diagnosed in young adulthood (e.g., melanomas) tend to be more aggressive than other cancers (National Cancer Institute, 2004). The primary cancers for females, ages 15-39 years of age, are breast (20.4%) and thyroid carcinomas (14.6%), melanoma (9.5%), carcinomas of the cervix and uterus (9.1%), Hodgkins lymphoma (3.7%), and carcinoma of the colon and rectum (3.4%); (National Cancer Institute, 2004). For males in this age group, the primary cancers are gonadal germ cell tumors (10.1%), melanoma (5.5%), non-Hodgkin's lymphoma (4.7%), carcinoma of the colon and rectum (3.6%), and thyroid carcinoma (2.9%) as reported by the National Cancer Institute (2010). According to the National Comprehensive Cancer Network (NCCN) colon cancer for this population tends to be at the more advanced stage at time of diagnosis, and there is an increased risk for additional malignant tumors (2012). The cancer diagnosis, therefore, may impact survival rates for this population. Additionally, there is a need for early detection with more aggressive forms of cancer.

## Risk Factors for Cancer in Young Adults

There appears is little evidence of a single common genetic component for developing cancer prior to age 30 (NCCN, 2012), and there are no identified risk factors for all cancers diagnosed for the 15-29-year-old age range (Bleyer, Viny, & Barr, 2006). However, young adults are at increased risk of developing a secondary malignancy due to chemotherapy and radiation exposure if they have a childhood cancer history. Additionally, maternal exposure to diethylstilbestrol (DES), a drug given to pregnant women in the past, increases the chance of vaginal and cervical cancers in offspring (Bleyer et al., 2006). Other risk factors include exposure to ultraviolet light and contracting the human papillomavirus (HPV), the latter which is a risk factor for cervical Carcinoma (NCCN, 2012). The Epstein-Barr infection and HIV are also risk factors for

Hodgkin's lymphoma and Kaposi Sarcoma and non-Hodgkin's lymphoma (NCCN, 2012).

Breast cancer is also more likely to occur in young adults when they possess the BRCA-1, BRCA2, and TP53 genetic mutation (National Cancer Institute, 2004) or they have received radiation for Hodgkin's lymphoma. Inflammatory bowel disease and radiation exposure are also risk factors for colorectal cancers in this age group (National Cancer Institute, 2004). Young adults may also possess a genetic mutation, referred to as Lynch syndrome, which is associated with colon cancer (Alman, Pajerski, Diaz-Cano, Corby, & Wolfe, 1997). There are also genetic mutations associated with the development of sarcomas in the young adult population (NCCN, 2012). Although, there is no single explanation for the development of cancer in the young adult population, there are some risk factors associated with developing specific cancers and secondary malignant tumors.

## Cancer Staging

The stage at which a person is diagnosed can also impact survival rates. Cancer staging is designed to describe the severity of the disease. Staging also assists in treatment planning and determining prognosis. Staging is determined by physical examination; pathology and laboratory reports; imaging techniques such as computerized axial tomography, magnetic resonance imaging, and positron emission tomography; in addition to surgical biopsies (National Cancer Institute, 2010). Staging involves identifying the site, size, and number of the primary tumor(s), whether or not there is lymph node involvement, the cell type and the degree to which it resembles normal tissue (i.e., grade), and whether or not the disease is localized or systemic (i.e., metastasized; National Cancer Institute, 2010). The current staging process is the TNM system (National Cancer Institute, 2010). T is indicative of the tumor size, N indicates whether or not the cancer has spread to the nearby lymph nodes, and M refers to whether distant metastasize has occurred (National Cancer Institute, 2010). Tumors are described as being in stage 0-IV, with IV being the most serious.

Based upon the staging of the disease, physicians use statistical data in order to provide a prognosis for the patient. A prognosis is an estimation of the outcome of the disease for the patient, with and without treatment (National Cancer Institute, 2010). Many factors can impact the prognosis, such as type and location of the tumor, size of the tumor, how quickly the tumor is growing, age, presence or absence of comorbid disease, the response to treatment, and the patient's adherence to the treatment regimen (National Cancer Institute, 2010). Cancer diagnosis and staging both influence treatment regimens, which will be discussed next.

## Treatment Regimens

Adolescent/young adult patients are more tolerant of intense therapies due to their decreased likelihood of having co morbidities, as compared to older patients. Although dose intensive treatment is associated with more positive outcomes, treatment effects must be closely monitored to avoid permanent organ damage (NCCN, 2012). The primary treatment options for the young adult cancer population are surgery, radiation therapy, chemotherapy, and stem cell transplantation (NCCN, 2012). Surgery is more tolerable for the young adult population, as opposed to pediatric and adolescent patients, because their bodies are fully developed. Additionally, pediatric patients are more sensitive to anesthesia, as are older patients. Older patients also have more co morbidities than young adults, making them less than ideal candidates for surgery (NCCN, 2012).

Radiation, which is another common treatment, has many side effects, including increased risk of secondary malignancies; lung, heart, and thyroid problems; other chronic health conditions; and growth dysfunction (Armstrong, Stovall, & Robinson, 2010). Additionally, radiation therapy to the testes and ovaries increases the risk of infertility, and chest radiation increases the risk of later developing breast cancer (Levine, Canada, & Stern, 2010). Cranial radiation therapy (i.e., radiation to the head region) also has many associated effects, including cognitive impairment which contributes to lower employment rates, relationship issues, and the decreased likelihood of living independently (Janson et al., 2009). .

Chemotherapy is a common treatment method for all age ranges, but it can lead to specific issues for the young adult population. Young adults are in the childbearing stage, so concerns about fertility issues in both males and females is an issue for this age range (Levine et al., 2010) Cardiac, central nervous system dysfunction, hearing loss (Schell et al., 1989), and renal dysfunction (Hijiya, Ness, Ribeiro, & Hudson, 2009) are also potential side effects of chemotherapy. Additionally, pain, fatigue, nausea, vomiting, hair loss, infection, oral inflammation, and inhibition of bone marrow function are common side effects (NCCN, 2012). Unless contraindicated, the dose should be as intense as possible for this population. However, dose reductions are implemented when necessary to avoid permanent organ damage (NCCN, 2012). Conditioned nausea and vomiting are also common chemotherapy side effects, and they occur more frequently in patients younger than 50 year of age (Roscoe, Morrow, Aapro, Molassiotis, & Olver, 2011).

Hematopoietic stem cell transplants, also known as a bone marrow transplant, have been found to be a curative option for young adults with leukemias and lymphomas. Unfortunately, as with any transplant, there is the potential for many serious side effects. Organ rejection and immune system suppression are two major concerns following transplant. Additionally, posttransplant complications, infections, and other organ dysfunction are also concerns (Oeffinger et al., 2004).

Although there are several treatment options available for young adults with cancer, they are not without their side effects and complications. It is not surprising that many individuals, both young and old, find the treatment regimen difficult to adhere too.

## Psychosocial Concerns for Young Adults with Cancer

There are many psychosocial issues to consider for adolescent and young adult cancer patients, including their living situation (e.g., are they living with their parents, alone, or with a partner), their involvement in work and/or school, and whether these areas of life will be disrupted. Additionally, concerns regarding alcohol/drug and tobacco usage, in addition to sexual behaviors, diet, exercise, and spirituality are all areas of consideration, given young adults are more likely to engage in unhealthy behaviors, as compared to older adults (Romer, 2003). Other areas to evaluate include family and partner interactions/relationships, peer relationships, social and athletic activities, concerns about fertility, and the young adult's ability to communicate with their health care providers. Insurance and finances can also be issues of concern, in addition to child care, transportation, and interest in alternative therapies (NCCN, 2012). An adolescent cancer patient may also be worried about cancer reoccurrences, body image, healthcare and finances, and may delay developmental tasks such as marriage or starting a career (Zeltzer, 1993). According to Zebrack, Mathews-Bradshaw, and Siegel (2010), all of these are issues which need to be addressed when treating the young adult population. Yet, unfortunately, many adult treatment centers neglect to provide services to address these psychosocial issues.

Other areas of concern may be more emotional in nature. For example, Sunmi (2001) conducted a narrative study with a young adult cancer patient and found three recurring themes in her study: (a) lack of understanding from her peers and a need for feedback and acknowledgement regarding her disease, (b) concerns about if and how her cancer illness could be integrated into her identity, and (c) feelings of isolation from her peers due to her newfound maturity as a result of her diagnosis, that resulted in alienation from her less mature peers. Although the cancer survivor in the study felt oppressed and isolated, she also felt that her diagnosis changed her values from being self-centered and materialistic, to a more socially conscious individual. Although this study only included one young adult cancer patient, her remarks could lead to insight into the mind of a young adult cancer patient.

A cancer diagnosis also increases the likelihood of developing other physical problems. Young adults with cancer are more likely to experience cardiovascular and other physical problems, compared to the general population (Chen, Colan, Diller, & Force, 2011) due to the effects of treatments. Therefore, it is imperative that adolescents and young adults with cancer lead a healthy lifestyle to help reduce the chance of future problems. Rabin (2011) explored the literature related to three health focused behaviors (i.e., exercise, smoking cigarettes, and alcohol and drug usage), and found that young adult cancer survivors are less likely to engage in physical activity, as compared to their healthy peers. However, they were also less likely to smoke cigarettes, use alcohol, or illicit drugs.

## Factors Influencing Cancer Survival in Young Adulthood

Cancer survival may be presented in one of four ways: (a) cancer-specific survival, (b) relative survival, (c) overall survival, and (d) disease-free survival. Cancer-specific survival pertains to the statistical percentages of individuals who have not died from a specific type and stage of cancer. Survival may be presented in terms of 1 year, 2 years, 5 years, etc. However, this method is prone to inaccuracies because it is based on what is identified as the cause of death in medical records, which may have errors. For this reason, relative survival rates may be presented. Relative survival rates compare survival of patients with a particular disease and stage of disease to the general population who are of the same age, race, and gender, but have not been diagnosed with cancer. Overall survival, on the other hand, is percentage of individuals that have not expired during a specific time period following diagnosis, whereas disease-free survival is the percentage of individuals who are cancer-free following treatment for a specific time period.  Cancer statistic reporting agencies, often present survival rates in terms of 5-year survival as compared to the general population (National Cancer Institute, 2010).

The National Cancer Institute (2004) has cited several reasons for the lack of increased survival rates in adolescent and young adult patients:  (a) physician inconsistency in treatment and follow-up recommendations, (b) a lack of knowledge regarding the biological and etiologic differences in young adult cancer patients, (c) poor data collection on survival rates by cancer reporting agencies, (d) low participation in clinical trials for this age group, and (e) lack of focus on prevention and early detection.

According to Bleyer, Budd and Motello (2006), whereas approximately 10% of 15-19 year old cancer patients participate in clinical trials, only 1-2% of the 20-39 year old age group does so.  Additionally, inconsistencies in treatment and presentation can also influence survival. McMillan and McArdle (2009) found that younger patients (less than 45 years) were more likely to present in an emergent state, have advanced disease and die of their cancer as compared to three groups of older patients, up to age 74 years. However, when controlling for state of presentation and disease stage, there was no longer a significant relationship between young age, and poorer survival outcome, which suggests that later diagnosis plays a major role in survival rates.

Martin et al. (2007) also cited health insurance status and delays in diagnosis, as an explanation for this discrepancy between survival rates in young adulthood, as compared to older adults and pediatric patients.  Additionally, Meyer et al. (2007) found that younger adults are more likely to delay decisions about cancer treatment than older adults.  Older adults have more knowledge about treatments and cancer, and make more immediate treatment decisions. Similarly, older female breast cancer patients are also more likely to make immediate treatment decisions according to Meyer et al. (1995). Delays in treatment, especially coupled with delays in diagnosis, could account for the lack of improvements in survival rates for young adult cancer patients (Meyer et al., 2007; Meyer et al., 1995).

Furthermore, decision-making strategies of young adults may also impact their follow through with treatment, and this could affect survival rates. Woodhead et al. (2011) conducted two studies comparing younger adults and older adults decision making strategies in a hypothetical lung cancer scenario. Results of these two studies indicated that younger adults were more likely to use data-driven strategies (i.e., information regarding survival and mortality data) for making decisions about treatment choices, as opposed to experience-driven decisions (e.g., making a decision based on what family or friends experienced when diagnosed). That is, young adults were more likely to make decisions based on concrete outcomes.

Although social support has also been tied to survival rates, social support has not been directly researched in relationship to survival. However, one might be able to speculate that social support, which encourages treatment adherence, might lead to better compliance, and subsequently improve survival rates (Magai, Consedine, Neugut, & Hershman, 2007).

## Survival as it Relates to Gender and Race

There are also differences in survival related to gender and race. According to the National Cancer Institute (2004), the mortality rates are higher for males, younger than

30 years of age, and older than 45 years of age. On the other hand, more females die of cancer between the ages of 30 to 44 years. Between 1975 and 2000, data shows that more males have died from cancer between the ages of 10 through 45 years of age, when comparing incidence rates. This suggests that cancers in adolescent and young adult males were more lethal than for females, or that treatment was not as effective.

Additionally, survival rates for African Americans are lower, in all age groups older than 15 years, and for all cancers, as compared to White non-Hispanics, Hispanics, Native Americans, and American Indians (National Cancer Institute, 2004). Additionally, although White non-Hispanics had the best survival rates, and African Americans had the worst survival, both of these groups experienced the least improvement in survival rates, over time, compared to other ethnic groups, with African Americans also having the least improvement, particularly for individuals between the ages of 15 and 24 years.

In summary, cancer survival, which can be measured in multiple ways, is influenced by many factors (e.g., clinical trial participation, stage of disease at diagnosis, delays in treatment, age, and gender). Treatment adherence is another factor, which may impact survival. This will be discussed in the upcoming section.

## Adherence

Treatment adherence is another factor that has been explored in young adult cancer patients. Although there have been studies exploring adherence in adolescents/young adults, only a few articles were found that explored the relationship between adolescents/young adulthood and cancer treatment adherence. Furthermore, articles which did focus on young adulthood, often included only up to the age of 23 years, and excluded the 23-39 year age group. Given the unique psychological, biological, and sociological features of young adults, poor treatment adherence could also be an explanation for the difference in survival rates. Following is a definition of adherence, a discussion on the ways in which it has been measured, in addition to a description of several studies which have explored adherence, and then some suggestions on how to improve adherence.

Treatment adherence, which is also known as treatment compliance in the medical literature, is one psychological factor in the biopsychosocial model that could affect health. Treatment adherence can be defined as the patient's cooperative behaviors in response to physician orders (Brannon & Feist, 2004). It can be operationally defined as taking medications as directed (Winkeljohn, 2010), following the steps of a stop smoking program, or completing treatments, such as chemotherapy on schedule, as directed by the physician (Weggelaar et al., 2011). According to Kondryn, Edmondson, Hill, and Eden (2009), adherence should not only be described in terms of behavior, but also in relationship to attitude (i.e., behavioral adherence could be operationally defined as nonadherence to medical advice, whereas attitudinal adherence could be described as the willingness and intention of the patient to complete treatment and/or their thoughts about treatment). Treatment adherence has been found to reduce poor treatment outcomes by 26% (DiMatteo, Giordani, Lepper, & Croghan, 2002).

The World Health Organization (2003) estimated that treatment adherence is 50% even in developing countries. Poor adherence, not only impedes medical progress, it leads to increased morbidities, decreased mortality, and an increase in health care expenses. Adherence involves a complex interplay between the patient, the provider, and the entire healthcare system, and nonadherence is affected by several factors, including social, economic, the health care team (i.e., services available, quality of communication), and the knowledge, beliefs, and attitudes of the patient (World Health Organization, 2003).

The issue of medical adherence has been studied for some time. According to Brannon and Feist (2004), adherence has been measured in 6 general ways: (a) gathering information from the physician, (b) self-report of the patient, (c) collecting information from others, (d) counting medications, (e) examining biochemical substances, or (f) a combination of the various measures. Kondryn, Edmondson, Hill, and Eden (2011) categorized the various ways to measure adherence into two groups, direct and indirect measure categories. They included those cited above, in addition to observations and the assessment of therapeutic outcomes.

Direct measures, according to Kondryn et al. (2011), include such approaches as observations and blood and urine screenings. Although observations by health care professionals can directly measure adherence, these measures can be time consuming and they do not necessarily typically take into consideration the health status of the individuals being assessed. Whereas blood and urine screenings provide objective confirmation that a drug has been taken, blood sampling is an invasive procedure, can be costly, and you must also consider such factors as absorption and metabolic rates. Urine screenings, on the other hand, are less invasive, but still can be costly and you must also consider pharmocokinetics of the medication (e.g., the half-life or metabolic absorption rates of the drug). Although, biochemistry measures do have disadvantages, they can provide a more objective way of measuring adherence. Unfortunately, not all treatments can be measured in this manner.

Kondryn et al. (2011) categorized patient self-reports, health professional ratings, prescription monitoring, pill counting, medication monitoring systems, and assessment of therapeutic outcomes, as indirect measures of adherence. Whereas patient self-reports and health professional ratings are easy to administer and implement, they are also not without flaws. The primary issue is accuracy or validity in reporting due to their subjectivity. On the other hand, individuals completing self-reports, may fail to report inaccuracies for various reasons (e.g., the patient does not want to appear non-compliant, forgetting).

Another indirect measure, prescription monitoring, involves measuring prescriptions filled. Although this can be very useful with large samples, it does not measure the amount of medication taken. Pill counting also is easy to implement, but does not actually confirm that the medication has been taken by the participant. For example, when counting medication, the patient may remove part of the medication to appear adherent (Kondryn et al., 2011).

Medication management systems, which continually assess timing and frequency of medication compliance, are based on the assumption that the medication has been consumed. This method can also be costly, and there is always the potential for mechanical failure. The literature shows that, although all approaches have their disadvantages, the least valid approach is physician report (Brannon & Feist, 2004).

## Young Adults with Cancer and Treatment Adherence

Although cancer is the leading natural cause of death for teenagers/young adults, according to Kondryn et al. (2009), there has been little research conducted in the area of nonadherence in this population. According to the authors, this may be due to the lack of valid measures to assess adherence in this age group. Whereas there are few articles related to treatment adherence in young adulthood, there are several studies which focus on treatment adherence in adolescent cancer patients. Most of these studies have been conducted in the United Kingdom and other countries outside of the United States. Additionally, most of these studies only investigate patients up to the age of 18, and two studies explore participants up to age of 24 (Kondryn et al., 2011), but did not include young adults between the ages of 25-40 years. Following are some of these studies.

Cohen (1986) conducted a retrospective chart review of 74 adolescent cancer patients between the ages of 13-19 years and found that 23% of the participants refused to complete all or part of their treatment. Festa, Tamaroff, Chasalow, and Lanzkowsky (1992) conducted two studies which assessed prednisone and penicillin compliance, as measured by blood and urine samples, respectively, and found nonadherence rates of 52% and 48% for adolescents, of a mean age of 15.6 and 19.1 years. Smith, Rosen, Trueworthy, and Lowman (1979) also found noncompliance rates of 63% with prednisone urine screenings, while Kennard et al. (2004) reported a nonadherence rate of

27% with serum assay analysis of an anti-infection drug prescribed to adolescent cancer patients, 13-17 years of age.

Dolgin, Katz, Doctors, and Siegel (1986), conducted two studies with 12-18 year old patients. Utilizing physician assessment to measure adherence rates, 46% and 11% of the patients, respectively, were rated by the physician to be “poor” or “very poor” compliers in the studies. Tebbi et al. (1986), measured adherence in 22 patients, between the ages of 10-23 years, by utilizing patient, and parent self-reports on self-administered chemotherapy. Compliance rates were measured at three points in time post diagnosis (i.e., 2 weeks, 20 weeks, and 50 weeks). The highest nonadherence rate in this study occurred at the 50 week post-diagnosis mark and was 47%.

Kondryn et al. (2009) investigated adherence in 33 adolescent/young adult cancer patients, ages 16-24 years of age, with solid tumors. In this study, adherence was measured with a 19 item questionnaire developed by the authors. Results of this study indicated that there were no differences in adherence rates in regards to age, gender, age at time of diagnosis, diagnosis, or time since diagnosis. However, patients did not adhere to approximately 38% of low-risk treatment components (e.g., taking the wrong dosage of medications) and up to 25% of high-risk treatment behaviors (e.g., seeking out help when developing a fever).

Mitchell et al. (2004) conducted a retrospective physician-rating and clinical note review of 665 patients from a cancer registry database. The participants were between the ages of 10-24 years of age. In this study, only 1% (i.e., 17) of the individuals was noncompliant in their treatment. Additionally, Jamison, Lewis, and Burch (1986a) also studied 12-18 year old patients using nursing ratings. In this study, 100% of the 27 outpatient participants were labeled as “moderately cooperative” with their treatment. Concerns regarding these studies include small sample sizes in all of the studies, with the exception of Mitchell et al. (2004). Additionally, the adherence rates range from 37% (Smith et al., 1979) to 100% (Jamison et al., 1986a).

### Other Adherence Studies for Adolescents/Young Adults

Wiener, Riekert, Ryder, and Wood (2004) compared and contrasted three medication adherence measuring methods in 35 adolescents/young adults, between the ages of 11-21 years, with HIV. The adherence rates in this study, ranged between 31% and 54% for the three adherence measures: (a) clinical nurse ratings, (b) retrospective self-report interview, and (c) a 24-hour phone diary. Friedman, Navaratnam, and McLaughlin (2010) found that the simpler the dosing regimen, the greater the adherence for asthma patients, ages 12-25 years of age. In another study with asthma patients, ages 12-20 years, Wamboldt, Bender, and Rankin (2011) found that beliefs, emotions, and knowledge effect adherence rates. In this study, the authors found that poor adherence was related to misinformation about medication, lifestyle factors, and inaccurate assumptions about one’s disease.

### Older Adults and Cancer Treatment Adherence

Several studies have investigated adherence in the older cancer population, but only one study was found which had compared adherence in younger adults to older adults. This study compared three groups of adult cancer patients (i.e., 50 years of age and younger, 50-65 years of age, and 65 years and older) in regards to their adherence to long-term adjuvant hormonal therapy for 8,796 early stage breast cancer patients. Only 49% of the participants were fully adherent in this study and those patients younger than 40 years of age and older than 75 years of age, were the least adherent. It is important to note that the therapy is prescribed for 5 years or longer (Hershman et al., 2010).

Cooper, Schultz, Simkins, and Lafata (2007) reviewed the medical claims and electronic medical records of 429 cancer patients receiving treatment, with the intent to cure the patient. Patients were studied throughout the initial 18-month follow-up period and categorized as either adhering to follow-up: (a) less than recommended, (b) recommended, or (c) greater than recommended, per the oncology practice guidelines. This study excluded patients younger than age 30, and the mean age of the patients was 62.4 +/- 11 years. The authors were attempting to determine the feasibility of using administrative record reviews to measure guideline adherence. Results of this study indicated that adherence rates were highest for laboratory tests, and lowest for physical examinations. Additionally, patient reports were consistent with the medical record data, and there did not appear to be differences, according to insurance type. The authors reported that there is little known about follow-up in cancer patients, and tumor registries do not do a good job of monitoring follow-up, or surveillance care, after treatment.

Other studies have also looked at older cancer patients. Weggelaar et al. (2011) compared three older breast cancer patient age groups (60-69 years, 70-79 years, 80+ years) in relationship to their adherence to surgery, radiation therapy, chemotherapy, systemic, and endocrine therapy, as recommended by the established guidelines in the Netherlands. Results of this study showed significantly lower treatment adherence rates for surgery, radiation, and systemic therapy for the 80+ year's age range, as compared to the two other groups, ages 60-69 years, and 70-79 years of age. However, the oldest group of participants was more likely to follow endocrine therapy recommendations as compared to the two younger groups.

In another study, Stensvold et al. (2011) found that over 88% and 80% of older male prostate cancer patients during two time periods, adhered to the recommended surgical and radiotherapy guidelines. Xu et al. (2012) found that adherence reduced over the course of a 5-year follow-up. In this study, 116 males diagnosed with receptor positive breast cancer, received a 5 year prescription for Tamoxifen. Adherence rates steadily dropped from 64% at the 1 year mark, 28.7% at the 3 year mark, to 17.7% at the 5 year mark.

## Other Adherence Studies

Stilley, Bender, Dunbar-Jacob, Sereika, and Ryan (2010), conducted three studies which explored cognitive function in relationship to medication nonadherence, and there was evidence of nonadherence in all three studies. The first was a longitudinal study and included patients 24-60 years of age and examined their adherence to a hyperlipidimia medication. Poor working memory appeared to account for poor medication adherence in this study. The second study included 350 adults diagnosed with Type 2 diabetes. The patients were, on average 63.7 years, and poor attention/psychomotor speed appeared to be a predictor of poor medication adherence in this study. In the third study, 34 breast cancer patients, with an average age of 59.76 years, were investigated in order to determine if a hormonal agent impacted cognitive function, and if poor cognitive function impacted medication adherence rates. Verbal learning, attention, and memory all predicted medication adherence.

Whereas Xu et al. (2012) found that social support appeared to be related to poor adherence rates, Foulon, Schoffski, and Wolter (2011) found that the patients' perceptions of the importance of the treatment and how satisfied they were with their medical care were the most important factors in adherence. Kirk and Hudis (2008) also explored the barriers of compliance with oral anticancer agents. Results of this study indicated that education on how the medication can improve clinical outcomes, and how well managed the side effects were the most important factors in treatment adherence.

Hillen, Hanneke, de Haes, and Smets (2011) reviewed 45 articles between the years of 1988 and 2008 and found that trust in the physician helped improve communication, reduce fears, and increase treatment adherence. The authors also noted that trust was enhanced by the physicians' competency level, honesty, and the degree to which they were patient-centered. Kaiser et al. (2010) found that Black women were less trusting of their primary physician and cancer treatment team than Caucasian and Hispanic women.

Garcia-Gonzalez et al. (2008), on the other hand, explored self-reported treatment adherence with rheumatoid arthritis and lupus patients. In this study, 40% of patients stopped medication due to the side effects and 20% stopped due to their belief that the medication was not effective. One third of the participants reported never forgetting to take their medication. In this study, 23% of ethnic minorities did not adhere, and individuals with lower education and more side effects were less likely to adhere.

Although variables, such as gender, ethnicity, education, and income, have been explored in relationship to adherence, individuals are very inconsistent in their adherence behaviors (e.g., someone may adhere to taking medication but not to an exercise regimen), so these variables may or may not be good predictors of adherence overall (Dunbar-Jacob & Schlenk, 2001). Following are some studies that have explored psychological and sociological variables related to adherence.

## Psychological Variables Explored in Relationship to Treatment Adherence

Psychological variables such as autonomy, identity, and risk taking behavior, as they relate to age, may also play a role in nonadherence (Kondryn et al., 2009). Blotcky, Cohen, Conatser, and Klopovich (1985) found that noncompliant adolescents reported lower levels of distress and state anxiety, but were higher on trait anxiety, religiosity, and external locus of control. Additionally, adolescents who reported higher levels of depression and lower levels of self-esteem were more likely to be noncompliant (Kennard et al., 2004).

A positive belief system regarding treatment side effects also can impact treatment adherence. That is, individuals with more negative belief systems are less likely to adhere to treatment recommendations (Fink, Gurwitz, Rakowski, Guadanoli, & Silliman, 2004). Additionally, Saratsiotou et al. (2010) found that patients' belief system about the effectiveness of treatment also impacted adherence. In this study, only 16.7% of patients who adhered to treatment reported that they believed it to be ineffective, whereas 62.5% of those who did not adhere reported that they believed the treatment to be ineffective.

Older patients are also less likely to adhere to treatment when depressed, possibly due to their decreased ability to tolerate treatment side effects (Demissie, Silliman, & Lash, 2001). DiMatteo, Haskard, and Williams (2007) reported that nonadherence increases times three if depression exists. Embarrassment is an emotion that also has been found to decrease the likelihood of receiving screenings for cancer, and may also be related to cancer treatment adherence (Magai et al., 2007).

Psychological factors, such as depression, anxiety, and one's belief system have been shown to be related to treatment adherence. Additionally, sociological factors have been explored in relationship to adherence.

## Sociological Variables Explored in Relationship to Treatment Adherence

Socioeconomic status is one sociological variable explored in relationship to treatment adherence. According to Kissane (2009), poor screening, delayed treatment, and poor treatment adherence are all factors which may be impacted by lower socioeconomic status. Whereas Jamison, Lewis, and Burrish (1986b) found only a moderate relationship between low socioeconomic status and treatment adherence, in a review of the literature, Kissane (2009) reported that low socioeconomic status and depression, are two of the most important psychosocial factors, which are directly tied to the behavioral pathway of treatment nonadherence.

The family social system may also impact treatment adherence rates. For example, parental involvement, especially the mother, has been shown to be related to treatment compliance to self-administered chemotherapy for teenage/young adult cancer patients (Malbasa, Kodish, & Santactoce, 2007). Kennard et al. (2004) also found that the greater the degree of incongruence, in the perception of the family environment between the parents and the child patients (ages 13-17 years), the increased likelihood of treatment noncompliance. This suggests that family conflict may also impact adherence. Additionally, in this study, those classified as noncompliant had lower survival rates 6 years after the study. DiMatteo (2004) also reported that social support and a cohesive family environment increases treatment adherence.

## Treatment and Disease Related Variables Associated with Adherence

There are also treatments and disease related variables which have been found to be associated with treatment adherence. Zebrack, Hamilton, and Wilder-Smith (2009) identified several factors related to a cancer diagnosis, which may impact treatment adherence for young adults. They include disruptions in their daily living (i.e., work, school, career, and family), changes in their physical appearance, and subsequent body image issues, decreased energy, pain, nausea, altered social relationships, changes in their view of themselves, the future, and the world, and concerns about having to face their own mortality.

According to Vermeire, Hearnshaw, Van Royen, and Denekens (2001), the more complex and the longer duration of the treatment regimen, and the more severe the side-effects, the increased likelihood of noncompliance in teen/young adult cancer patients. On the other hand, treatment at a pediatric oncology facility, as opposed to an adult facility, increases the likelihood of treatment compliance for this population, likely due to the additional psychosocial services available and training of the healthcare team in dealing with adolescent and young adults (Bleyer, 2007; McTieran, 2003), in addition to the higher participation in clinical trials in pediatric centers (Bleyer et al., 1997).

Oral chemotherapy regimens also are related to poor treatment adherence. In one study, 42 breast and colon patients and 10 medical professionals were interviewed regarding patient adherence rates. Results of this study showed poor adherence to the dose schedule and the inability to recognize the signs of toxicity, as opposed to deliberate nonadherence, suggesting poor understanding by the patient, or poor education by the treatment professionals. With the increased usage of self-administered oral chemotherapy drugs, this is an area which will require further exploration (Denois et al., 2011).

Saratsiotou et al. (2010) also found that length of time since diagnosis was the most important factor related to intentional treatment adherence. In this study, 33% of patients who were newly diagnosed (i.e., less than 6 months) were not adherent to oral chemotherapy, as compared to 16.7% and 8.3% of patients diagnosed 6-24 months, and 2-5 years, respectively. The participants in this study ranged in age from 30-91 years. Although the study did not explore survival, one could speculate that those who were 2-5 years since diagnosis, survived due to better adherence throughout treatment.

## Strategies for Increasing Adherence

Due to the seriousness of the issue of treatment adherence with any cancer population, the lower treatment adherence rates of the young adult population, in addition to their lack of increase in survival rates, ways to improve adherence is an extremely important topic to consider. The National Cancer Institute (2004) state that the biggest issue in adolescent/young adult oncology is the failure to recognize and address the unique psychosocial needs of this population. Furthermore, the Institute of Medicine (2003) state that whereas state-of-the-art biomedical treatment is available, there is a lack of psychosocial support, and the latter contributes to treatment nonadherence.

Rabin, Simpson, Morrow, and Pinto (2010) interviewed 20 young adult cancer patients, between the ages of 18-39 years. Participants were questioned regarding the behavioral and psychosocial oncology program needs and the barriers to program utilization. The participants reported that they were interested in information related to exercise and physical activity, relaxation, receiving emotional support, nutrition, and weight loss. They also reported that being able to make choices, having flexible and convenient treatment schedules, and being able to connect with others in their age range, was very important. The barriers they identified included time constraints, lack of knowledge regarding programs, health related and treatment side-effect issues (e.g., fatigue and nausea), and low motivation.

Zebrack, Hamilton, and Wilder-Smith (2009), recognize young adults with cancer as an underserved population, and advocate for treatment programs which help young adults maintain or develop independence, help them seek out information regarding their disease and treatment, manage their stress, cope with disease and treatment related side effects, seek out support, and maintain a positive attitude. Other psychosocial needs of this population, according to Zebrack et al. (2009), are access to and an understanding of health care coverage, a multidisciplinarian approach to cancer care, access to clinical trials, and psychosocial counseling. According to Sheard and Maguire (1999), group therapy may be more effective than individual therapy, in reducing depression and anxiety in cancer patients, which one might speculate could improve adherence.

The NCCN (2012) offered suggestions on how to increase adherence which includes education about treatment side effects at the onset of treatment, but also when treatment changes. Education should also include a list of medications, dosage, purposes, and adverse side effects. Additionally, the dosing schedule should be simplified, and the adolescent/young adult patients' lifestyle should be taken into consideration when determining the timing, frequency, or mode of administration of medication. Other recommendations include flexibility in scheduling appointments, education on healthy sexuality, recommending a healthy diet and exercise, and providing referrals when there are concerns about substance abuse. Additionally, counseling and education on fertility preservation should be done at the onset of treatment, and concerns about faith should be addressed appropriately. Providing links and education to patients on Medicaid, social security, and/or disability, in addition to food stamps may be necessary. It may also be necessary to help identify respite care for patients with children, and provide information on survivorship and follow-up.

Vourlekes and Ells (2007) reported that a social work, case management approach to helping promote adherence at all levels of medical care (e.g., prevention, treatment, follow-up) for a wide range of medical conditions is being developed. They advocate for a psychosocial case management "best practices" approach to improve treatment adherence, which includes an understanding to the barriers to treatment adherence, and provides a conceptual and theoretical framework to help with this. Secondly, they recommend a link between this framework with specific activities which promote adherence, and thirdly, the approach should be utilitarian and effective. The authors further described a case management approach which includes five essential components. They reported that the approach must be integrated into the medical treatment, be multicultural, be individualized, the interventions must involve multiple systems, and there must be quality improvement studies to assess the effectiveness of the interventions. The authors recommended a case manager be assigned to the patient, and that the case manager be an active participant in the treatment team. The case manager must have access to the patient's chart and be readily available to the patient and healthcare team. Case managers should also be well versed in the understanding of different cultures, be multilingual if possible, and respect patients health care decisions which are influenced by their cultural beliefs and practices. Case management interventions must also be individualized and patient-centered. Each patient should be thoroughly assessed for their personal barriers to adherence, and interventions should be designed to reduce these barriers. The adherence interventions should address multiple systems (i.e., the patient, the family, the heath care providers, the clinic, etc.). Interventions should be designed to target barriers, such as transportation issues, childcare problems, and clinic hours, provide low cost or free medications, translation services, assistance with insurance/financial problems, and legal services. Finally, the case management program should be assessed periodically for quality improvement, and then steps taken to improve the quality of care, once a deficiency is identified.

Winkeljohn (2010) recognized nursing interventions to be a critical component in increasing adherence, particularly to oral chemotherapies, which are becoming increasingly more common in cancer treatment. Winkeljohn advocated for nursing staff to be active participants in patient education regarding such issues as side effects (e.g., nausea and vomiting, diarrhea, hypertension, skin reactions, and suppression of the immune system), and side effect management, in addition to providing assistance in accessing medications.

Kissane et al. (2012) also advocated for communication skills training for oncology professionals, in order to increase treatment adherence. They believed that professionals should be trained to effectively educate patients on adverse reactions, how to share one's diagnosis with family and friends, coping with survivorship, transitioning to palliative care, and prognosis. Future communication challenges, according to the authors, include educating patients on issues related to genetic testing, the concept of "watchful waiting", the cumulative effects of treatment, how to find accurate and useful internet information, and clinical trials.

## Summary and Conclusions

In spite of improvements in survival for both pediatric and older adult cancer patients, survival rates have not increased for young adult cancer patients for two decades (American Cancer Society, 2012). There have been several biological, psychological, and social factors which have been explored and theorized to help explain this lack of improvement in survival rates. However, the majority of these studies have focused on adolescent and young adult patients, between the ages of 15 and 23 years of age, or older adults.

One biopsychosocial factor that may influence survival rates, treatment adherence, has received a great deal of attention in the literature. Adherence rates in the adolescent literature has ranged from 33 to 60% (Kennard et al., 2004), and some studies have shown 100% compliance (Jamison et al., 1986a). Although, treatment adherence in adolescence has been investigated, studies are lacking for the age range of 25-39 years, which is a group that also has not experienced an increase in survival. There has also been one study that has been found thus far, which compares younger adults to older adults (Hershman et al., 2010). However, this study is exploring adherence rates to oral chemotherapy which is prescribed for 5 years or longer.

Additionally, although there is a sizable body of literature related to pediatric, young adult survivors of childhood cancer, and older oncology patients, there is less research on the adolescent/young adult population, and when studies are conducted on this population, the adolescents/young adults are often lumped in with the pediatric or older adult patients (Zebrack et al., 2009), such as in the Hershman et al. (2010) study. At this point, the gap in the literature appears to be related to the young adult population, more specifically the 25-39 year age range. Therefore, due to this gap in the literature, it was worthy to explore the adherence rates of young adults, ages 18-39 years of age. Poor adherence may also be an explanation for the differences in survival rates related to gender and race. Due to these differences in gender and race in terms of survival

(National Cancer Institute, 2004), these variables were also of interest in relationship to adherence rates for this study.

# Chapter 3: Research Method

## Introduction

Young adult cancer patients have not shown an increase in survival rates over the past two decades, in spite of increases in survival for both pediatric and older oncology patients (American Cancer Society, 2012). Although this lack of increase in survival rates may be related to many factors, one variable in consideration is treatment adherence. The following study explored the relationship between the age of cancer patients and their adherence to radiation treatments and follow-up appointments. More specifically, the study measures adherence rates to radiation treatments and follow-up appointments for young adult cancer patients, ages 18-39 years, as compared to cancer patients, ages 40 and older.

The social change implications of the study are that it will potentially increase the knowledge base on the psychological factors which may explain the lack of increased longevity for younger adult cancer patients, as compared to pediatric and older oncology patients. Furthermore, improved longevity in younger adult cancer patients would be expected to also have a positive impact on future generations.

## Purpose or Aim of the Study

The purpose of the study was to explore radiation treatment and follow-up adherence rates for young adult oncology patients. Failure to adhere to treatment and follow-up appointment recommendations may help explain the lack of improved longevity for the young adult group.

This chapter includes a description of the research questions and hypotheses, the research design and rationale for such design, followed by the history of the Cancer Registry, which is the data base, from which the data was collected. Additionally, the methodology will be discussed, which includes a description of the setting, participants, the measurement of variables, and the procedure for data collection, followed by a description of the statistical and power analysis. Additionally, ethical, validity, and reliability issues will be explored.

## Research Questions and Hypotheses

This study explored the relationship between age of the cancer patient and adherence to cancer radiation treatment recommendations and physician recommended follow-up appointments.

The following are the research questions and hypotheses for the study:

1. Is there a significant difference in radiation treatment adherence for young adult patients as compared to older adult oncology patients?

$H_0$1: Young adult oncology patients do not adhere to radiation treatment less than older adult oncology patient.

$H_1$1: Young adult oncology patients do adhere to radiation treatment less than older adult oncology patients.

2. Is there a difference between young adult cancer patients and older adult cancer patients, in terms of adherence to follow-up appointment recommendations?

$H_0$2: Young adult oncology patients do not adhere to follow-up appointments less than older adult oncology patients.

$H_1$2: Young adult oncology patients do adhere to follow-up appointments less than older adult oncology patients.

3. Does gender impact adherence to radiation treatment?

$H_0$3: There is no association between gender and radiation treatment adherence.

$H_1$3: There is an association between gender and radiation treatment adherence.

4. Does gender impact adherence to follow-up appointments?

$H_0$4: There is no association between gender and adherence to follow-up appointments.

$H_1$4: There is an association between gender and adherence to follow-up appointments.

5. Does race impact adherence rates to radiation treatment appointments?

$H_0$5: There is no association between race and radiation treatment adherence.

$H_1$5: There is an association between race and radiation treatment adherence.

6. Does race impact adherence to follow-up appointments?

$H_0$6: There is no association between race and adherence to follow-up appointments.

$H_1$6: There is an association between race and adherence to follow-up appointments.

The independent variable was age group, and the dependent variables were adherence to radiation treatments and follow-up appointments (i.e., operationally defined as the completion of at least 95% of the recommended treatment and follow-up appointments). Gender and race were also explored in relationship to adherence.

## Research Design and Rationale

The study was retrospective and quantitative in nature. It included a secondary analysis of cancer registry data from which information about radiation treatment and follow-up adherence, cancer diagnosis, and demographic variables were extracted. Information not included in the registry data was gathered through paper and/or electronic patient chart review. The data was gathered from the Cancer Registry of a community hospital in the Midwest. Following is a description of the history and purpose of the Cancer Registry.

## Cancer Registry

According to the Cancer Registry Bylaws, the first documented case with an etiology of cancer, occurred in the European Bills of Mortality in England in 1629, and the first collection of cancer data occurred in London in 1728. From the mid 1800’s to mid 1900’s, various state and national cancer data collection registries developed in the United States and Europe. Then, in the 1930’s, the Commission on Cancer (CoC) of the American College of Surgeons (ACoS), began collecting clinical information and approving cancer clinics. By 1956, the Commission on Cancer began requiring CoC approved programs to have a cancer registry collecting cancer data. As part of the Cancer Registry, cancer registrars are responsible for gathering data which provides a comprehensive summary of the patients’ history, diagnosis, treatment, and disease status for every cancer patient treated at their centers. Demographic information collected by the registrars include: age of diagnosis, gender, race/ethnicity, birthplace and current residence. Additionally the medical history (i.e., physical findings, screening information, occupation, history of previous cancer) and diagnostic findings (i.e., types, dates, and results of procedures) for the patient are included in the records. Specific cancer information (i.e., primary site, cell type, extent of disease) and information related to therapies (i.e., surgery, radiation therapy, chemotherapy, hormone therapy, and immunotherapy) are also collected, in addition to follow-up information, such as reoccurrences and current patient status. This data collection occurs in all approved programs in the United States and other countries. The survival graph is the primary outcome objective of the cancer registry data collection, with the ultimate goal of improving treatment, thereby leading to a cure for cancer (Hutchinson, Menck, Burch, & Gottschalk, 2004).

The National Cancer Data Base, which began in 1989, now contains cancer registry records from 1,500 accredited Commission on Cancer programs in the United States and Puerto Rico, with 29 million patient records (Hutchinson et al., 2004). The program from which data will be extracted for this study was first accredited by the Commission on Cancer in 1977 (S. Dickinson, personal communication, March 5, 2015). The demographics for the database included in the study are: (% male and female, % White, %Black, %Hispanic, %American Indian, % Other, % diagnosed between 18-39 years; % diagnosed between ages of 40 and older). Following is the Methodology for the study.

# Methodology

## Setting

The setting of the data collection was a hospital-based community cancer center located in the Midwest. The Cancer Registry department is located in the outpatient department of the cancer center, and employs two certified cancer registrars.

## Participants

The target population for the study was oncology patients entered into the tumor registry of the aforementioned Midwestern Hospital. With the assistance of a certified cancer registrar, the 46 available young adult cases were identified, and then 46 older adult cancer patients were matched on gender, race, and diagnosis. Electronic and paper charts were then reviewed to gather data on treatment and follow-up attendance. The target population consisted of two groups, one 18-39 years of age, and the other, ages 40 and older. Informed consent was not necessary, since the data was extracted from an already existing data base with prior consent given by the patients. Power and sample size will be discussed later in the chapter.

## Procedure for Data Collection

With the assistance of the Cancer Registrar, data from 46 patients diagnosed between the ages of 18 and 39 years, and data from 46 random patients diagnosed between the ages of 40 years and older was extracted from the cancer registrar's data pool. Once again, patients were matched on gender, ethnicity, and type of cancer, so that the groups were as similar as possible, with the exception of age range which is the variable being studied. The *METRIQ* 2.82 (2015) cancer registry software was used for extracting the data. This software has the capabilities of extracting data by several variables, including age of diagnosis, year of diagnosis, gender, ethnicity, and year of first contact. Data was extracted for patients diagnosed between January 2005 and August 2014.

In order to determine radiation and treatment follow-up appointments, data collection then moved to chart review, either paper chart or electronic chart (which depended upon the admission date for the patient). The electronic and paper charts have a listing of the date of treatment, activity or type of treatment, and status (which includes whether the treatment was completed or cancelled by the patient). The information extracted from the electronic and paper charts was done manually by this researcher.

## Measurement of Variables

Adherence to radiation treatments was measured utilizing a dichotomous variable of adherent vs. non-adherent to radiation treatments and follow-ups. A cutoff of 95% of the recommended radiation treatments determined adherence, which is the recommended dosage for radiation treatment (International Commission on Radiation Units and Measurement, 2014; Radiation Therapy Oncology Group, 2011). Additionally, follow-up appointments were measured for the 2 years after completion of treatment, also with 95% of the appointments attended as scheduled being the cut-off for adherence. This information was measured, in that, follow-up appointments are recommended by the physician and recorded in the patient's record, and then appointment status is documented in the records after completion or cancellation.

Appointments with other medical personnel were not included in the analysis, because of the difficulty in measuring these appointments. In the case of missing data, every attempt was made to gather information from other areas of the patient record. If the information could not be found, then the case was eliminated from the study. Additionally, patients who stopped treatment due to change of treatment centers were eliminated from the study.

## Operationalization of Variables

Independent Variable: Age range categorized into two groups (Young adults with cancer, ages 18-39 years of age, and Older adult cancer patients, age 40 years and older)

Dependent Variable 1: Radiation treatment adherence was dichotomized as either adherent vs. non-adherent with attending a minimum of 95% of radiation treatment appointments as scheduled, being considered adherent.

Dependent Variable 2: Follow-up appointment adherence was dichotomized as either adherent vs. non-adherent with 95% of appointments attended, within 2 weeks of the recommended appointment time being considered adherent.

Gender: Categorized as either Male or Female

Race: Categorized as Minority or non-Hispanic Whites

## Data Analysis

IBM SPSS Statistics 21 (IBM Corp., 2012) and Vassarstats online calculator (2016; vassarstats.net/propcorr.html) were utilized for the data analysis. McNemar's test was utilized to examine the association between ages (i.e., young adults versus older adult oncology patients as the independent variable) in relationship to the two dependent variables, adherence rates (dichotomized as adherent vs. non-adherent) to radiation treatment and follow-up appointments. Pearson's Chi-square analysis was used to examine the associations between gender, and race to the two dependent variables (radiation adherence and follow-up adherence).

### Power and Sample Size

Sample size analysis for McNemar's with a power of .80, using a one-tailed test with an alpha of .05 indicates that the study will need at least 18 participants (http://powerandsamplesize.com/Calculators/Compare-Paired-Proportions-McNemar-Z-test-1-Sided). Eligible participants were patients who were diagnosed between January 2005 and August 2014. In order to compensate for missing data, over sampling was utilized and there will be 92 participants (i.e., 46 matched pairs) in the study.

## Ethical Issues

Because the data were already collected, there were no concerns for influencing the data. Additionally, the data were de-identified to protect the confidentiality of the patients in the event of publications and presentations. However, one potential ethical issue was that this data collector works as an oncology counselor in the setting where the data was collected, and when accessing the medical records by this counselor, the data then became identified. However, once again, the data cannot be influenced by the researcher.

## Threats to Validity and Reliability

The measurement of radiation treatment attendance and follow-up treatment attendance was a good measure of adherence, giving the study good face validity.

However, because the data was only extracted from one hospital, the results cannot be generalized to other cancer registry data. Additionally, datum could be missing on some of the cases, thus adding concerns about sample selection. Furthermore, the measure may not have had good predictive validity (i.e., it does not necessarily predict adherence to chemotherapy or other forms of cancer treatment). This also directly ties with divergent validity, in that, the adherence rates to radiation treatment and follow-up appointments, do not necessarily correlate with other treatment modalities (e.g., chemotherapy, surgery). Additionally, radiation treatment adherence and follow-up treatment adherence may also not be related. For instance, some patients adhered to radiation treatment in this study, but did not adhere to follow-up appointments, thus making the modality of treatment, an extraneous variable.

Additional concerns about threats to external validity included that the study cannot be generalized to diseases and treatments, other than cancer. Additionally, the study cannot be generalized to other time periods, past or present, and only applies to the time period for which the data was extracted. Additionally, since this is the first study of its kind, comparing young adult and older cancer patients, on radiation and treatment follow-up adherence, it is unclear if subsequent studies will have similar outcomes, so replication is recommended in order to determine the reliability of the results.

## Summary

This study was a quantitative analysis of Cancer Registry data. It was hypothesized that there would be a difference in radiation treatment and follow-up adherence rates for young adult oncology patients, as compared to older oncology patients. Additionally, gender and race were explored to determine if these variables impact adherence rates. The implications of the study were that a better understanding of treatment adherence rates, would lead to better treatment compliance, thus improving survival rates for young adult cancer patients.

# Chapter 4: Results

## Introduction

The purpose of the study was to compare young adult oncology patients' adherence rates to radiation treatment and follow-up appointments, to older oncology patients' adherence rates to radiation treatment and follow-up appointments. Age was explored in relationship to adherence to radiation treatment and follow-up appointments using McNemar's nonparametric test for matched pairs (i.e., two related samples), and Pearson's chi-square analysis was used to examine the associations between gender and race with radiation and follow-up appointment adherence. The following will include a description of the data collection procedure and the results of the study.

## Data Collection

The data were collected in March 2015 from the cancer registry database of a Midwestern community hospital-based cancer center. Data were gathered on all young adult cancer patients (ages 18-39 years of age) who had received radiation treatment at the aforementioned cancer center, with an initial cancer diagnosis between January 2005 and August 2014. Demographic data including gender and race, in addition to primary diagnosis and age of diagnosis, were extracted from the database with the assistance of the cancer registrar. Fifty-nine young adult cases were identified, but 11 were not included due to them having a thyroid diagnosis, which is treated differently than the standard external beam radioactive therapy received for the other diagnoses. Additionally, one case was a duplicate case, which received treatment followed by palliative care radiation treatment at a later date, and another case was a duplicate with two similar diagnoses, with only one course of treatment completed. This left 46 young adult cases for analysis.

For the older adult population, there were 1,502 cases identified, including 689 females and 813 males. The thyroid cases were also not considered from this population for the reason stated previously. The older adult sample was identified by matching gender, race, and primary diagnostic site to the young adult sample. When there were multiple matches, an online randomization tool called the Stat Trek Random Number Generator (http://stattrek.com/statistics/random-numb) was used to choose a match. Six of the young adult cases did not have an identical match on all variables. For four of those cases, they were matched on all variables with the exception of diagnosis. In those instances, a case was identified with a similar diagnostic site (e.g., oropharynx was substituted for a nasal cavity). In one of those four cases, an unknown primary site was substituted with a randomly chosen lung case. Two cases could be matched on gender, and diagnosis, but not for race; hence, a patient with a different race was randomly chosen. Additionally, four of the older adult cases did not have sufficient information to analyze the follow-up appointment adherence. For example, one patient moved after treatment, another was referred to the medical oncologist for follow-up, and another was referred to hospice. For these four cases, four substitute cases were randomly chosen matched on gender, race, and diagnosis. Because one of these cases did not have a match on diagnosis, a similar site was chosen (e.g., lymphoma was replaced with a lung diagnosis).

Once the cases were identified, radiation treatment and follow-up data were extracted from the patients' electronic and/or paper chart. Radiation treatment appointments were measured as being completed on time if the patient completed the appointment as scheduled. Absences were only considered excused if the patient's radiation oncologist recommended a pause in treatment, or if the patient had a documented medical emergency or procedure that prevented him or her from attending his or her treatment appointment. Follow-up appointment data were gathered for 2 years post the final treatment date. Patients were considered adherent if they attended the follow-up appointment within 2 weeks of the recommended time period according to the patients' follow-up summaries in their charts. Patients were considered adherent on both variables if they attended 95% of their appointments as scheduled.

## Results

Table 1 includes the demographic data for the young adult (*N*=46) and older adult (*N*=46) samples. Both samples were predominantly female and White/non-Hispanic. The most common occurring diagnosis for both samples was breast cancer. The average age of the older adults was 64.54 years, while the younger adult sample mean age was 33.17. According to the study results, the two groups were perfectly matched on gender.

Table 1

*Demographic Characteristics for Young Adults (N=46) and Older Adults (N=46)*

| Age M (SD) | 33.17 (59.30)- 18-39 years | | 64.54 (11.62)-_42-92 years | |
|---|---|---|---|---|
| | N | % | N | % |
| Females | 33 | 71.74 | 33 | 71.74 |
| Males | 13 | 28.26 | 13 | 28.26 |
| Asian/Non-Hispanic | 2 | 4.30 | 1 | 2.20 |
| Black/Non-Hispanic | 2 | 4.30 | 2 | 4.30 |
| Filipino/Non-Hispanic | 1 | 2.20 | 1 | 2.20 |
| Pakistani/Non-Hispanic | 1 | 2.20 | 1 | 2.20 |
| Unknown/Unknown | 1 | 2.20 | __ | __ |
| White/Hispanic | 7 | 15.20 | 7 | 15.20 |
| White/Non-Hispanic | 31 | 67.40 | 33 | 71.70 |
| White/ Unknown | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Base of Tongue | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Benign Brain | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Brain | 2 | 4.30 | 2 | 4.30 |
| Diagnosis: Breast | 20 | 43.50 | 20 | 43.50 |
| Diagnosis: Cervix | 2 | 4.30 | 2 | 4.30 |
| Diagnosis: Kidney | __ | __ | 1 | 2.20 |
| Diagnosis: Liver | 1 | 2.20 | __ | __ |
| Diagnosis: Lung | __ | __ | 2 | 4.30 |
| Diagnosis: Lymphoma | 6 | 13.00 | 5 | 10.90 |

*Table Continues*

| | | | | |
|---|---|---|---|---|
| Age M (SD) | 33.17 (59.30)- 18-39 years | | 64.54 (11.62)- 42-92 years | |
| Diagnosis: Nasal Cavity | 1 | 2.20 | — | — |
| Diagnosis: Oropharynx | — | — | 1 | 2.20 |
| Diagnosis: Pancreas | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Parotid | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Rectosigmoid Junction | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Rectum | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Sarcoma | 2 | 4.30 | 2 | 4.30 |
| Diagnosis: Skin | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Small Intestine | — | — | 1 | 2.20 |
| Diagnosis: Stomach | 2 | 4.30 | 1 | 2.20 |
| Diagnosis: Testis | 1 | 2.20 | 1 | 2.20 |
| Diagnosis: Unknown | 1 | 2.20 | — | — |
| Diagnosis: Vagina | 1 | 2.20 | 1 | 2.20 |

Table 2 shows the frequencies and descriptive statistics for radiation treatment adherence and follow-up appointment adherence for both the young adult and older adult patients. Whereas the majority of both young adults and older adult patients were adherent to radiation treatment, only a minority of both young adults and older adults were adherent to follow-up appointments.

Table 2

*Frequencies and Descriptive Statistics for Radiation Treatment and Follow-Up Appointment Adherence*

| | Adherent N (%) | Nonadherent N (%) | Min% Max % |
|---|---|---|---|
| Radiation Young Adults | 37 (80.43) | 9 (19.57) | 72.22/100.00 |
| Radiation Older Adults | 41 (89.13) | 5 (10.87) | 82.14/100.00 |
| Follow-Up Appointments Young Adults | 5 (10.87) | 41 (89.13) | .00/100.00 |
| Follow-Up Appointments Older Adults | 13 (28.26) | 33 (71.74) | .00/100.00 |

*Note*. Min%/Max% = minimum % and maximum % of treatments and follow-up appointments completed by participants.

Tables 3 and 4 show the adherence rates for young adult cancer patients (under 39 years of age) and their matched controls on gender and race, for adherence to radiation treatment (Table 3) and adherence to follow-up appointments (Table 4).

Table 3

*Adherence to Radiation Treatment Among 46 Cancer Patients Under 39 years and Their Matched Controls*

| | Older Adherent | Older Nonadherent | Total |
|---|---|---|---|
| Younger Adherent | 34 | 3 | 37 |
| Younger Nonadherent | 7 | 2 | 9 |
| Total | 41 | 5 | 46 |

*Note.* Numbers in table are for pairs.

Table 4

*Adherence to Follow-Up Among 46 Cancer Patients Under 39 years and Their Matched Controls*

| | Older Adherent | Older Nonadherent | Total |
|---|---|---|---|
| Younger Adherent | 2 | 3 | 5 |
| Younger Nonadherent | 11 | 30 | 41 |
| Total | 13 | 33 | 46 |

*Note.* Numbers in table are for pairs.

### Hypothesis 1

Hypothesis 1 stated that young adult cancer patients (ages 18-39 years) would adhere less to radiation treatment than older adult cancer patients. The independent variable was age (i.e., young adult oncology patients versus older adult oncology patients), and the dependent variable was adherence, versus nonadherence to radiation treatment. According to the results of the McNemar's test, there was no difference between young adult and older adult radiation treatment adherence. See Table 5.

### Hypothesis 2

Hypothesis 2 stated that young adult cancer patients (ages 18-39 years) adhere less to follow-up appointments than older adult cancer patients. The independent variable was age (i.e., young adult oncology patients versus older adult oncology patients), and the dependent variable was adherence versus nonadherence to follow-up appointments. According to the results of the McNemar's test, there was a significant difference between young adults and older adults in adherence to follow-up appointments ($p < .05$, OR=3.67, 95% CI of 1.02, 13.14). That is, the odds of adhering to follow-up were 3.67 times higher for older adults relative to younger adults. See Table 5.

Table 5

*McNemar's Nonparametric Test for Age Predicting Radiation Treatment Adherence and Follow-up Appointments Adherence*

| | *p* | Odd Ratio | 95% CI |
|---|---|---|---|
| Radiation Treatment Adherence by Age | .1719 | 2.33 | [.60,9.03] |
| Follow-Up Appointment Adherence by Age | .0287 | 3.67 | [1.02,13.14] |

*Note*: *p*=exact binomial, 1-tailed

## Hypothesis 3

Hypothesis 3 stated that there is an association between gender and radiation treatment. The independent variable was gender, and the dependent variable was radiation treatment adherence. Pearson's chi-square analysis was used to analyze if gender was related to radiation treatment adherence. According to the results of Pearson's chi-square analysis, gender was not related to radiation treatment adherence. See Table 6.

## Hypothesis 4

Hypothesis 4 stated that there is an association between gender and adherence to follow-up appointments. The independent variable was gender, and the dependent variable was follow-up appointment adherence. Pearson's chi-square analysis was used to analyze if gender had an impact on follow-up appointment adherence. According to the results of the chi-square analysis, males were more likely to adhere to follow-up appointments than females, with a chi-square value of 5.216 and $p < .05$ and OR =.298 and 95% CI (.102, .870); this effect was with a degree of certainty. See Table 6.

### Hypothesis 5

Hypothesis 5 stated that there is an association between race and adherence to radiation treatment. Although it was proposed in Chapter 3 that African Americans would be compared to all other races, due to the small number of African Americans ($n$=4), White/non-Hispanics ($n$=64) were compared to all other races combined ($n$=28). The independent variable was race, and the dependent variable was radiation treatment adherence. Pearson's chi-square was used to analyze if race impacted radiation treatment adherence. According to the results of the chi-square analysis, race was not related to radiation treatment adherence. See Table 6.

### Hypothesis 6

Hypothesis 6 stated that there is an association between race and adherence to follow-up appointments. The independent variable was race (i.e., non-Hispanic Whites versus minorities), and the dependent variable was adherence to follow-up appointments. Pearson's chi-square analysis was also used to analyze if race was related to follow-up appointment adherence. According to the results of the chi-square analysis, race did not impact follow-up appointment adherence. See Table 6.

Table 6

*Associations Between Gender, Race, and Adherence to Radiation Treatment and Follow-Up Appointments*

| | Pearsons Chi Sq | Asym Sig | Odds Ratio | 95% CI |
|---|---|---|---|---|
| Radiation Treatment Adherence by Gender | 1.591 | .207 | .375 | [.078,1.807] |
| Radiation Treatment Adherence by Race | .217 | .641 | .753 | [.227,2.491] |
| Follow-Up Appointments by Gender | 5.216 | .022 | .298 | [.102,.870] |
| Follow-Up Appointments by Race | .713 | .398 | .595 | [.177,2.002] |

## Summary

The purpose of the study was to compare young adult oncology patients' (ages 18-39 years of age) adherence to radiation treatment and follow-up appointments, to older oncology patients' (i.e., age 40 years and older) adherence rates. Additionally, I explored race and gender and their association with radiation treatment and follow-up appointments. Overall, I found that there was a significant difference between young adult oncology patients and older adult oncology patient in follow-up appointment adherence, with older adults' adherence being 3.67 times higher than younger adults. Gender was related to the follow-up appointment adherence, but not radiation treatment adherence, with males more likely to adhere to follow-up than females. However, due to the small number of males in the groups, these results should be interpreted more cautiously than Hypotheses 2.  Chapter 5 will provide a summary of the key findings, along with the limitations of the study, and the research and therapeutic implications of the findings.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

The purpose of the study was to measure young adults' radiation treatment adherence and follow-up appointment adherence to older adults' adherence. The independent variables were age (i.e., young adult oncology patients as compared to older adult oncology patients), gender (i.e., male versus female) and race (i.e., minorities versus White/non-Hispanic), and the dependent variables were radiation treatment adherence and follow-up appointment adherence. McNemar's nonparametric test was the means of analysis for the first two hypotheses, and Pearson's chi-square analysis was used for Hypotheses 3 through 6. Participants were matched on gender, race, and diagnosis.

The central findings of the study were that young adult oncology patients adhere to follow-up appointments to a significantly lesser degree than older adult oncology patients, with 37 of the 46 young adults, and 41 of 46 older adults, adhering to radiation treatment, and only five of the 46 young adults adhering to follow-up appointments, as compared to 13 of the 46 older adults. The range of adherence was 0 to 100% for both groups with the average being 61.08% adherence for young adults. Because adherence to treatment and follow-up can impact long-term survival, there is a need to further explore the reasons for low adherence rates to radiation and follow-up appointments for young adults.

The central finding of this study was consistent with previous studies that have found young adults to exhibit poor adherence to medical treatments for a variety of illnesses, including HIV and asthma (Friedman et al., 2010; Wamboldt et al., 2011). Although there have been few studies on treatment adherence for young adult oncology patients, for those studies that did include young adults in the sample, they were combined with adolescents and did not include young adults between the ages of 25-40 years. Similar to the present study, for those studies that did include young adults, the adherence rates ranged from 53% to 75% (Kondryn et al., 2009; Tebbi et al., 1986). Additionally, researchers have not explored radiation treatment and follow-up appointment adherence, and only one study compared young adults to older adult oncology patients (Hershman et al., 2010). Instead, the researchers measured medication dosage compliance and chemotherapy attendance. In the Hershman et al. (2010) study, patients younger than 40 years of age and older than 75 years of age were less adherent to a long-term adjuvant hormonal therapy, as compared to adults between the ages of 40 and 75 years. The results of the Hershman et al. study cannot be likened to this study due to the long-term treatments (5 years) of the previous study, as compared to the few months of radiation treatment and 2 years of follow-up explored in the current study.

I also found that gender was related to follow-up appointment adherence, with a certain degree of certainty. However, these results should be interpreted more cautiously due to the differences in sample size between males and females. Furthermore, unexpectedly, it was females who adhered less than males. Because the mortality rates are higher for males less than 30 years of age, and older than 45 years of age, it would be important to further study this topic of adherence, comparing larger samples of males to females to assess gender as a variable that impacts adherence. Additionally, African

Americans have the lowest cancer survival rates for all age groups older than 15 years (National Cancer Institute, 2006). Therefore, this is also an area that requires further exploration with a larger sample to compare ethnic groups. Additionally, scholars who have studied adherence and have compared gender and ethnicity have shown inconsistent results (Dunbar-Jacob & Schlenk, 2001), which indicate further exploration of gender and ethnicity as moderating variables in cancer treatment and follow-up appointment adherence with larger samples. Also of interest, although not a hypothesis in the study, are the overall low adherence rates to follow-up appointments for both groups as compared to radiation treatment adherence.

Although there were no identified scholars who compared radiation treatment adherence to follow-up appointment adherence, one researcher found that adult oncology patients, 31 years of age and older (with a mean age of 62.4 years), were more likely to adhere to laboratory tests and were less likely to adhere to physical examinations (Cooper et al., 2007). In another study, there were lower rates of adherence for patients 80 years of age and older for surgery, radiation, and chemotherapy (Weggelaar et al., 2011). Cooper et al. (2007) that found that older adults are less likely to adhere to physical examination appointments is consistent with the results of the low adherence rates for follow-up appointments, the latter which is similar to a physical examination.

## Assumptions

This study was based on the assumption that the demographic data, radiation treatment adherence, and follow-up appointment attendance information were entered correctly in the patients' electronic and paper chart files. Given that humans are not fallible, there is always the possibility that there may be errors in the data, and because I did not directly collect the initial data, there is no way of knowing this. Additionally, the data are secondary in nature and were not gathered for the purpose of this study; therefore, it may not have been collected in a way that was best for this study.

## Delimitations

In this study, I measured radiation treatment adherence and follow-up appointment adherence for young adult oncology patients as compared to older adult oncology patients. I did not measure chemotherapy adherence due to the multiple variables (e.g., diverse treatment regimens, side effects, and other complications that may interfere with treatment). Additionally, I did not measure medical oncologist (i.e., chemotherapy) follow-up appointment adherence, primarily due to some of the patients attending follow-up with their medical oncologist in his/her office and some being followed at the clinic of the hospital from which the data were collected. Additionally, I did not control for stage of disease or compare diagnoses as contributing factors to the adherence.

## Limitations

One limitation of the study was that some patients may have continued to follow-up with their medical oncologist, as opposed to the radiation oncologist, in spite of the recommendations of the latter. This was not analyzed in the study. However, this is not to imply that a medical oncologist would be a substitute for the radiation oncologist. There are many important reasons for following up with both as prescribed. Radiation treatment can have long lasting effects on the skin and other organs that are not side effects of chemotherapy. Therefore, it would be equally important to follow through with radiation and follow-up appointments, in addition to medical oncologist follow-ups.

Another limitation of the study was the difficulty in measuring follow-up appointment adherence. Follow-up appointment adherence was measured by reviewing physician documentation in order to determine when the next patient follow-up appointment was scheduled. Although follow-ups were documented, this was not as clear cut as the quantitative analysis of patients' radiation treatment adherence whereas radiation treatment appointments were scheduled consecutively and clearly marked as absent or present, and follow-up appointments were not consistent across diagnosis or time period.

Another limitation of the study was the small number of males versus females (i.e., 26 males and 66 females) and the small number of minorities (i.e., 28 versus 64 non-Hispanic Whites). Therefore, although Pearson's chi-square analysis was conducted, and there were significant findings for gender on follow-up adherence, I cannot definitively state that gender did have an impact due to the smaller number of males in the study.

Another limitation was that, although every attempt was made to exclude patients who stopped their follow-up appointments due to death, there was a minute possibility that some patients included in the study may have discontinued for that reason, and this was not documented in the records. Furthermore, I did not consider cohort effects, diagnosis, stage of disease, insurance status, or transportation as contributing factors to adherence rates, nor did I explore a direct relationship between adherence and survival rates. Additionally, the study cannot be generalized to young adult patients with other medical issues, adherence to chemotherapy, or to treatment regimens which may change due to advances in treatment or changes in the diagnosis. Another limitation was that I did not examine causal relationships.

## Implications

The implications of the findings of the study are that lower adherence rates to radiation treatment and follow-up appointments for the young adult oncology population could be one explanation for the lack of increased survival rates for this age group. Young adults are the only age group of oncology patients that have not seen an increase in longevity over the past 20 years (National Cancer Institute, 2004). A better understanding of the reasons behind such low adherence to follow-up appointments for this age group could potentially increase adherence rates, thus leading to earlier diagnosis of reoccurrences and leading to earlier treatment, thus potentially saving money by avoiding more advanced and longer treatments, and most importantly, increasing longevity. Additionally, there is a need for interventions to improve adherence rates for young adult oncology patients.

## Recommendations

Further studies should be conducted with larger samples and with more equal groups in regards to gender and race so that the interactions could be analyzed with more certainty. Additionally, it is recommended that the reasons for adherence to follow-up appointments be furthered explored because the rates were low for both age groups. Because I did not directly explore the relationship between adherence rates and longevity, another area to explore is whether or not adherence rates are directly tied to survival rates. Perhaps a better understanding of gender and race as variables impacting adherence, along with a better understanding of the reasons for lower adherence to treatment follow-up appointments, could increase survival rates, decrease medical costs, and reduce insurance costs to patients and families. Also because young adults are more likely to have young children, the psychological, sociological, and economic benefits of increased survival rates for young adult oncology patients could lead to social change (e.g., children with two living parents are less likely to endure the pain and suffering of loss and remain psychological healthy and continue to be contributing members to society).

## Conclusion

In this study, I found lower adherence rates for young adult oncology patients to follow-up appointments, as compared to older adult oncology patients. Additionally, gender did impact follow-up appointment adherence. However, the latter results should be interpreted more cautiously due to the unequal sample sizes for males and females. There is a need for further exploration of the topic in order to determine if adherence rates do have a direct impact on survival rates of the young adult oncology population.

# References

Albritton, K., & Bleyer, W. A. (2003). The management of cancer in the older adolescent. *European Journal of Cancer, 39*(18), 2584-2599. doi:10.1016/j.ejca.2003.09.013

Alman, B. A., Pajerski, M. E., Diaz-Cano, S., Corboy, K., & Wolfe, H. J. (1997). Aggressive fibromatosis (desmoids tumor) is a monoclonal disorder. *Diagnostic Molecular Pathology 6*(2), 98-101. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9098648.

American Cancer Society. (2012). *Cancer facts and figures 2012*. Atlanta, Georgia: American Cancer Society.

Armstrong, G. T., Stovall, M., & Robinson, L. L. (2010). Long-term effects of radiation exposure among adult survivors of childhood cancer: Results from the Childhood Cancer Survivor Study. *Radiation Research, 174*(6B), 840-850. doi:10.1667/RR1903.1

Arria, A. M., Garnier-Dykstra, L. M., Caldeira, K. M., Vincent, K. B., & O'Grady, K. E. (2011). Prescription analgesic use among young adults: Adherence to physician instructions and diversion. *Pain Medicine, 12*(6), 898-903. doi:10.1111/j.1526-4637.2011.01107.x

Benson, J. E., Kirkpatrick Johnson, M., & Elder, G. H. (2011). The implications of adult identity for educational and work attainment in young adulthood. *Developmental Psychology*, *48*(6), 1751-1758. doi:10.1037/a0026364

Blanchard-Fields, F., & Norris, L. (1994). Causal attributions from adolescence through adulthood: Age differences, ego level, and generalized response style. *Aging, Neuropsychology and Cognition, 1*(1), 67-86. doi:10.1080/09289919408251451

Bleyer, A. (2007). Young adult oncology: The patients and their survival challenges. *CA: A Cancer Journal for Clinicians, 57*(4), 242-255. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/1762610.

Bleyer, A., Barr, R., Hayes-Lattin, B., Thomas, D., Ellis, C., & Anderson, B. (2008). The distinctive biology of cancer in adolescents and young adults. *Nature Reviews Cancer, 8*, 288-298. doi:10.1038/nrc2349

Bleyer, A., Budd, T., & Motello, M. (2006). Adolescents and young adults with cancer: The scope of the problem and criticality of clinical trials. *Cancer, 107*(7), 1645-1655. doi:10.1002/cncr.22102

Bleyer, A., O'Leary, M., Barr, R., & Ries, L.A. G. (Eds.). (2006). *Cancer epidemiology in older adolescents and* young *adults 15-29 years of age, including SEER incidence and survival 1975-2000*. National Cancer Institute. (NIH Publication No. 06-5767).

Bleyer, A., Viny, A., & Barr, R. (2006). Cancer in 15- to 29-year olds by primary site. *The Oncologist, 11*(6), 590-601. doi:10.1634/theoncologist.11-6-590

Bleyer, W. A., Tejeda, H., Murphy, S. B., Robison, L. L, Ross, J. A, Pollock, B. H.,… Ungerleider, R. S. (1997). National cancer clinical trials: Children have access; adolescents do not. *Journal of Adolescent Health, 21*(6), 366-373. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9401854.

Blotcky, A. D., Cohen, D. G., Conatser, C., & Klopovich, P. (1985). Psychosocial characteristics of adolescents who refuse cancer treatment. *Journal of Consulting Clinical Psychology, 53*(5), 729-731. Retrieved from http://www.apa.org/pubs/journals/ccp/

Brannon, L., & Feist, J. (2004). *Health psychology: An introduction to behavior and health* (5th ed.). Belmont, CA: Wadsworth/Thomson Learning.

Chen, M. H., Colan, S. D., Diller, L., & Force, T. (2011). Cardiovascular disease: Cause of morbidity and mortality in adult survivors of childhood cancers. *Circulation Research, 108,* 619-628. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/21372293

Cohen, D. G. (1986). Treatment refusal in adolescents. *Seminars in Oncology Nursing*, *2*(2), 112-116. doi:10.1016/0749-2081(86)90019-7

Cooper, G. S., Schultz, L., Simpkins, J., & Lafata, J. E. (2007). The utility of administrative data for measuring adherence to cancer surveillance care guidelines. *Medical Care, 45*(1), 66-72. doi:10.1097/01.mlr.0000241107.15133.54

Demissie, S., Silliman, R. A., & Lash, T. L. (2001). Adjuvant tamoxifen: Predictors of use side effects and discontinuation in older women. *Journal of Clinical Oncology, 19*(2), 322-328. Retrieved from https://www.google.com/?gws_rd=ssl#q=Journal+of+Clinical+Oncology

Denois, V. R., Poirson, J., Nourissat, A., Jacquin, J. P., Guastalla, J. P., & Chauvin, F. (2011). Adherence with oral chemotherapy: Results from a qualitative study of the behaviour and representations of patients and oncologists. *European Journal of Cancer Care, 20*(4), 520-527. Retrieved from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/issues

DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology, 23*(2), 207-218. doi:10.1037/0278-6133.23.2.207

DiMatteo, M., Giordani, P., Lepper, H., & Croghan, T. (2002). Patient adherence and medical treatment outcomes: A meta-analysis. *Medical Care, 40*(9), 794-811. Retrieved from http://journals.lww.com/lww-medicalcare/Pages/default.aspx

DiMatteo, M. R., Haskard, K. B., & Williams, S. L. (2007). Health beliefs, disease severity and patient adherence: A meta-analysis. *Medical Care, 45*(6), 521-528. doi:10.1097/MLR.0b013e318032937e

Dolgin, M. J., Katz, E. R., Doctors, S. R., & Siegel, S. E. (1986). Caregivers' perception of medical compliance in adolescents with cancer. *Journal of Adolescent Health Care, 7*(1), 22-27. Retrieved from http://www.jahonline.org/

Dolinoy, D. C., & Jirtle, R. L. (2008). Environmental epigenomics in human health and disease. *Environmental and Molecular Mutagenesis, 49*(1), 4-8. doi:10.1002/em.20366

Dunbar-Jacob, J., & Schlenk, E. A. (2001). Patient adherence to treatment regimen. In A. Baum, T. A. Revenson, & J. E. Singer (Eds.). *Handbook of health psychology (*pp. 571-580). Mahwah, NJ: Lawrence Earlbaum.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129-136. doi:10.1126/science.847460

Engel, G. L. (1992). The need for a new medical model: A challenge for biomedicine. *Family Systems Medicine, 10*(3), 317-331. doi:10.1126/science.847460

Engel, G. L. (1997). From biomedical to biopsychosocial: Being scientific in the human domain. *Psychotherapy and Psychosomatics, 66*(2), 57-62. doi:10.1159/000289109

Engel, G. L. (2005). A response from George Engel to Joseph Herman-May 5, 1989. *Families, Systems, & Health, 23*(4), 377-378. doi:10.1037/1091-7527.23.4.377

Festa, R. S., Tamaroff, M. H., Chasalow, F., & Lanzkowsky, P. (1992). Therapeutic adherence to oral medication regimens by adolescents with cancer: Laboratory assessment. *The Journal of Pediatrics, 120*(5), 807-811. doi:10.1016/S0022-3476(05)80256-2

Fink, A. K., Gurwitz, J., Rakowski, W., Guadagnoli, E., & Silliman, R. A. (2004). Patient beliefs and tamoxifen discontinuance in older women with estrogen receptor-positive breast cancer. *Journal of Clinical Oncology, 22*(16)*,* 3309-3315. doi:10.1200/JCO.2004.11.064

Fisher, L., & Feldman, S. S. (1998). Familial antecedents of young adult health risk behavior: A longitudinal study. *Journal of Family Psychology, 12*(1), 66-80. doi:10.1037/0893-3200.12.1.66

Foulon, V., Schoffski, P., & Wolter, P. (2011). Patient adherence to oral anticancer drugs: An emerging issue in modern oncology. *Acta Clinica Belgica: International*

*Journal of Clinical and Laboratory Medicine, 66*(2), 85-96. doi:10.2143/ACB66.2.206225.

Friedman, H. S., Navaratnam, P., & McLaughlin, J. (2010). Adherence and asthma control with mometasone furoate versus fluticasone propionate in adolescents and young adults with mild asthma. *Journal of Asthma*(9)*, 47*, 994-1000. doi:10.1080/02770903.2010.513076

Garcia-Gonzalez, A., Richardson, M., Popa-Lisseanu, M. G., Cox, V., Kallen, M. A., Janssen, N.,…Suarez-Almazor, M. E. (2008).Treatment adherence in patients with rheumatoid arthritis and systemic lupus erythematosus. *Clinical Rheumatology, 27*(7), 883-889. doi:10.1007/s10067-007-0816-6

Geraci, M., Eden, T. O. B., Alston, R. D., Moran, A., Arora, R. S., & Birch, J. M. (2009). Geographical and temporal distribution of cancer survival in teenagers and young adults in England. *British Journal of Cancer, 101*, 1939-1945. doi:10.1038/sj.bjc.6605410

Green, J., & Shellenberger, R. (1990). *The dynamics of health and wellness: A biopsychosocial approach*. Fort Worth, TX: Holt, Rinehart, & Winston.

Grinyer, A. (2003). Young adults with cancer: Parents' interactions with health care professionals. *European Journal of Cancer, 13*(1), 88-95. doi:10.1111/j.1365-2354.2004.00458.x

Haase, J. E., & Phillips, C. R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing, 21*(3), 145-149. doi:10.1177/1043454204264385

Hershman, D. L., Kushi, L. H., Shao, T., Buono, D., Kershenbaum, A., Tsai, W. Y., …Neugut, A. I. (2010). Early discontinuation and nonadherence to adjuvant hormonal therapy in a cohort of 8,796 early stage breast cancer patients. *Journal of Clinical Oncology, 28,* 1-10. Retrieved from http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2009.25.9655

Hijiya, N., Ness, K. K., Ribeiro, R. C., & Hudson, M. M. (2009). Acute leukemia as a secondary malignancy in children and adolescents: Current findings and issues. *Cancer, 115*(1), 23-35. doi:10.1002/cncr.23988

Hillen, M. A. D., Hanneke, C. J., M., de Haes, H. C. J. M., & Smets, E. M. A. (2011). Cancer patients' trust in their physician-a review. *Psycho-Oncology, 20*(3), 227-241. Retrieved from http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1099-1611

Hockenbury, D. H., & Hockenbury, S. E. (2012). *Psychology* (6th ed.). New York, NY: Worth Publishers.

Holland, H. (2009). Teenage and young adult oncology: Challenges for the specialty. *Paediatric Nursing, 21*(4), 38-41. Retrieved from http://www.pediatricnursing.org/

Hutchinson, C. L., Menck, H. R., Burch, M., & Gottschalk, R. (Eds.). (2004). *Cancer registry management: Principles and practice* (2nd Ed.). Dubuque, Iowa: Kendall/Hunt Publishing Company.

IBM Corp. (2012). *IBM SPSS statistics for Windows 21*. Armonk, NY: IBM Corp.

Institute of Medicine (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. In B. D. Smedley, A. Y. Stith, & A. R. Nelson (Eds.). Washington: DC: National Academic Press.

International Commission on Radiation Units & Measurement (2014). Retrieved from http://www.icru.org/

Jamison, R. N., Lewis, S., & Burish, T. G. (1986a). Cooperation with treatment in adolescent cancer patients. *Journal of Adolescent Health Care, 7*(3), 162-167. doi:10.1016/s0197-0070(86)800328

Jamison, R. N., Lewis, S., & Burish, T. G. (1986b). Psychological impact of cancer on adolescents: Self-image, locus of control, perceptions of illness, and knowledge of cancer. *Journal of Chronic Diseases, 39*(8), 609-617. doi:10.1097/01241398-198703000-00076

Janson, C., Leisenring, W., Cox, C., Termuhlen, A. M., Mertens, A. C., Whitton, J. A., …Kadan-Lottick, N. S. (2009). Predictors of marriage and divorce in adult survivors of childhood cancers: A report from the Childhood Cancer Survivor Study. *Cancer Epidemiology, Biomarkers, and Prevention, 18*, 2626-2653. doi:10.1158/1055-9965.EPI-08-0959

Kaiser, K., Rauscher, G. H., Jacobs, E. A., Strenski, T. A., Ferrans, C. E., & Warnecke, R. B. (2010). The import of trust in regular providers to trust in cancer physicians among White, African American, and Hispanic breast cancer patients. *Journal of General Internal Medicine, 26*(1), 51-57. doi:10.1007/s11606-010-1489-4

Kennard, B. D., Stewart, S. M., Olvera, R., Bawdon, R. E., hAilin, A. O., Lewis, C. P., &Winick, N. J. (2004). Nonadherence in adolescent oncology patients: Preliminary data on psychological risk factors and relationships to outcome. *Journal of Clinical Psychology in Medical Settings, 11*(1), 31-39. doi:10.1023/B:JOCS.0000016267.21912.74

Kirk, M. C., & Hudis, C. A. (2008). Insights into barriers against optimal adherence to oral hormonal therapy in women with breast cancer. *Clinical Breast Cancer, 8*(2), 155-161. doi:10.3816/CBC.2008.n.016

Kissane, D. (2009). Beyond the psychotherapy and survival debate: The challenge of social disparity, depression, and treatment adherence in psychosocial cancer care. *Psycho-Oncology, 18*(1), 1-5. doi:10.1002/pon.1493

Kissane, D. W., Bylund, C. L., Banerjee, S. C., Bialer, P. A., Levin, T. T., Maloney, E. K., & D'Agostino, T. A. (2012). Communication skills training for oncology professionals. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 30*(11), 1242-1247. Retrieved from http://jco.ascopubs.org/

Kondryn, H. J., Edmondson, C. L., Hill, J.W., & Eden, T. O. B. (2009). Treatment non-adherence in teenage and young adult cancer patients: A preliminary study of patient perceptions. *Psycho-Oncology, 18*(12), 1327-1332. doi:10.1002/pon.1541

Kondryn, H. J., Edmondson, C. L., Hill, J., & Eden, T. O. B. (2011). Treatment non-adherence in teenage and young adult patients with cancer. *Lancet Oncology, 12*(1), 100-108. doi:10.1016/S1470-2045(10)70069-3

Levine, J., Canada, A., & Stern, C. J. (2010). Fertility preservation in adolescents and young adults with cancer. *Journal of Clinical Oncology, 28*(32), 4831-4841. doi:10.1200/JCO.2009.22.8312

Magai, C., Consedine, N., Neugut, A. I., & Hershman, D. L. (2007). Common psychosocial factors underlying breast cancer screening and breast cancer treatment adherence: A conceptual review and synthesis. *Journal of Women's Health (Larchmt), 16*(1)*,* 11-23. doi:10.1089/jwh.2006.0024

Malbasa, T., Kodish, E., & Santactoce, S. J. (2007). Adolescent adherence to oral therapy for leukemia: A focus group. *Journal of Pediatric Oncology Nursing, 24*(3), 139-151. doi:10.1177/1043454206298695

Martin, S., Ulrich, C., Munsell, M., Taylor, S., Lange, G., & Bleyer, A. (2007). Delays in cancer diagnosis in underinsured young adults and older adolescents. *The Oncologist, 12*(7), 816-824. doi:10.1634/theoncologist.12-7-816

McMillan, D. C., & McArdle, C. S. (2009). The impact of young age on cancer-specific and non-cancer-related survival after surgery for colorectal cancer: 10-year follow up. *British Journal of Cancer, 101,* 557-560. doi:10.1038/sj.bjc.6605222

McTieran, A. (2003). Issues surrounding the participation of adolescents with cancer in clinical trials in the UK. *European Journal of Cancer Care, 12*(3), 233-239. Retrieved from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/issues

METRIQ Electra Cancer Registry Software-Version 2.82 (2015). (http;//www.eleckta.com/software-solutions/knowledge).

Meyer, B. J. F., Russo, C., & Talbot, A. (1995). Discourse comprehension and problem solving: Decisions about the treatment of breast cancer by women across the lifespan. *Psychology and Aging, 10*(1), 84-103. doi:10.1037/0882-7974.10.1.84

Meyer, B. J. F., Talbot, A. P., & Ranalli, C. (2007). Why older adults make more immediate treatment decisions about cancer than younger adults. *Psychology and Aging, 22*(3), 505-524. doi:10.1037/0882-7974.22.3.505

Miller, A. B., To, T., Baines, C. J., & Wall, C. (2002). The Canadian National Breast Screening Study-1: Breast cancer mortality after 11 to 16 years of follow-up: A randomized screening trial of mammography in women age 40-49 years. *Annals of Internal Medicine, 137*(5), 743-747. doi:10.2214/ajr.155.5.2120947

Mitchell, A. E., Scardella, D. L., Rigutto, G. L., Ashley, D. M., Thursfield, V. J., Giles, G. G., & Sexton, M. (2004). Cancer in adolescents and young adults: Treatment and outcome in Victoria*. The Medical Journal of Australia, 180*(2), 59-62. Retrieved from https://www.mja.com.au/

Mor, V., Allen, S., & Malin, M. (1994). The psychosocial impact of cancer on older versus younger patients and their families. *Cancer, 74*, 2118-2127. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8087779

National Cancer Institute. (2004). Surveillance, Epidemiology, and End Results (SEER ) Program. Retrieved March 25, 2012, from http://www.seer.cancer.gov

National Cancer Institute. (2010). Cancer staging. Retrieved from http://www.cancer.gove/cancertopics/factsheet/detection/staging

National Comprehensive Cancer Network. (2012). NCCN clinical practice guidelines in oncology: Adolescent and young adult (AYA) oncology. Retrieved from https://www.nccn.org/professionals/physician_gls/f_guidelines.asp

Oeffinger, K. C., Mertens, A. C., Hudson, M. M., Gurney, J. G., Casillas, J., Chen, H.,…Robinson, L. (2004). Health care of young adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Annals of Family Medicine, 2*(1), 61-70. doi:10.1370/afm.26

Papalia, D. P., & Duskin-Feldman, R., & Martorell, G. (2012). *Experience human development* (12th ed.). New York, NY: McGraw-Hill.

Park, M. J., Mulye, T. P., Adams, S. H., Brindis, C. D., & Irwin, C. E. (2006). The health status of young adults in the United States. *Journal of Adolescent Health, 39*(3), 305-317. doi:10.1016/j.jadohealth.2006.04.017

Power and Sample Calculator. (http://powerandsamplesize.com/Calculators/Compare-Paired-Proportions-McNemar-Z-test-1-sided).

Rabin, C. (2011). Review of health behaviors and their correlates among young adult cancer survivors. *Journal of Behavioral Medicine, 34*, 41-52. doi:10.1007/s10865-010-9285-5

Rabin, C., Simpson, N., Morrow, K., & Pinto, B. (2010). Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research, 21*(6), 796-806. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/20705863

Radiation Therapy Oncology Group. (2011). A prescription template for RTOG protocols. Retrieved from www.eortc.org

Reyna, V. F., Estrada, S. M., DeMarinis, J. A., Myers, R. M., Stanisz, J. M., & Mills, B. A. (2011). Neurobiological and memory models of risky decision making in adolescents versus young adults. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 37*(5), 1125-1142. doi:10.1037/a0023943

Romer, D. (Ed.). (2003). *Reducing adolescent risk: Toward an integrated approach.* Thousand Oaks, CA: Sage Publications.

Roscoe, J. A., Morrow, G. R., Aapro, M. S., Molassiotis, A., & Olver, I. (2011). Anticipatory nausea and vomiting. *Support Care Cancer, 19,* 1533-1538. doi:10.1007/s00520-010-0980-0

Saratsiotou, I., Kordoni, M., Bakogiannis, C., Livadarou, E., Skarlos, D., Kosmidis, P. A., & Razis, E. (2010). Treatment adherence of cancer patients to orally administered chemotherapy: Insights from a Greek study using a self-reported questionnaire. *Journal of Oncology Pharmacy Practice, 17*(4), 304-311. doi:10.1177/1078155210380292

Schell, M. J., McHaney, V. A., Green, A. A., Kun, L. E., Hayes, F. A., Horowitz, M., & Meyer, W. H. (1989). Hearing loss in children and young adults receiving cisplatin with or without prior cranial irradiation. *Journal of Clinical Oncology, 7*(6)*,* 754-760. Retrieved from http://jco.ascopubs.org/

Sheard, T., & Maguire, P. (1999). The effect of psychological interventions on anxiety and depression: Results of two meta-analyses. *British Journal of Cancer, 80*(11), 1770-1780. doi:10.1038/sj.bjc.6690596

Smith, S. D., Rosen, D., Trueworthy, R. C., & Lowman, J. T. (1979). A reliable method for evaluating drug compliance in children with cancer. *Cancer, 43*(1), 169-173. doi:10.1002/1097-0142(197901)43:1%3C169::AID-CNCR2820430125%3E3.0.CO;2-F

Stava, C. J., Lopez, A., & Vassilopoulou-Sellen, R. (2006). Health profiles of younger and older breast cancer survivors. *Cancer, 107*(8), 1752-1759. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16967441

Steinberg, L. (2007). Risk taking in adolescence: New perspectives from brain and behavioral science. *Current Directions in Psychological Science, 16*(2), 55-59. doi:10.1111/j.1467-8721.2007.00475.x

Stensvold, A., Dahl, A. A., Fossa, S. D., Axcrona, K., Lilleby, W., Brennhovd, B., & Smeland, S. (2011). Clinicians' use of guidelines as illustrated by curative treatment of prostate cancer at a comprehensive cancer center. *Acta Oncologica, 50*(3), 408-414. Retrieved from http://www.tandfonline.com/journal/ionc20#.V5Kr76IerOs

Stilley, C. S., Bender, C. M., Dunbar-Jacob, J., Sereika, S., & Ryan, C. M. (2010). The impact of cognitive function on medication management: Three studies. *Journal of Health Psychology, 29*(1), 50-55. doi:10.1037/a0016940

Sunmi, C. L. (2001). The use of narrative in understanding how cancer affects development: The stories of one cancer survivor. *Journal of Health Psychology, 6*(3), 283-293. Retrieved from http://hpq.sagepub.com/

Tebbi, C., K., Cummings, K. M., Zevon, M. A., Smith, L., Richards, M., & Mallon, J. (1986). Compliance of pediatric and adolescent cancer patients. *Cancer, 58*(5), 1179-1184. doi:10.1002/1097-0142(19860901)58:5%3C1179::AID-CNCR2820580534%3E3.0.CO;2-E

Vassarstats online calculator. (2016). Retrieved from vassarstats.net/propcorr.html

Vermeire, E., Hearnshaw, H., Van Royen, P., & Denekens, J. (2001). Patient adherence to treatment: Three decades of research: A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics, 26*(5), 331-342. doi:10.1046/j.1365-2710.2001.00363.x

Vourlekes, B., & Ells, K. (2007). Best practice case management for improved medical adherence. *Social Work in Health Care,, 44*(3), 161-177. doi:10.1300/J010v44n03_03

Wamboldt, F. S., Bender, B. G., & Rankin, A. E. (2011). Adolescent decision-making about use of inhaled asthma controller medication: Results from focus groups with participants from a prior longitudinal study. *The Journal of Asthma: Official Journal of the Association for the Care of Asthma, 48*(7), 741-750. doi:10.3109/02770903.2011.598204

Weggelaar, I., Aben, K. K., Warle, M. C., Strobbe, L. J., & van Spronsen, D. J. (2011). Declined guideline adherence in older breast cancer patients: A population based study in the Netherlands. *The Breast Journal, 17*(3), 239-245. doi:10.1111/j.1524-4741.2011.01074.x

Wiener, L., Riekert, K., Ryder, C., & Wood, L. V. (2004). Assessing medication adherence in adolescents with HIV when electronic monitoring is not feasible. *AIDS Patient Care and STDs, 18*(9), 527-538. doi:10.1089/apc.2004.18.527

Winkeljohn, D. (2010). Adherence to oral cancer therapies: Nursing interventions. *Clinical Journal of Oncology Nursing, 14*(4), 461-466. doi:10.1188/10.CJON.461-466

Wood, S. E., Green-Wood, E., & Boyd, D. (2011). *The world of psychology* (7th ed.). Boston, MA: Allyn & Bacon.

Woodhead, E. L., Lynch, E. B., & Edelstein, B. A. (2011). Decisional strategy determines whether frame influences treatment preferences for medical decisions. *Psychology and Aging, 26*(2), 285-294. doi:10.1037/a0021608

World Health Organization. (2003). Adherence t**o** long-term therapies. Evidence for action 2003.Retrieved from http://www/who.int/chp/knowledge/publications/adherence_report/en

Wray, J., Water, S., Radley-Smith, R., & Sensky, T. (2006). Adherence in adolescents and young adults following heart or heart-lung transplantation. *Pediatric Transplantation, 10*(6), 694-700. doi:10.1111/j.1399-3046.2006.00554.x

Xu, S., Yang, Y., Tao, W., Song, Y., Chen, Y., Ren, Y.,...Pang, D. (2012). Tamoxifen adherence at its relationship to mortality in 116 men with breast cancer. *Breast Cancer Research and Treatment, 136*(2), 495-502. doi:10.1007/1S10549-012-2286-2

Zebrack, B., Hamilton, R., & Wilder-Smith, A. (2009). Psychosocial outcomes and service use among young adults with cancer. *Seminars in Oncology, 36*(5), 468-477. doi:10.1053/j.seminoncol.2009.07.003

Zebrack, B., Mathews-Bradshaw, B., & Siegel, S. (2010). Quality cancer care for adolescents and young adults: A position statement. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 28*(32), 4862-4867. doi:10.1200/JCO.2010.30.5417

Zelter, L., K. (1993). Cancer in adolescents and young adults psychosocial aspects: Long-term survivors. *Cancer, 71*(10), 3463-3468. Retrieved from http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142