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EVALUATION OF LIVE**STRONG**® AT THE YMCA, A CANCER SURVIVORSHIP PROGRAM AT A MIDWEST FACILITY; A RETROSPECTIVE STUDY

A Chapter Style Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Public Health

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ABSTRACT

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The study analyzed retrospective data of a Midwest LIVE**STRONG**® cancer survivorship program to better understand if it was meeting its goals, as well as provide information for future program modifications. The study analyzed both pre and post program participant data from the sample of 332 cancer survivors. The study focused on measures of quality of life as well as physical functional assessments to measure these goals. Of the 18 dependent variables analyzed, 11 (61.1%) revealed a statistically significant decrease between pre and posttest measures. These results can be utilized to inform recommendations for future cancer survivorship programming.

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CHAPTER I

INTRODUCTION

Background of the Problem

The American Cancer Society defines cancer as a group of diseases characterized by the uncontrolled growth and spread of abnormal cells (American Cancer Society, 2016). As a disease, cancer affects over 14 million Americans nationwide with new cases being diagnosed daily (American Cancer Society, 2016). According to the National Cancer Institute (NCI), overall cancer mortality has been declining since the early 1990s (NCI, n.d., b). With the overall cancer death rate decreasing, the number of people living beyond a cancer diagnosis is on the rise. According to the Annual Report to the Nation on the Status of Cancer, from 2002 to 2011 the cancer death rate has decreased by 1.8 percent per year among males, and 1.4 percent per year among females (Kohler et al., 2015). Additionally, the National Cancer Institute identifies that the number of individuals living with cancer in the United States is expected to rise to almost 19 million by 2024 (NCI, n.d., c). Although cancer rates are increasing, more people are surviving cancer due to the increase in early detection as well as advancements in treatment and better follow-up care (Centers for Disease Control and Prevention, 2011).

A cancer survivor is defined by the Center for Disease Control and Prevention (CDC, 2007) as anyone who has been diagnosed with cancer, from the time of diagnosis through the balance of his or her life. To better support individuals affected by cancer beyond clinical treatments, cancer survivorship programs are vital (Ligibel, 2012;

Loprinzi & Lee, 2012). Currently, there is an array of cancer survivorship programs offered in a variety of settings across the United States (Underwood et al, 2015).Programs tailored to address mental and physical needs of individuals affected by cancer are typically offered by organizations such as medical clinics, community centers, universities, or fitness facilities. LIVE**STRONG**® at the YMCA is a nation wide cancer survivorship program offered in many states across the nation.

LIVE**STRONG**® at the YMCA, referred to as LIVE**STRONG**® for the purpose of this paper, is a survivorship program offered at YMCA facilities throughout the country. This survivorship program developed out of collaboration between the LIVE**STRONG**® Foundation and the YMCA (LIVE**STRONG**® Foundation, 2015). The main goals of LIVE**STRONG**® are to: (a) improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life (LIVE**STRONG**® Foundation, 2015). As of September 2015, LIVE**STRONG**® has served over 33,000 survivors, and is built on a model that offers physical and social support at no cost to participants (LIVE**STRONG**® Foundation, 2015).

LIVE**STRONG**® is a program facilitated by YMCA-certified instructors addressing physical and mental components of a cancer survivor's well-being (LIVE**STRONG**® Foundation, 2015). The program sessions are 90-minutes, two days a week, and are held in YMCA Wellness Centers (LIVE**STRONG**® Foundation, 2015). The sessions include activities such as cardiovascular conditioning, strength training, balance exercises, flexibility exercises, and small-group discussions. Additionally, the program utilizes data collection tools including functional and quality of life assessments,

both before and after program participation, to collect program and participant information (D. Malone, Personal Communication, February 17, 2015). Prior to participating in the program, individuals must have a physician completed medical clearance form, which is supplied to the individual by LIVE**STRONG**® certified staff. After medical clearance, participants can be enrolled in the program if they are 18 years or older, and are currently going through cancer treatment or have gone through some form of cancer treatment in the past. Additional criteria for participation include a strong personal desire to participate, a personal commitment to attend all 24 class sessions, completing screening forms, answering the health questionnaire, as well as giving permission to the LIVE**STRONG**® project manager to contact one's health care provider if medically necessary (LIVE**STRONG**® Foundation, 2015).

Evaluating LIVE**STRONG**® is essential to ensure that as a cancer survivorship program, it is meeting its goals and the needs of its participants. Utilizing information from participant outcomes can contribute to identification of potential areas for modification within the program. The program reaches a wide number of cancer survivors, and it is vital that it continues on its current trajectory to improve the health and well-being of cancer survivors.

Purpose of the Study

The purpose of this study was to evaluate LIVE**STRONG**®, a cancer survivorship program, to better understand if it was meeting its goals, as well as provide information for future program modifications through the analysis of retrospective data.

Need for the Study

Current research suggests there are various survivorship programs offered at a variety of locations across the United States for cancer survivors (Underwood et al, 2015). While survivorship programs offered at individual facilities should not be overlooked, LIVE**STRONG®** is a cancer survivorship program offered at many local YMCA facilitates nationwide. Therefore, LIVE**STRONG®** has the capacity of reaching many individuals across the nation.

There are currently 174 LIVE**STRONG®** programs in existence across 37 states (LIVE**STRONG®** Foundation, 2015). The accessibility of this YMCA program provides an opportunity for a variety of cancer survivors to participate in survivorship programing. The program is available across the nation, reaching a large number of individuals. The program's prevalence across the country makes it crucial to evaluate the program's successes and areas for improvement as a means to continuously enhance the program to provide the best services possible.

Significance of the Study

The LIVE**STRONG®** program at the Midwest facility utilized in this study collected valuable information on participants and program impacts through structured instruments. This data was used to evaluate the program. By analyzing pre and post intervention data, which included performing descriptive analyses of the data, as well as completing various statistical analyses, the question of whether or not the program is meeting its goals was addressed. Based on this study, recommendations were made to the LIVE**STRONG®** in regards to how the program may be modified to better meet its goals on both a local and national level. Additionally, this evaluation may serve as a starting

point for ongoing assessment and tailoring of the program at this specific program location in the future.

Research Questions

The current study investigated the following research questions:

1. Was there a change in quality of life among participants who completed LIVE**STRONG®**?
2. Was there a change in physical function among participant who completed LIVE**STRONG®**?

Hypotheses

1. Hypothesis One: There is a positive change in physical function between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis One: There is a negative change in physical function between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Null Hypothesis One: There is no change in physical function between pre and posttest measurement for participants who completed LIVE**STRONG®**.

2. Hypothesis Two: There is a positive change in anxiety between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis Two: There is a negative change in anxiety between pre and posttest measurement for participants who completed LIVE**STRONG®**

   Null Hypothesis Two: There is no change in anxiety between pre and posttest measurement for participants who completed LIVE**STRONG®**

3. Hypothesis Three: There is a positive change in depression between pre and posttest measurement for people who completed LIVE**STRONG®**.

   Alternative Hypothesis Three: There is a negative change in depression between pre and posttest measurement for people who completed LIVE**STRONG®**.

   Null Hypothesis Three: There is no change in depression between pre and posttest measurement for people who completed LIVE**STRONG®**.

4. Hypothesis Four: There is a positive change in fatigue between pre and posttest measurement for people who completed LIVE**STRONG®**.

   Alternative Hypothesis Four: There is a negative change in fatigue between pre and posttest measurement for people who completed LIVE**STRONG®**.

   Null Hypothesis Four: There is no change in fatigue between pre and posttest measurement for people who completed LIVE**STRONG®**.

5. Hypothesis Five: There is a positive change in sleep disturbance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis Five: There is a negative change in sleep disturbance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Null Hypothesis Five: There is no change in sleep disturbance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

6. Hypothesis Six: There is a positive change in social role satisfaction between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis Six: There is a negative change in social role satisfaction between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Null Hypothesis Six: There is no change in social role satisfaction between pre and posttest measurement for participants who completed LIVE**STRONG®**.

7. Hypothesis Seven: There is a positive change in pain interference between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis Seven: There is a negative change in pain interference between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Null Hypothesis Seven: There is no change in pain interference between pre and posttest measurement for participants who completed LIVE**STRONG®**.

8. Hypothesis Eight: There is a positive change in pain intensity between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Alternative Hypothesis Eight: There is a negative change in pain intensity between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Null Hypothesis Eight: There is no change in pain intensity between pre and posttest measurement for participants who completed LIVE**STRONG®**.

9. Hypothesis Nine: There is a positive change in six-minute walk test pre heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Alternative Hypothesis Nine: There is a negative change in six-minute walk test pre heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   Null Hypothesis Nine: There is no change in six-minute walk test pre heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

10. Hypothesis Ten: There is a positive change in six-minute walk test post heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Ten: There is a negative change in six-minute walk test post heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Ten: There is no change in six-minute walk test post heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

11. Hypothesis Eleven: There is a positive change in six-minute walk distance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Eleven: There is a negative change in six-minute walk distance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Eleven: There is no change in six-minute walk distance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

12. Hypothesis Twelve: There is a positive change in upper body strength between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Alternative Hypothesis Twelve: There is a negative change in upper body strength between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Null Hypothesis Twelve: There is no change in upper body strength between pre and posttest measurement for participants who completed LIVE**STRONG®**.

13. Hypothesis Thirteen: There is a positive change in lower body strength between pre and posttest measurements for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Thirteen: There is a negative change in lower body strength between pre and posttest measurements for participants who completed LIVE**STRONG®**.

    Null Hypothesis Thirteen: There is no change in lower body strength between pre and posttest measurements for participants who completed LIVE**STRONG®**.

14. Hypothesis Fourteen: There is a positive change in flexibility of the right shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Fourteen: There is a negative change in flexibility of the right shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Fourteen: There is no change change in flexibility of the right shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

15. Hypothesis Fifteen: There is a positive change in flexibility of the left shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Fifteen: There is a negative change in flexibility of the left shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Fifteen: There is no change in flexibility of the left shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

16. Hypothesis Sixteen: There is a positive change in balance of the right leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Alternative Hypothesis Sixteen: There is a negative change in balance of the right leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Null Hypothesis Sixteen: There is no change in balance of the right leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

17. Hypothesis Seventeen: There is a positive change in balance of the left leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Seventeen: There is a negative change in balance of the left leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Seventeen: There is no change in balance of the left leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

18. Hypothesis Eighteen: There is a positive change in left side arm reach between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Alternative Hypothesis Eighteen: There is a negative change in left side arm reach between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    Null Hypothesis Eighteen: There is no change in left side arm reach between pre and posttest measurement for participants who completed LIVE**STRONG®**.

Data Collection and Analysis

For the purpose of this study, data analysis consisted of statistical investigation of pre and post participant information utilizing retrospective data collected by LIVE**STRONG®** certified staff. Data was entered into IBM SPSS Version 23 computer software (SPSS) as de-identified pairs. A pearson's product-moment correlation coefficient was utilized to measure the linear correlation, if any, between dependent variables in the study. If there was a positive correlation, that is, a value between zero and one, variables were combined for future data analysis due to association. If there was no correlation, dependent variables were analyzed individually. Based off of the pearson's

product- moment correlation coefficient results, a paired samples t-test, also known as dependent t-tests, were run for each variable. Each dependent t-test measured two related groups of pre and post data for a specific depended variable, to determine if there was a significant change between means.

There were 18 different dependent variables. Dependent t-tests were run on the following variables: physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference, pain intensity, six-minute walk test pre heart rate, six-minute walk test post heart, six-minute walk test distance, lower body strength, upper body strength, flexibility of the right shoulder, flexibility of the left shoulder, balance of the right leg, balance of the left leg, and left side arm reach. There was one dependent t-test run for each variable, for a total of 18 tests. The results from the t-test allowed for determination of the null hypothesis regarding whether or not each hypothesis set could be rejected, based off of the set alpha level, and if the alternative hypothesis could in turn be accepted. Additionally, analysis of this data was beneficial in providing an understanding of the changes in quality of life and physical function as well as whether or the program was meeting its goals.

Delimitations

1. A delimitation of this study was data analysis only includes participants from 2011-2015 due to differing data collection instruments prior to 2011.
2. A delimitation of this study was program success was measured within the bounds of the LIVE**STRONG**® questionnaires the program utilized.

3. A delimitation of this study was data collection being limited to information collected by LIVE**STRONG**® employees between 2011-2015 and participants with missing data were excluded from analysis.

Limitations

1. A limitation of this study was the questionnaire responses were self-reported; therefore responses could not be guaranteed to be completely honest.
2. A limitation of this study was that the retrospective data was collected by someone other than the researcher. Thus, there was no way to verify levels of encouragement each participant group may have had during pre and post functional assessment performance, which could have affected their results.
3. A limitation of this study was that certain events may have taken place during the time between pre and post program participation data collection that may have influenced a subject's response to PROMIS-29 self-evaluation items in unknown ways.
4. A limitation of this study was program participation was not consistently tracked over 12 weeks; therefore there was no way to verify that each participant attended the 24-offered program sessions.

Assumptions

1. An assumption of this study was that all participants answered the questionnaires honestly and in a forthright manner.
2. An assumption of this study was that all participants performed to the best of their abilities during the pre and post functional assessments.

3. An assumption of this study was that all participants understood the purpose of, and content included within the PROMIS-29 self-evaluation.
4. An assumption of this study was that all participants completed all 24 sessions within the 12-week program duration

Definition of Terms

Cancer Prevention: Refers to reduction in cancer occurrence, such that at any age fewer people have cancer than otherwise would be the case (American Cancer Society, 2015)

LIVESTRONG® Foundation: Organization serving people affected by cancer through collaborative programs and direct support services (LIVE**STRONG®** Foundation, n.d.)

LIVESTRONG®: A 12-week cancer survivorship program carried out by certified YMCA staff at YMCA facilities across the nation. The program was developed from collaboration between the LIVE**STRONG®** foundation and the YMCA. (LIVE**STRONG®** Foundation, 2015).

Summary

Overall, the content of this chapter provided insight into the effect cancer has on individuals within the United States, as well as emphasized the importance of cancer survivorship programming. Facilities have identified survivorship needs and have developed programs to address the growing population of cancer survivors. Specifically, LIVE**STRONG®** is a survivorship program offering essential programming for the health of individuals after a cancer diagnosis. Evaluation of such programs is key to continue to meet the participants' needs. The following chapter will delve deeper into cancer as a disease, identifying its prevalence, the risk factors contributing to the disease, various cancer treatment methods, and cancer survivorship. It also describes the

LIVE**STRONG®** cancer survivorship program in greater depth, and discusses program evaluation techniques.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

The purpose of this chapter is to discuss and explore issues related to cancer as well as cancer survivorship. After completing a detailed review of research on the topic, six main areas have been found which include the following: (a) cancer and its prevalence, (b) cancer related risk factors, (c) cancer treatment, (d) cancer survivorship, (e) LIVE**STRONG®,** and (f) program evaluation techniques.

The following sections of the paper discuss the current prevalence of cancer in the United States and its effect on an individual's life. In addition, programs created to benefit a cancer survivor's health, specifically LIVE**STRONG®**, will be highlighted. Literature searches were conducted in EBSCOhost with key words including cancer, cancer programs, risk factors, cancer morbidity, cancer mortality, cancer programming, cancer prevalence, cancer treatment, cancer recovery, survivorship support, and LIVE**STRONG®**.

Cancer and its Prevalence

Cancer is a disease affecting men and women all across the world. The American Cancer Society (ACS) defines cancer as a group of diseases characterized by the uncontrolled growth and spread of abnormal cells (ACS, 2016). According to the ACS, nearly 14.5 million Americans with a history of cancer were alive on January 1, 2014,

and approximately 1,685,210 new cases are expected to be diagnosed in 2016 (ACS, 2016). Cancer is affecting a large proportion of the population, and it is important to note that lifestyle factors can contribute to the prevention of cancer. It is essential to recognize the relationships between food, nutrition, physical activity, body composition, and the risk of cancer (ACS, 2016). Body fatness, physical inactivity, excessive alcohol consumption and/or poor nutrition are suspected to be related to about 20% of all cancer diagnoses in the United States (World Cancer Research Fund and American Institute for Cancer Research, 2007). With a proportion of cancer prevalence stemming from modifiable risk factors, the importance of health education and preventive practices must be shared.

While there are varying types of cancer, the most common types of cancer affecting individuals in the United States include breast, prostate, lung, and colorectal (ACS, 2016). The leading type of cancer cases and deaths varies among gender. Prostate cancer is the leading cancer in males with an estimated 4,550 new cases to emerge in 2016, accounting for 18% of new cancer cases in males. The leading type of cancer for women is currently breast at 11,090 cancer cases, and predicted to account for 34% of all new cases to emerge in females in 2016. For males, the second most prevalent type of cancer contributing to new cases are estimated to be lung and bronchus at 3,460 and colorectal at 2,990 cases, and for females, thyroid cancer cases at 3,320, and lung and bronchus cases at 3,030 (Cancer Facts and Figures, 2016). With cancer affecting so many lives, it is essential that our society becomes aware of measures to improve individuals' health. Preventive measures, treatment options, and survivorship programming for

recovery should be encouraged to limit the negative effects cancer can have on an individual's wellbeing, and strive for optimal health for all individuals.

Cancer Related Risk Factors

Preventive measures can be taken to decrease an individual's risk of developing cancer. The World Cancer Research Fund International estimates that about 20 percent of cancer diagnoses in the United States are related to modifiable risk factors such as the food choices one makes, daily nutrition, physical activity levels, and body composition (World Cancer Research Fund, n.d.). For example, the ACS identifies approximately 188,800 of the estimated 595,690 cancer deaths in the United States in 2016 will be caused by cigarette smoking (ACS, 2016). Whether an individual smokes or not can influence their health greatly because tobacco use is strongly correlated to an increased risk for developing cancer (National Cancer Institute, n.d., b).

The ACS identifies that lung cancer is the leading cause of cancer death in the United States for all individuals, accounting for approximately one in every four cancer deaths (ACS, 2016). Cigarette smoking is the leading cause of many cancers including acute myelogenous leukemia, bladder cancer, esophageal cancer, kidney cancer, lung cancer, oral cavity cancer, pancreatic cancer, and stomach cancer. Additionally, recent evidence suggests that tobacco smoking may cause female breast cancer (United States Department of Health and Human Services, 2014).

In addition to tobacco habits, individuals should be cognizant of other potential modifiable health behaviors within their control. The World Cancer Research Fund and American Institute for Cancer Research identify that if an individual is overweight or obese, this increases their risk of developing some cancers (World Cancer Research Fund

International and American Institute for Cancer Research, 2007). Research findings also suggest that maintaining a healthy weight throughout one's life may be one of the most vital ways to protect against developing cancer (ACS, 2016).

Physical activity also protects against some cancers by decreasing obesity (ACS, 2016). The World Cancer Research Fund and American Institute for Cancer Research have noted that since the 1970's, physical activity throughout the day is decreasing. This is attributed to it becoming increasingly uncommon for people to be moving throughout the day for reasons such as tasks in the workplace and at home becoming more mechanized, as well as an increase use of vehicles (The World Cancer Research Fund and American Institute for Cancer Research, 2007). The United States Department of Health and Human Services Healthy People 2020 goals and reports identified that in 2014, only 21.3 percent of adults in the United States 18 years of age and older were meeting the physical activity guideline recommendations, meaning approximately 80 percent of individuals were not meeting the physical activity guidelines (United States Department of Health and Human Services, 2016). Current recommendations for adults in regards to physical activity is participation in at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous- intensity aerobic physical activity (or an equivalent combination of both), as well as muscle-strengthening activities of moderate or high intensity involving all major muscle groups two of more days a week for substantial health benefits (United States Department of Health and Human Services, 2008).

Diet is another important aspect of one's cancer risk. Foods may be protective or detrimental to an individual's health. For example, unhealthy food may serve as an

avenue to an unhealthy weight, increasing the chance of becoming obese and future cancer risk. While there are foods that may increase the risk of developing cancer, research has shown consumption of several plant-based foods may protect against cancers developing at various sites of the body (ACS, 2016). Consuming fruits and vegetables, and limiting one's consumption of red meat, refined grains, and sugar-sweetened beverages may decrease risk of cancer mortality (ACS, 2016). Additionally, the consumption of alcohol is a risk factor for various cancers, and consumption should be limited. According to the ACS, the risk of mouth, pharynx, larynx, esophagus, liver, colorectal, female breast, and potentially pancreatic cancer increases with the consumption of more than two alcoholic drinks per day (ACS, 2016).

While individual choices may play a large role in the development of cancer, it is important to also note that environmental risk factors contribute to cancer risk and may be hard to avoid. For example, location of residence, access to healthy foods, availability of health education, and various factors can be influenced by socioeconomic status, putting individuals at an increased risk of diminished health beginning at birth. According to a study completed by Brownson and colleagues (2001), out of a sample of participants, individuals with lower incomes were 20 percent as likely to report heavy traffic in their neighborhoods, as well as greater incidence of unattended dogs, and air pollution among both men and women. These issues demonstrate how environmental factors may affect one's access to safe outdoor physical activity and deter their participation (Brownson, Baker, Housemann, Brennan, & Bacak, 2001). Individuals who do not feel as safe outdoors due to factors such as traffic, animals, or air pollution in the

areas they live, exemplify how factors such as how a place of residence which may be influenced by socioeconomic status, may also influence cancer risk.

From the many influences on cancer development, it is evident that multiple factors can play a role in an individual's risk of developing cancer. While lifestyle and environmental factors influence the development of cancer, genetics can also impact one's risk of developing cancer. According to the ACS, genetics can contribute to an individual being more predisposed to developing cancer (ACS, 2016). The ACS states:

> "some types of cancer run in certain families but most cancers are not clearly linked to the genes we inherit from our parents, rather, gene changes in an individual's cells over the course of their life are the main cause of most cancers" (ACS, 2016).

This statement further supports why it is essential for all individuals to be cognizant of their health behaviors, strive to limit the presence of modifiable risk factors, and focus on protective risk factors to limit cancer risk. As evident by cancer prevalence data from across the United States, cancer cannot always be prevented, and for individual's who do develop cancer, there are various treatment options available (Cancer Facts and Figures, 2016).

Cancer Treatments

Depending on what type of cancer an individual has and which treatment plan a patient and doctor decide on, there are various types of cancer treatments available. These treatment options include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, hormone therapy, clinical trials or a combination of several (National Institute of Cancer, 2015). Common types of cancer treatment are chemotherapy,

radiation therapy, and/or surgery. As the National Institute of Cancer explains, chemotherapy is a form of treatment to decrease the size of tumors before surgery or radiation. It can also be used to destroy remaining cancer cells after radiation or combat cells that have spread to other parts of an individual's body (National Institute of Cancer, 2015). Radiation is another type of treatment option. It is typically used alongside other treatments to combat cancer prior to surgery. Radiation is utilized to shrink the size of the cancer before and/or after surgery to kill any cancer cells remaining in the body (National Institute of Cancer, 2015). Another treatment method for many people is surgery, often used to remove solid tumors in one area of the human body (National Institute of Cancer, 2015). Each of these treatment methods has varying side affects and are an important factor to consider in an individual's recovery.

Today, more people than ever are surviving cancer. This rise in survivorship can be attributed to the increase in early detection as well as advancements in treatment and better follow-up care (Centers for Disease Control and Prevention, 2011). Death rates have been falling on average 1.5 percent each year from 2003 to 2012 (ACS, 2016). With a high number of individuals living with cancer, tailored programs need to be created to support the physical and psychological health of these individuals after treatment.

Cancer not only impacts an individual physically, but financially as well. Along with a cancer diagnosis comes additional medical costs such as doctor appointments, treatment, medication, and also other costs such as travel, childcare, home care, or other financial issues that may be associated with employment (American Society of Clinical Oncology, 2015). According to the Agency for Healthcare Research and Quality, it is estimated that direct medical costs for cancer within the United States in 2013 were 74.8

billion dollars (ACS, 2016). Analyzing costs for cancer at the individual level, cost projections created by the National Cancer Institute (n.d., a), indicate the mean net cost of care for individuals 65 years and older for prostate cancer was an average of 19,710 dollars in the initial year after diagnosis. For breast cancer, this cost reached 23,078 dollars on average (National Cancer Institute, n.d., a). Therefore, it is not only financially responsible to focus on prevention, but also to create low cost and effective cancer survivorship programming.

Cancer Survivorship

After cancer diagnosis and treatment, it is important to continue to focus on the health of individuals who have been affected by cancer. Research supports that individuals who have been diagnosed with cancer have a higher risk of developing second primary cancers, as well as increased risk for the development of other diseases such as cardiovascular disease, diabetes, and osteoporosis (American Society of Clinical Oncology, 2015). Physical activity has been suggested as an avenue to decrease cancer reoccurrence for some cancer types (Loprinzi, Cardinal, Winters-Stone, Smit, & Loprinzi, 2012).

Loprinzi and Lee (2014) have suggested the following:

"cancer survivors are relatively inactive, but the promotion of physical activity among this population is highly encouraged because it may help to reduce the risk of cancer recurrence and cancer-related mortality, increase cancer treatment rates, reduce pain and other side effects associated with cancer treatment, improve physical and mental health, and improve biologic parameters associated with various chronic diseases" (Loprinz & Lee, 2014, p. 123).

Additionally, according to Van Blarigan and Meyerhardt (2015), "observational data strongly support a beneficial effect of physical activity after colorectal cancer diagnosis on cancer-specific and overall survival" (Van Blarigan & Meyerhardt 2015). In addition, research also suggests that individuals participating in regular physical activity may reduce their risk of breast cancer reoccurrence and breast cancer-related mortality (Ibrahim & Al- Homaidh, 2011). Therefore, it is essential to have programs available to encourage cancer survivors to be physically active.

Luckily, many such programs exist across the United States for individuals who have been affected by cancer. Although these cancer survivorship programs are available, the extent of services provided and program comprehensiveness between mental and physical health varies, as well as the cost and location among programs (Wolin, Colditz, & Proctor, 2011). Programs may be offered through medical clinics, universities or community organizations, ranging from offering solely social support, physical rehabilitation, strength training, endurance, or a combination of all. Additionally, financial burden may vary across the programs as well. It is important that programs be vigilant of the needs of its members and ensures they are meeting their program goals. Therefore, research should delve deeper into a subsample of the nation's programming, and evaluate their effectiveness.

LIVESTRONG®

The LIVE**STRONG®** foundation is an organization with a purpose "to serve millions of individuals affected by cancer through collaborative programs and direct support services that fill critical financial, emotional, physical and practical gaps in care" (LIVE**STRONG®** Foundation, 2015). The LIVE**STRONG®** foundation addresses

cancer education and programing in a variety of ways, one of which is through involvement with community partners and community programs. LIVE**STRONG®** has programs at schools, research facilities, as well as at YMCAs across the nation. The LIVE**STRONG®** foundation has partnered with the YMCA to offer cancer survivors the LIVE**STRONG®** program.

LIVE**STRONG®** is an evidence-based program created to "help adult cancer survivors reclaim their health and well-being following a cancer diagnosis" (LIVE**STRONG®** Foundation, 2015). The program provides a focus on survivors improving their strength and physical fitness, diminishing the severity of therapy side effects, developing supportive relationships, and improving their quality of life through a 12-week program (LIVE**STRONG®** Foundation, 2015). LIVE**STRONG®** identifies specific program outcomes as the following: (a) help survivors meet or exceed the recommended amount of physical activity, (b) help survivors significantly increase their cardiovascular endurance, and (c) improve cancer survivors' overall quality of life and decrease their cancer related fatigue (LIVE**STRONG®** Foundation, 2015). The program has served over 33,116 cancer survivors in 37 different states, at over 453 different YCMA locations (LIVE**STRONG®** Foundation, 2015).

While programs such as LIVE**STRONG®** were created to help ease the transition from treatment to a healthy lifestyle, it is important to investigate the effects these programs had on participants, and if program goals were being met. LIVE**STRONG®** serves many individuals nationwide. As our country is becoming more diverse in a variety of ways, the program must be evaluated keeping in mind the magnitude of individual's characteristics and tailoring the program curriculum to all individuals. The

interconnection of various lifestyle and demographic factors may affect the success of some participants, thus evaluating program data may be useful for future program recommendations.

Program Evaluation

It is hard to know if the needs both the participant and program goals are being met unless there is continuous evaluation of programs. Patton (1997) describes program evaluation as "the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development (Patton, 1997). Program evaluation is an essential tool used to guide decisions about program implementation as well as to focus on improvement of program effectiveness (CDC, 2012).

Program evaluation techniques can be utilized in a variety of settings and among many different populations. An example of a program evaluation is that of a breast and colon cancer survivorship program completed by McCollum and colleagues (2014). Researchers utilized a quality of life (QOL) survey pre and post program, and a program evaluation to "assess program participants physical, psychosocial, social, and spiritual well-being changes that may have occurred as a result of program participation" (McCollum, Wood, & Auriemma, 2014, p. 1). After collection of data, researchers concluded that no statistically significant changes of QOL were identified on the surveys, but the program evaluation responses provided insight, which affirmed a positive evaluation of the program. This is an example of how a program evaluation can guide future programming, and suggest modifications to current programs.

The benefits of program evaluation are essential to tailoring a successful program. The LIVE**STRONG®** program collects a variety of data from its participants that could be used for evaluation. For example, the Patient Reported Outcomes Measurement Information System (PROMIS-29) is a survey that pertains to a participant's quality of life. The PROMIS-29 self-evaluation survey has 29 questions with eight different scale-score items including: (a) physical function, (b) anxiety, (c) depression, (d) fatigue, (e) sleep disturbance, (f) satisfaction with social role, (g) pain interference, and (h) pain intensity. This survey can be utilized as a means of program evaluation, addressing if participant responses improved from pre to post program.

Summary

The available research discussed within this chapter identified the importance of cancer survivorship programing and the specific goals and involvement of the nation wide LIVE**STRONG®** program, as well as discussed the importance of program evaluation. Currently the research has focused on the effectiveness of cancer survivorship programs. The programs have the potential to help improve the overall lives of many cancer survivors. It is imperative that research be conducted to assess programs such as LIVE**STRONG®**. The following chapter will discuss and describe the research methodology utilize to evaluate LIVE**STRONG®**.

CHAPTER III

METHODS AND PROCEDURES

Introduction

LIVE**STRONG®** is an evidence-based program created to "help adult cancer survivors reclaim their health and well-being following a cancer diagnosis" (LIVE**STRONG®** Foundation, 2015). The program serves hundreds of cancer survivors and is offered in over 30 states across America. LIVE**STRONG®** identifies specific program outcomes as the following: (a) help survivors meet or exceed the recommended amount of physical activity, (b) help survivors significantly increase their cardiovascular endurance, and (c) improve cancer survivors' overall quality of life and decrease their cancer related fatigue (LIVE**STRONG®** Foundation, 2015). For the purpose of this study, LIVE**STRONG®** offered at a Midwest YMCA facility was evaluated to determine if the program met its goals: (a) to improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life (LIVE**STRONG®** Foundation, 2015). LIVE**STRONG®** is a program "helping people move beyond cancer in spirit, mind, and body" (LIVE**STRONG®**, n.d.). The program includes a combination of individual and group activities, as well as a variety of workouts focused on cardiovascular exercise, strength training, stretching, and balance (LIVE**STRONG®,** n.d.). Individuals within this program have access to the workout facilities of the YMCA and are guided through two 90-minute classes each week of the 12-week program by certified LIVE**STRONG®** staff

(LIVE**STRONG**®, n.d.). The program collected data utilizing a variety of data collection instruments. Certified LIVE**STRONG**® staff had participants complete an intake form prior to participation, and also had individuals complete a self-evaluation (PROMIS-29) pre and post program participation. Individuals also completed pre and post program physical functional assessments. The program's process was then to file each evaluation away without formal analysis. The data-collection process has the ability to provide the program staff with valuable information and insight into an individual's level of success over the course of the 12-week program. Therefore, for the purpose of this study, the aforementioned data was analyzed.

Subject Selection

This was a retrospective non-experimental study. The study was conducted utilizing data collected between 2011 and 2015 from participants of the 12-week program at a mid-western location. Inclusion criteria for participants in LIVE**STRONG**®, and therefore for the inclusion in this study, were as follows: (a) participants have been or were currently affected by cancer, (b) participants completed the initial intake form as well as pre and post program PROMIS-29 profile form, and pre and post physical functional assessments (c) program participants signed an informed consent at time of participation in the study, and (d) individuals were at least 18 years of age. Participants were then selected based on their year of program participation. The years 2011 through 2015 time frame was selected for inclusion criteria based off of the LIVE**STRONG**® program data collection techniques. Beginning in 2011, data collection practices became uniform among LIVE**STRONG**® certified staff. Identical questionnaires were then distributed and completed by all participants. Prior 2011, data collection techniques

varied between sessions. Therefore individuals who completed LIVE**STRONG®** at this Midwest facility between the years of 2011 and 2015 reported information on the same evaluations forms.

Program completion was defined as participants having completed the pre and post evaluation tools facilitated by LIVE**STRONG®** staff. While staff tracked daily attendance, there was not a uniform reporting system for this information. Additionally, when data were entered into Microsoft Access, the number of program sessions attended was not included.

Each participant's information was entered into IBM SPSS Statistical Software Version 23 from the original Microsoft Access document and de-identified with a numeric identifier. Participant inclusion for analysis was determined with the analysis inclusion technique; meaning that a case (or participant) was only included in each specific analysis if their de-identified number contained complete information on the variable being analyzed. The data set consists of 332 participants. There were 50 males (15.5%) and 273 females (84.6%) ranging in age from 21 years of age to 91 years of age, with a mean age of 58.8 years of age. Nine (2.7%) of the 332 did not indicate gender and were treated as subjects with missing data.

Instrumentation

A variety of data-collection instruments were completed by the program participant's pre and post participation in the LIVE**STRONG®** program. These forms included: (a) the intake form which is done at the beginning of the program, (b) the PROMIS-29 self evaluation completed at the beginning and end of the program, and (c) the physical functional assessment forms which are also done at the beginning and end

program after the completion of the physical functional assessments. Below are further descriptions of what each form recorded.

1) *Intake form* (see Appendix A). This instrument was a questionnaire gathering basic demographic information, as well as health and physical activity information. The instrument consisted of five pages including both open and closed questions. Questions were designed to collect ratio and ordinal data.

2) *Patient Reported Outcomes Measurement Information System (PROMIS-29)* (see Appendix B). The PROMIS-29 was completed by each participant both pre and post program participation. The PROMIS-29 was a self-evaluation, consisting of 29 questions. Questions were divided into eight different scale-score groups. The scale-score groups included physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, and pain interference each made up of four questions (scale score items) and participants responded to each scale score item using a 5-point Likert scale. The eighth scale score item was intensity consisting of one question with a 10-point Likert scale. Content validity as well as reliability of the PROMIS-29 had previously been established for this survey and is evident through tests represented in professional literature (PROMIS, n.d.) Focus groups and cognitive interviews were used to test the question bank, as well as field-testing (DeWalt, Rothrock, Yount, Stone, 2007).

3) Physical Functional Assessment Form Each participant performed physical functional assessments pre and post program participation and results were recorded by certified LIVE**STRONG®** staff on the physical functional assessment, which was a blank sheet of paper. Information was gathered on results from a variety of assessments.

Data Collection

Data collection was completed by the LIVE**STRONG®** program certified staff at Midwest YMCA facility utilizing the three aforementioned forms. LIVE**STRONG®** employees administered evaluations and utilized data-collection tools during the first and last session of the 12-week program. Pre and post questionnaires were administered to each participant as well as the physical functional assessments. Baseline collection instruments included the intake form, the PROMIS-29 as well as completing functional assessments for aerobic function, strength testing, as well as flexibility and balance, which were all documented. Upon program completion, the PROMIS-29 and physical functional assessments were again completed.

Each functional assessment was administered to participants by LIVE**STRONG®** certified staff both pre and post program participation. A six-minute walk test was completed to assess aerobic function (Enright, Sherrill, 1998; Schmidt, Vogt, Thiel, Jäger, & Banzer, 2013) including a measure of heart rate before and after the six-minute walk, and the total distance walked measured in meters (m). The test consisted of individuals walking on a marked course as far as possible for six minutes without jogging or running (American Thoracic Society, 2002; Enright, 2003).

Additionally, a one-repetition maximum test was completed which consisted of a chest press to assess strength of the upper and a leg press to assess strength of the lower body measured in pounds (lbs). For the upper body assessment, individuals completed a one-repetition maximum test on the machine chest press. First a lift was performed with no weight loaded to ensure proper form. Next, weight was set to an achievable amount and participants completed one repetition at this weight to ensure confidence with the

procedure and proper technique. Weight was then incrementally added in bouts of five to ten pounds until momentary muscle failure was reached by the participant (LIVE**STRONG®**, 2015). This weight in pounds was then recorded.

The same process was repeated for the assessment of lower body strength on the machine leg press. Individuals went through the same process of practicing proper form and then incrementally adding weight until the one repetition maximum weight was reached. Results were then recorded (Phillips, Batterman, Valenzuela, & Burkett, 2004)

Flexibility back scratch was utilized to measure flexibility of both the right and left shoulder measured in centimeters (cm). The test was done with participants in a standing position. It began by participants placing one of their hands behind their head and back over the shoulder, and then reaching as far as possible down the middle of the back with the palm facing their body and fingers in a downward position. The other arm is then placed behind the back with the palm facing outward and the fingers in an upward position. From there participants were to reach up as far as they can with the goal of attempting to touch or overlap the middle fingers of the hands. The measurement was then taken. If the fingers touched, a score of zero was recorded, if fingers did not touch, the distance between the finger tips represented by a negative score was taken in centimeters. If the fingers overlapped, the distance of overlap represented by a positive score was recorded (Jones & Rikli, 2002; LIVE**STRONG®**, 2015).

The three balance tests completed by participants consisted of a right leg single leg stance, left leg single leg stance measured in seconds balanced (sec), and an arm reach (done on the left side). The balance stand test, completed by participants on each leg, consisted of participants removing the shoes and placing their hands at their sides.

Participant then raised one foot off the ground, and stood on the other leg for up to one minute. The test ended after one minute elapsed or was ended if the participant hopped in any direction or the non-supporting food made contact with the flood or other leg (Centers for Disease Control and Prevention, n.d.; LIVE**STRONG®**, 2015). Tests were performed for both legs, and time balanced was then recorded.

The arm reach test was also completed by participants to assess balance. Participants stood with their left shoulder close to the wall. The wall had tape on it at shoulder height of the participant. Participants then aligned their arm parallel with the floor, and fingers aligned with the tape. With their feet shoulder with apart, participants reached as far forward as possible without losing balance. Distance reached was measured in centimeters (LIVE**STRONG®**, 2015; NIH Senior Health, n.d.)

Methods

Following Institutional Review Board approval, data analysis was completed retrospectively on each of the study participant's recorded information. Each participant's data from 2011-2015 was entered into Microsoft Access by a YMCA employed Information Technology Specialist prior to this study. Participants from 2011-2015 were chosen as they completed the same questionnaires throughout this date range. Prior to 2011, different modes of data-collection were utilized, measuring different variables. When entered into Microsoft Access, participant's name and information was recorded. When the information was transferred into SPSS, each participant was assigned a number to which all of their data was linked anonymously. Numbers were assigned from one upward as participants were added to the database linking their pre and post results.

Data was transferred from the Microsoft Access document containing participant data into SPSS for analysis. Data analysis was done in SPSS and descriptive statistics were utilized to summarize the data as well as describe characteristics of participants within the dataset. Mean age and age range were calculated as well the frequency of gender.

Dependent variables analyzed were the participant's self evaluation scores recorded on the PROMIS-29. This analysis included the scale score groups of physical function, anxiety, depression, fatigue, sleep disturbance, social role satisfaction, pain interference, pain intensity pulled from the PROMIS-29. Each scale score group was made up of four questions. The scale score items were scored on a Likert scale from one to five with a range of four to twenty. The one exception to this was pain intensity, which was measured by one question on a Likert scale of one to ten. Though the five-point Likert scale was consistently employed, response choices varied slightly for items on the PROMIS-29 (see Appendix B). For example, the variable of physical function had response choices ranging from without any difficulty (scored as a one), with a little difficulty, with some difficulty, with much difficulty and unable to do (scored as a five), as listed on the PROMIS-29. While anxiety and depression had response choices which ranged from never (scored as one), to rarely, sometimes, often, and always (scored as five). When entered into SPSS, all responses were recorded as one (most positive), two, three, four, and five (most negative). Therefore, a higher value recorded represented a lower level of physical function, or higher levels of anxiety and depression. Additionally, results from physical functional assessments including the six-minute walk test pre heart rate, six-minute walk test post heart, six-minute walk test distance, lower body strength,

upper body strength, flexibility of the right shoulder, flexibility of the left shoulder, balance of the right leg, balance of the left leg, and left side arm reach were analyzed. For each of these dependent variables, there were different dependent-tests run. These 18 dependent variables were then utilized to determine changes from pre to post measurement among participants.

The first step of data analysis was running a pearson's product- moment correlation coefficient on each of the dependent variables identified from the PROMIS-29 questionnaire to determine if there was any positive relationship between each of the eight scale score groups. This was done on the eight dependent variables from the PROMIS-29 due to them all contributing to a measure of quality of life, and having the likelihood of being related. These scale scores, and therefore the dependent variables consist of physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference, and pain intensity.

The pearson's product- moment correlation coefficient tests were run because, it is recognized that having a large number hypothesis and in turn a large number of dependent variables creates greater chance that a type one error is possible; that being an incorrect rejection of a true null hypothesis, or a false positive due to chance (type one error). Therefore the pearson's product- moment correlation coefficient tests were utilized to determine if any dependent variables were correlated closely enough to combine multiple variables into one dependent variable for analysis purposes. If there was a significant correlation among groups as identified by the pearson's product-moment correlation coefficient, represented by an r value of greater than .8, variables

were combined for analysis purposes. If there was no significant correlation, dependent variables were tested on their own.

The eight dependent variables of physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference, and pain intensity were also accompanied by the dependent variables six-minute walk test pre heart rate, six-minute walk test post heart, six-minute walk test distance, lower body strength, upper body strength, flexibility of the right shoulder, flexibility of the left shoulder, balance of the right leg, balance of the left leg, and left side arm reach. Since each of the physical function tests were completed independent of each other, there were no pearson's product- moment correlation coefficient tests completed on these for the purpose of this study.

Next, t-tests were performed. With the pearson's product- moment correlation coefficient tests indicating no strong practical significance to combine variables, there was a different dependent-test run for each variable, equaling a total of 18 paired t-tests performed. While the risk for error with a large number of hypothesis and performing multiple tests on the same data set was realized, this study focused on retrospective data, and data-collection means practices were out of the control of the researcher. To account for possible error, the Bonferroni correction was utilized.

The Bonferroni correction is a method utilized to address the potential problem of multiple comparisons resulting in an output that is occurring by chance. Running multiple statistical tests on the same data set increases the likelihood of finding a result by chance. Therefore, by modifying the alpha level, and making a conservative adjustment is a way to address the risk. To do this correction, it requires dividing the original alpha level of

.05 by the number of dependent variables. In this case, the alpha level of .05 was divided by eight dependent variables, representing the eight depended variables pulled from the PROMIS-29 self-examination. The reason the eight dependent variables were selected versus the total of 18 is because the eight dependent variables from the PROMIS-29 have the greatest likelihood of multiple comparisons identifying an outcome occurring by chance, being on the same evaluation tool, since the PROMIS-29 self evaluation tool is looking at factors similar to each other.

After the Bonferroni correction was completed, each of the 8 dependent variables from the PROMIS-29 t-test's results were analyzed to assess if statistically significant changes in mean scores pre and post program participation occurred. These eight dependent variables were held to the Bonferroni modified alpha level. The remaining eight dependent variables from the physical functional assessments were held to the alpha level of .05. Information was organized into tables, and data analysis findings are explained further in chapter four. This information, which was gathered from data analysis, was utilized to drive future research and program recommendations.

Summary

This chapter discussed the in depth identification of the sampling procedures as well as data-collection techniques and analysis completed for the purpose of this study. The study analyzed quantitative retrospective data, which provided descriptive statistics and the ability to perform statistical analysis to identify differences of participant measures before and after program participation. The results from the analysis will be presented in chapter four.

CHAPTER IV

RESULTS

Introduction

The purpose of this study was to examine if LIVE**STRONG®** met its program goals: (a) to improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life (LIVE**STRONG®** Foundation, 2015). The program consisted of two 90-minute sessions per week for 12-weeks. The LIVE**STRONG®** program, a cancer survivorship fitness program at a Midwest facility was analyzed for the purpose of this study. During the 12-week program, the sessions included workouts of cardiovascular exercise, strength training, stretching and balance work (LIVE**STRONG®** Foundation, 2015). To evaluate the program, participant demographics such as age and sex, as well as pre and post scores on the PROMIS-29 and functional assessments were analyzed.

Demographic Analysis

This study included 332 participants. For data analysis purposes, participants of the program from 2011-2015 were analyzed. Participants were excluded pairwise, or analysis-by-analysis, meaning subjects missing required data for the specific analysis being run were not included for that specific test. The sample consisted of 50 males equaling 15.5% of the total participants, and 273 females, compromising the majority of the total participants at 84.5%. Nine (2.7%) of the 332 did not indicate gender and were

treated as subjects with missing data. Information on age was collected from 296 (89.1%) out of the 332 participants (see Table 1). Age ranged from 21 to 91 years of age with a mean age of 58.7. The standard deviation was 11.05 years of age (see Table 2).

Table 1. Gender Demographics

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	50	15.10	15.50	15.50
Male	273	82.20	84.50	100.0
Female	323	97.30	100.0	
Missing	9	2.70		
Total	332	100.0		

Table 2. Age Demographic

	N	Minimum	Maximum	Mean	Std. Deviation
Age	296	21.00	91.00	58.78	11.05

Data Analysis

Data were entered into SPSS to compare participant scores pre and post program participation. The dependent variables identified for analysis included those on the self reported PROMIS-29 evaluation of physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference, pain intensity. Additionally, physical functional assessments performed were include consisting of the six-minute walk test pre heart rate, six-minute walk test post heart, six-minute walk test distance,

lower body strength, upper body strength, flexibility of the right shoulder, flexibility of the left shoulder, balance of the right leg, balance of the left leg, and left side arm reach. For the purpose of this study, there were dependent t-tests were run on each of the dependent variables to determine difference in means between Time 1 and Time 2.

The first analysis was done on variables from the PROMIS-29 self-evaluation. The data was pulled from related pairs identified by a numeric identifier. The eight scale score groups for physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference, and pain intensity were made up of a total of 29 questions. Each scale score group was made up of four questions with scale items scored form one to five with a range of four to twenty with the exception of pain intensity, which was one question and had a scale item score ranging from one to ten. For the purpose of the study, the eight scale score groups were analyzed this way due to the format of preexisting data from the PROMIS-29.

A pearson's product- moment correlation coefficient was performed on all scale score groups from the PROMIS-29 questionnaire to determine the extent of any relationships between each of the eight items. If correlations (r of .8 or greater) existed between these variables of physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, pain interference and pain intensity, variables were combined to decrease the risk of type I error. The pearson's product- moment correlation coefficient were run on the PROMIS-29 dependent variables due to them being on the same questionnaire and relating to quality of life measures. I did not choose to run pearson's product- moment correlation coefficient tests on the physical function tests because of each test being performed individually. After performance of each

pearson's product- moment correlation coefficient tests, a statistical significance was found between all but two correlations (sleep disturbance and depression, and depression and sleep disturbance) with an alpha level of .05. While this statistical significance exists, practical significance as indicated by the correlation (r) output indicates that no variables should be combined, and thus variables were analyzed individually and not combined for the purpose of this study (see Table 3).

Table 3. Pearson Correlation Coefficient Results

Variable 1	Variable 2	Correlation (r)	Significant at x level
Physical Function	Anxiety	.16	.01
Physical Function	Depression	.29	.01
Physical Function	Fatigue	.50	.01
Physical Function	Sleep Disturbance	-.12	-----
Physical Function	Social Role	-.58	.01
Physical Function	Pain Interference	.47	.01
Anxiety	Depression	.67	.01
Anxiety	Fatigue	.38	.01
Anxiety	Sleep Disturbance	.03	.01
Anxiety	Social Role	-.34	.01
Anxiety	Pain Interference	.14	.05
Anxiety	Pain Intensity	.13	.05
Depression	Fatigue	.50	.01
Depression	Sleep Disturbance	-.01	-----
Depression	Social Role	-.43	.01
Depression	Pain Interference	.24	.01
Depression	Pain Intensity	.28	.01
Fatigue	Sleep Disturbance	-.15	.05
Fatigue	Social Role	-.62	.01
Fatigue	Pain Interference	.37	.01
Fatigue	Pain Intensity	.34	.01
Sleep Disturbance	Social Role	.18	.01
Sleep Disturbance	Pain Interference	-.14	.05
Sleep Disturbance	Pain Intensity	-.17	.01
Social Role	Pain Interference	-.41	.01
Social Role	Pain Intensity	-.36	.01
Pain Interference	Pain Intensity	.74	.01

T-tests were then performed for each of the dependent variables from the PROMIS-29 questionnaire and physical function tests. Each of the variables was run separately in the paired samples t-tests, to analyze participants' values pre and post program participation. There were a total of 18 two tailed t-tests completed. Variables which t-tests were performed on included the 18 dependent variables of: a) physical function, b) anxiety, c) depression, d) fatigue, e) sleep disturbance, f) social role, g) pain interference, h) pain intensity, i) six minute walk test pre heart rate, j) six minute walk test post heart, k) six minute walk test distance, l) lower body strength, m) upper body strength, n) flexibility of the right shoulder, o) flexibility of the left shoulder, p) balance of the right leg, q) balance of the left leg, and r) left side arm reach. While each dependent variable was run individually for analysis purposes, due to the pearson's product- moment correlation coefficient indicating no practical significant to combine variables, this does not guarantee that they were not closely related. To account for a possible inflated type one error risk from a large number of dependent variables, a Bonferroni correction was utilized.

The Bonferroni correction is a method utilized to address the potential issue that may arise during testing of multiple comparisons from the same data. Running multiple statistical tests on the same data set where dependent variables may be related increases the likelihood of finding a statistically significant result by chance (type one error). Modifying the alpha level and making a conservative adjustment is one way to address this risk. The Bonferroni correction is a very conservative approach. It is important to realize that while attempting to decrease type one error with this conservative approach,

in turn, the chance of type two error increases. This was a compromise for the purpose of this study.

To do this correction, the original alpha value of .05 was divided by the number of dependent variables decided upon for the purpose of this study. In this case, the alpha of .05 was divided by eight dependent variables. This number of eight came from the scale group scores on the PROMIS-29 self-examination. The new alpha level as indicated by the Bonferroni correction became .00625. Therefore, results for the dependent variables off the PROMIS-29 were deemed statistically significant if a p value of less than .00625 was generated. The remaining dependent variables from physical function assessments were deemed statistically significant if a p value of .05 or less was generated.

The reason the eight dependent variables were selected for the denominator versus the total of 18 dependent variables was because the eight dependent variables from the PROMIS-29 survey had the greatest conceptual and operational likelihood of being significantly related, thus increasing the type I error risk. This likelihood was because the PROMIS-29 self-examination looked at factors similar to each, and each of the eight dependent variables was pulled from the same data collection tool.

Variables were analyzed independently of one another and pre post group means were compared for each variable. The ten physical functional assessment dependent variables were specific measurements. Each variable measurement varied depending on the test, and labels indicate unit of measurement. Heart rate was measured in beats per minute (bpm), distance of the six-minute walk was measured in meters (m), chest press and leg press were measured in pounds (lbs), back scratch was measured in centimeters (cm), single leg stance was measured in seconds (sec), and arm reach was measured in

centimeters (cm). There was a statistically significant difference between the pre and post test scores physical function, depression, fatigue, satisfaction with social role and pain intensity among dependent variables from the eight scale score groups of the PROMIS-29. These variables were measured against the Bonferroni corrected alpha level of .00625. In regards to physical functional assessment variables, individuals had statistically significant improvements in their distance walked for the six-minute walk, chest press, leg press, back scratch on the left side, as well as both the left leg single leg stance, and the right leg single leg stance (see Table 4 & Table 5).

Table 4. Paired Sample T-Test Results

Variable	P value (2-tailed)
Physical Function	.00 **
Anxiety	.01 *
Depression	.00 **
Fatigue	.00 **
Sleep Disturbance	.12
Satisfaction with Social Role	.00 **
Pain Interference	.03 *
Pain Intensity	.00 **
Aerobic Function	
Beginning HR (bpm)	.51
Ending HR (bpm)	.98
Distance (m)	.00 **
Chest Press (lbs)	.00 **
Leg Press (lbs)	.01 *

* Indicates significant at alpha of .05
**Indicates significant at alpha of .00625

Table 5. Paired Sample T-Test Results

Variable	Significance (2-tailed)
Back Scratch (cm) Right Side	.12
Back Scratch (cm) Left Side	.00 **
Single Leg Stance (sec) Right Side	.00 **
Single Leg Stance (sec) Left Side	.00 **
Arm Reach (cm) Left Side	.67

* Indicates significant at alpha of .05

**Indicates significant at Bonferroni correction alpha of .0062

Hypotheses

1. Null Hypothesis One: There is no change in physical function between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's physical function. There was a statistically significant decrease in score from Time 1 (M= 7.13, SD=2.75) to Time 2 (M=6.28, SD =2.72), $t(70)$= 3. 08, p<.000 (two-tailed). The mean decrease in physical function score was .845 suggesting an overall improvement in physical function.

2. Null Hypothesis Two: There is no change in anxiety between pre and posttest measurement for participants who completed LIVE**STRONG®**

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's anxiety. There was not a statistically significant decrease in score from Time 1 (M=6.92, SD=2.86) to Time 2 (M=6.33, SD =2.88), t(105)=2.57 , p<.000 (two-tailed). The mean decrease in anxiety score was .594 suggesting an overall improvement in anxiety.

3. Null Hypothesis Three: There is no change in depression between pre and posttest measurement for people who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's depression. There was a statistically significant decrease in score from Time 1 (M=6.30, SD=2.87) to Time 2 (M=5.54, SD =2.52), t(104)=3.15 , p<.002 (two-tailed). The mean decrease in depression score was .762 suggesting an overall improvement in anxiety.

4. Null Hypothesis Four: There is no change in fatigue between pre and posttest measurement for people who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's fatigue. There was a statistically significant decrease in score from

Time 1 (M=9.91, SD=3.81) to Time 2 (M=8.62, SD =3.07), t(104)=4.15, p<.000 (two-tailed). The mean decrease in fatigue score was 1.29 suggesting an overall improvement in fatigue.

5. Null Hypothesis Five: There is no change in sleep disturbance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participants sleep disturbance. There was not a statistically significant increase in score from Time 1 (M=11.18, SD=1.85) to Time 2 (M=11.56, SD =1.20), t(98)=-1.55 , p<.123(two-tailed). The mean increase in sleep disturbance score was -.374 suggesting an overall improvement in sleep disturbance.

6. Null Hypothesis Six: There is no change in social role satisfaction between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's social role satisfaction. There was a statistically significant increase in score from Time 1 (M=13.83, SD=4.01) to Time 2 (M=15.99, SD =3.29), t(99)=-6.45, p<.000 (two-tailed). The mean increase in social role satisfaction score was -2.16 suggesting an overall improvement in social role satisfaction.

7. Null Hypothesis Seven: There is no change in pain interference between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's pain interference. There was not a statistically significant decrease in score from Time 1 (M=7.57, SD=3.22) to Time 2 (M=6.88, SD =3.31), t(101)=2.17 , p<.032 (two-tailed). The mean decrease in pain interference score was .686 suggesting an overall improvement in pain interference

8. Null Hypothesis Eight: There is no change in pain intensity between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's pain intensity. There was a statistically significant decrease in score from Time 1 (M=2.50, SD=1.80) to Time 2 (M=2.01, SD =1.89), t(100)=2.96 , p<.004 (two-tailed). The mean decrease in pain intensity was .485 suggesting an overall improvement in pain intensity.

9. Null Hypothesis Nine: There is no change in six-minute walk test pre heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

   A paired-samples t-test was conducted to evaluate the impact of the program on a participant's aerobic function (pre walk heart rate). There was not a statistically

significant decrease in heart rate from Time 1 (M=73.73, SD=11.49) to Time 2 (M=75.83, SD =50.09), t(247)=-.664 , p<.507 (two-tailed). The mean increase in six-minute walk test pre heart rate was -2.10 suggesting an overall decline in aerobic function (pre walk heart rate).

10. Null Hypothesis Ten: There is no change in six-minute walk test post heart rate between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's aerobic function (post walk heart rate). There was not a statistically significant decrease in heart rate from Time 1 (M=95.51, SD=17.92) to Time 2 (M=95.55, SD =16.00), t(243)=-.031, p<.975 (two-tailed). The mean increase in six-minute walk test post heart rate was -.032 suggesting an overall improvement in aerobic function (post walk heart rate)

11. Null Hypothesis Eleven: There is no change in six-minute walk distance between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's aerobic function (distance). There was a statistically significant increase in score from Time 1 (M=220.82 , SD=65.27) to Time 2 (M=246.05, SD =56.15), t(249)=-7.28 , p<.000 (two-tailed). The mean increase in aerobic function (distance) was -25.22 suggesting an overall improvement in aerobic function (distance).

12. Null Hypothesis Twelve: There is no change in upper body strength between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's upper body strength. There was a statistically significant increase in score from Time 1 (M=52.04, SD=35.07) to Time 2 (M=62.53, SD =37.74), t(242)=-8.33 , p<.000 (two-tailed). The mean increase in upper body strength was -10.49 suggesting an overall improvement in upper body strength.

13. Null Hypothesis Thirteen: There is no change in lower body strength among participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's lower body strength. There was a statistically significant increase in score from Time 1 (M=189.43, SD=137.69) to Time 2 (M=211.80, SD =78.28), t(243)=-2.70 , p<.007(two-tailed). The mean increase in lower body strength was -22.37 suggesting an overall improvement in lower body strength.

14. Null Hypothesis Fourteen: There is no change in flexibility of the right shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's right side back scratch. There was not a statistically significant increase in score from Time 1 (M=-6.54, SD=12.68) to Time 2 (M=-5.28,SD =12.79), t(251)=-1.58 , p<.115 (two-tailed). The mean decrease in right side back scratch score was -1.26 suggesting an overall improvement in right side back scratch.

15. Null Hypothesis Fifteen: There is no change in flexibility of the left shoulder between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's left side back scratch. There was a statistically significant increase in score from Time 1 (M=-9.29, SD=12.82) to Time 2 (M=-6.14, SD =12.83), t(253)=-3.89 , p<.000 (two-tailed). The mean increase in left side back scratch was -3.14 suggesting an overall improvement in the left side back scratch.

16. Null Hypothesis Sixteen: There is no change in balance of the right leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's right leg single leg stance. There was a statistically significant increase in score from Time 1 (M=31.32, SD=23.07) to Time 2 (M=36.37, SD =23.41), t(265)=-5.01 , p<.000 (two-tailed). The mean increase in right leg single leg stance was -5.05 suggesting an overall improvement in the right leg single leg stance.

17. Null Hypothesis Seventeen: There is no change in balance of the left leg between pre and posttest measurement for participants who completed LIVE**STRONG®**.

    A paired-samples t-test was conducted to evaluate the impact of the program on a participant's left leg single leg stance. There was a statistically significant increase in score from Time 1 (M=30.41, SD=23.55) to Time 2 (M=35.31, SD =22.94), t(262)=-4.45 , p<.000 (two-tailed). The mean increase in left leg single leg stance was -4.90 suggesting an overall improvement in left leg single leg stance.

18. Null Hypothesis Eighteen: There is no change in left side arm reach between pre and posttest measurement for participants who completed LIVE**STRONG®**.

A paired-samples t-test was conducted to evaluate the impact of the program on a participant's left side arm reach. There was not a statistically significant increase in score from Time 1 (M=14.47, SD=9.50) to Time 2 (M=14.88, SD =9.70), t(254)=-.430 , p<.668 (two-tailed). The mean increase in left side arm reach was -.40 suggesting an overall increase in left side arm reach.

Summary

Overall, pearson's product- moment correlation coefficient testing and paired samples t-tests allowed for detailed data analysis of dependent variables related to physical and mental health for the study population. Of the 18 dependent variables tested, 11 (61.1%) revealed a statistically significant improvement between pre and posttest measures. These results were essential to determine whether LIVE**STRONG®** met its goals to: (a) improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life. From the results presented in this chapter, it can be determined, that LIVE**STRONG®** at the YMCA did meet its' goals in terms of specific dependent variables such as the improvement of physical function, depression, fatigue, satisfaction with social role, pain intensity, distance walked in the six-minute walk test (aerobic function), chest press (upper body strength), left side back scratch (shoulder flexibility), left side single leg stance (balance), and right leg single leg stance (balance). While there were overall improvements in PROMIS-29 scores, as well in aerobic function, strength, balance and flexibility, there are a few dependent variables, which did not improve at a statistically significant value, but those results may still prove insightful and will be discussed in detail in the next chapter. The following chapter will discuss data results as well as determine recommendations for future program recommendations for LIVE**STRONG®**. Conclusions drawn from data analysis supplied information informing

an evidence-based executive report, which can be utilized for future programming, as a means of creating tailored survivorship programming and will be discussed in detail in the following chapter five.

CHAPTER V

DISCUSSION AND CONCLUSION

Purpose of Study

The purpose of this study was to examine if LIVE**STRONG**®, a cancer survivorship program was meeting its program goals. LIVE**STRONG**® goals include: (a) improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life (LIVE**STRONG**® Foundation, 2015). This study investigated participant information pre and post program participation for a variety of variables from self-evaluations as well as physical function assessment scores.

Findings

Overall, this study quantitatively evaluated a LIVE**STRONG**® program at a Midwest YMCA location, utilizing retrospective data. This 12-week cancer survivorship program collected information on program participants in a variety of ways, to include the utilization of an intake form to gather general information, a PROMIS-29 self evaluation completed pre and post program participation, as well as by recording performance of physical functional assessment testing completed before and after program participation. The PROMIS-29 and physical functional assessment data were analyzed to investigate the differences, if any, in participant scores before and after the program.

The study data set consisted of 332 participants from the years 2011 to 2015. The mean age of participants was 58.7 years old and the majority of the sample was female. A total of 18 dependent variables were analyzed including: (a) physical function, (b) anxiety, (c) depression, (d) fatigue, (e) sleep disturbance, (f) satisfaction with social role, (g) pain interference, (h) pain intensity, (i) aerobic function as measured by heart rate prior to the six minute walk test, (j) participant heart rate after the six minute walk test, (k) six minute walk test distance, (l) individual's strength measured by the chest press to assess upper body strength (m) leg press to assess lower body strength, (n) the back scratch test on the left side to assess shoulder flexibility, (o) back scratch on right side, (p) left leg single leg stance to assess balance, (q) right leg single leg stance as well as (r) left side arm reach to assess balance. Each of these variables was analyzed to evaluate the program and determine if it was meeting its goals.

Analysis of the participant data yielded vital information to be utilized for the evaluation of a LIVE**STRONG®** program at this Midwest location, and results provided guidance for making recommendations for future research and practice. Parametric inferential analysis of scale scores from the PROMIS-29 form identified that physical function, depression, fatigue, satisfaction with social role, and pain intensity significantly improved from pre to post. Additionally, there were statistically significant improvements between pre and posttests for multiple physical functional assessment measurements including, the six minute walk test distance, chest press, leg press, back scratch on the left side, as well as both left an right single leg stance. An improvement in all of these

variables provide evidence indicating LIVE**STRONG®** to be succeeding in various capacities in meeting its program goals.

While there were many positive and significant improvements for program participants from pre to post program participation, there were several dependent variables analyzed that did not show significant improvement overtime. The scale group scores drawn from the PROMIS-29, which did not statistically significantly improve included anxiety, sleep disturbance, and pain interference. The physical function assessments variables not indicating a statistically significant improvement include pre and post six minute talk test heart rate, leg press, back scratch on the right side, and arm reach. It is essential to recognize the accomplishments that were evident from pre to post program measures, as well as identify reasons for potential shortcomings, which can be discussed as well as analyzed in future research to suggest ways to improve participant's health outcomes.

Discussion

Overall, the study provided results from which insightful conclusions were drawn. Based on results, practical recommendations were made for the Midwest LIVE**STRONG®** program. Additionally, results also proved useful for nation wide recommendations to be made as well.

Evaluating the program identified program areas for this specific LIVE**STRONG®** program to focus on in the future. The analysis of variables that did or didn't change from pre to post will help the program to better address program goals. With no statistical significant improvements in anxiety, sleep disturbance, and pain interference scores as identified on the PROMIS-29, as well as among functional

assessments measures of beginning and ending heart rate, right side back scratch, and arm reach, it is important to look further into potential reasons for these outcomes.

With no statistically significant improvements in anxiety, sleep disturbance, and pain interference, it is important to consider why these results may have occurred. While noting no significant change in anxiety among participants, it is important to reflect on if the program is truly addressing an individual's anxiety throughout the program offerings. The same can be said for sleep disturbance. If there is no education on anxiety and sleep disturbance within the program or skills taught to manage these issues, it is not surprising that no change was found in these variables. Additionally, no change in pain interference may indicate a need for focus on improving specific physical limitations of participants due to pain. Focusing on individual needs may be necessary within this group setting to identify limiting factors and addressing these with supplemental strengthening exercises or additional attention. As identified within the review of the literature, individuals may have a magnitude of treatments to treat their cancer, each of which may affect individuals differently. Various treatment options come with differing side effects, and individual needs must be considered.

In regards to functional assessments and specifically heart rate measurements within the program, beginning and ending heart rate were measured as a part of the six-minute walk test. An individual's heart rate was taken prior to, as well as after the test by LIVE**STRONG**® certified staff. This was done for both pre testing physical functional assessments and post program physical functional assessments. Since it was found that individuals did not experience a significant change in cardiovascular fitness from pre program participation to post program participation, possible reasons for this lack of

improvement must be explored. To analyze this result further, future studies could assess adequacy of if aerobic workouts during each session of the LIVE**STRONG**® program. This could be done by tracking number of sessions attended, time exercised each time, as well as intensity. If participation is occurring as planned and no change in aerobic function represented by heart rate can be detected, that may indicate the need for a potential revamping of some of the physical aspect of the program during some or all sessions over the 12-week program period.

A lack of change in heart rate among participants could be attributed to other reasons beside a lack of true cardiovascular improvement. After the implementation of a cardiovascular program, a positive result would be indicated by a lower resting and exercise heart rate. One potential reason for lack of change in heart rate could be that while LIVE**STRONG**® at the YMCA staff are trained certified professionals, human error could be a potential cause for result discrepancy. If one staff member executed the measurement of heart rates pre and post prior to program participation, and a different staff member assessed heart rates pre and post the six- minute walk after program participation, their techniques could vary slightly and alter results.

Another possible explanation for this result is that heart rate is a value that fluctuates throughout the day and can be affected by many different factors. For example, if participants rushed to the program, or increased their heart rate on the way to the assessment in other ways, a higher reading would be recorded. Additionally, caffeine intake or stress could also have an affect on an individual's heart rate (Collora, 2013). Each of these factors should be taken into consideration and accounted for in future data collection. For example, recording on data collection instruments the amount of time a

participant rests before the test could be a potential improvement. This could also include creating a set amount of time for the participant to sit and rest before the test is administered.

An additional dependent variable important to discuss is the right side back scratch functional assessment score, which showed no statistically significant improvement from pre to post. The back scratch was a test utilized within this program and study to assess shoulder flexibility. Potential reasons for no change in flexibility could be attributed to limited attention on flexibility throughout the program activities. Additionally, test administration error, or a difference in participant effort during pre versus post measurement could affect scores in a way that detection of change over time becomes difficult. It is also interesting to note that while the right side back scratch did not show a statistically significant change from pre to post, the left side back scratch did. A potential explanation for this phenomenon could be that is 85-90% of people are right handed (Starr, 2013). Therefore, the right hand and arm are typically utilized more throughout the day for many people, increasing an individual's risk of having an injury affecting that arm. Therefore, this idea of overuse injury on the dominant side, or potential right side disability could be coming out in the measurement. To better assess flexibility, it may prove beneficial to have multiple flexibility tests performed, and more than one measurement taken into account to assess the flexibly of participants.

Arm reach also did not show a statistically significant improvement from pre to post. It is interesting to note that arm reach is a measurement of balance, which was also measured within this program by the right and left single leg stance assessment. While arm reach did not show a significant improvement from pre to post program participation,

single leg stance on both sides did. It is important to identify a potential reason for the discrepancy between these balance assessments. The single leg stance is a balance assessment when the individual stands stationary for a maximum of 60 seconds. The arm reach test is a test that consists of the participant reaching forward while keeping their balance. Therefore, the single leg stance is more static in nature, while the arm reach is more dynamic. This points to a possible need for focus on dynamic balance exercises throughout the program to improve participant's balance while in motion. An additional explanation for lack of statistically significant improvement among participants in the arm reach could be due to test administration error. If the arm reach testing technique was not constant among staff, or measurement techniques varied, this could have affected pre and post participation results.

While there were several results that were not statistically significantly different from pre to post program participation, various results did improve over time, and are important to identify. For example, the statistically significant improvement of self-reported physical function on the PROMIS-29 questionnaire, as well as a decrease in pain intensity is a result of great importance. Research identifies that physical activity may decrease risk of cancer reoccurrence (Ibrahim & Al- Homaidh, 2011; Loprinz & Lee, 2014). Therefore, with individuals having improvements in physical function and decreases in pain intensity, this may increase their ability to perform physical activity.

Recommendations for Future Research

Overall, the data analysis indicated that LIVE**STRONG**® is meeting its goals. For example, it does appear to be improving individuals' strength and physical fitness as represented by statistically significant improvements in the chest press and arm press.

The program also appears to be meeting its goals to improve individual's quality of life, by improvements shown on PROMIS-29 scale groups. In the future it would be beneficial to pinpoint specific ways to measure if the program is meeting its goals of the development of supportive relationships and diminishing the severity of therapy side effects as well. Overall, analyzing a wide array of variables allowed for the identification of ways LIVE**STRONG**® is meeting its goals, and also identified areas where the program is not associated with significant participant health improvements. From this study, there are various recommendations that can be made for LIVE**STRONG**® nationwide, as well for LIVE**STRONG**® at the specific Midwest facility used in this study.

National Recommendations

In regards to nationwide recommendations, suggestions for future research include the investigation of participant data at sites nationwide, as well as determining if LIVE**STRONG**® is meeting it's participant goals. Looking at different descriptive indicators of groups to compare changes from pre to post program participation would also be an important step. Additionally, the creation of smaller objectives to determine how the primary LIVE**STRONG**® goals are being met will also be beneficial to the program.

Performing future studies such as the one presented in this research, and focusing on the program success from different LIVE**STRONG**® facilities nationwide will allow sites to determine whether goals are being met. Having different regional YMCA facilities perform program evaluations will allow for better determination if goals are being met at their facility. Nationwide program evaluation would also opens up the

opportunity to analyze nation wide trends as well as consideration for program recommendations for the program overall.

Another aim for future studies should be to investigate whether the program is meeting not only its program goals, but the program participant's goals as well. For example, while participants may show improvement in all or some of the variables analyzed for the purpose of this study, it is vital to determine if these changes matter to individuals. It is possible that there are other areas of health participants would like to improve in that did not change as a result of program participation. Insights into the minds and interests of participants can help shape the program to meet the true needs of the population.

In future studies, one way to determine participant's interests and wants for the program is the completion of focus groups with past and future program members. The facilitation of focus groups can generate participant opinions to fuel program plans. Programs nationwide, as well as at the specific Midwest LIVE**STRONG®** program of this study can work with past participants to discuss health measures that did not show significant improvement in this study, including variables from the PROMIS-29 survey as well as functional measures to determine how participants feel about these items or the participant's options of the program as a whole.

Another area of importance for future research is looking at different descriptive statistics among the sample population and making conclusions on grouping variables. For example, it may be beneficial to include race, type of cancer, and other factors in data set analysis to compare program participant's scores by groups. The analysis of an individual's race and age, as well as their results at pre and post, can indicate whether

certain demographic groups are improving more than others. Inferences may then be based on those types of results. An additional example could be comparing females to males at pre and post to determine if there is major difference based on gender pre and post program. In addition to identifying whether the program has a greater likelihood of being associated with health improvements for certain groups, these types of analyses would also address whether variables measures in the program are significantly different between groups at the time of program initiation.

One last recommendation for the nationwide LIVE**STRONG®** program is a more specific way to measure program goals. Currently, the goals of LIVE**STRONG®** are: (a) improve participant's strength and physical fitness, (b) diminish the severity of therapy side effects, (c) develop supportive relationships, and (d) improve participant's quality of life. These goals, while very pertinent to the program, are broad and often difficult to measure. LIVE**STRONG®** can develop program objectives as stepping stones to meet these goals, which would in turn make goal successes easier to measure. This idea will be discussed in further detail in the next section of this paper, focusing on recommendations specifically for LIVE**STRONG®** the Midwest facility used for this study.

Local Recommendations

While suggestions can be made for how the nationwide LIVE**STRONG®** program may improve, it is important to identify specific recommendations for the LIVE**STRONG®** program studied for the purpose of this research. Analyzing data from this specific Midwest program provides a unique opportunity to make tailored recommendations.

A recommendation for future studies would be to analyze a fewer number of dependent variables. Identifying a few variables of interest from the PROMIS-29 or physical functional assessments, and analyzing these within the sample could be beneficial for several reasons. First, fewer dependent variables means the Bonferroni correction would not be necessary and a less conservative alpha level could be utilized. Therefore, more variables may prove to be statistically significant. Additionally, it would be helpful for the program and interesting to see if other samples yielded similar results. From there, more conclusions could be drawn regarding program goals and future suggestions for the program moving forward in regards to ways to tailor the program.

LIVE**STRONG**® is a multifaceted program, offering many potentially beneficial program components to cancer survivors in a community setting. The program evaluation tools in place provide rich data to gage improvements among participants from pre to post program and should be recognized as a means to collect useful data. Supplemental data collection instruments should also be considered to further enhance the insights gained from participants, as well as to more specifically be able to determine if the program is meeting its goals.

Looking at the specific measures of quality of life drawn from the PROMIS-29 form that did not show significant improvements in this study, it can be suggested that anxiety, sleep disturbance and pain intensity are areas to begin focusing on for future program successes. Utilizing a theory such as the social cognitive theory with constructs what align with behavior change, will provide constructs to base program activities on within the LIVE**STRONG**® program for the future. The use of the social cognitive theory and its constructs may promote behavior change and in turn promote success in

reaching the program's goals (United States Department of Health, Human Services and National Institutes of Health, and National Cancer Institute, 2005). In regards to anxiety and sleep disturbance, the program can focus on addressing these quality of life measures by first having individuals identify reasons that they may be experiencing high levels of anxiety, or why their sleep may be being disturbed throughout the night. If individuals are nervous about their treatment, and this is giving them anxiety, program leaders can identify that the unknowns of treatment may affect anxiety levels. From there, they can educate participants on what to expect from treatment, or teach techniques to control anxiety, in turn improving a participant's behavioral capacity, knowledge, and skill level to perform anxiety control behaviors. According to the social cognitive theory, if an individual knows what to do and how to do it, a behavior change is much more likely (United States Department of Health, Human Services and National Institutes of Health, and National Cancer Institute, 2005).

Utilizing this same construct of behavioral capacity, if a participant is identifying that their sleep is disturbed on a regular basis, program leaders may educate participants on relaxation techniques, or behaviors that may decease sleep disturbances. Techniques such as relaxing before bed, or habits of avoiding electronics, and limiting caffeine consumption before bedtime may be included in such an educational session. After individuals have the behavioral capacity to make the change, goal setting or a means of self-regulation may also come into play. If individuals make specific goals of perhaps not drinking a 12 ounce soda before bed, or limiting screen time on electronic devices to at least 30 minute before they go to sleep, and keep a log of their behaviors in regards to this, their self efficacy in regards to the behavior may improve. An increase in self-

efficacy or ones belief they can do something, may in turn make positive contributions to succeeding in meeting program goals (United States Department of Health, Human Services and National Institutes of Health, and National Cancer Institute, 2005).

With pain interference not significantly improving for the participants in this study, one way to address this quality of life indicator may be to first have individuals identify where and when in their life pain is interfering. The program leaders can then find ways to address or minimize this impact. For example, LIVE**STRONG®** staff can modify the program to include exercises that may increase a participants ability to perform certain daily tasks, or exclude exercises that may cause unwanted pain. Participants can also journal about their pain interference on a daily basis to determine if pain interference is lessening or increasing with certain daily activities, which will serve as a way to monitor the pain and in turn be able to better modify the program for the individual. This idea of keeping a journal is a means of self-regulation, another construct of the social cognitive theory.

Lastly, in regards to physical functional assessments that did not show significant improvements from pre to post measurements, it may be wise for the Midwest LIVE**STRONG®** program to track associated measures of these direct indicators of health to be able to demonstrate incremental accomplishments and lay the foundation of long-term success. For example, while heart rate may be an indicator of physical function, having participant's focus on smaller more incremental goals may increase an individual's exercise self-efficacy. This may then in turn increase their overall success in the program. For instance, providing individuals with information on recommendations regarding the number of minutes and the intensity level per week they should be

exercising for, and then having each individual make plans to achieve their goals, can be another measurement of success among participants within the program. The same idea can be utilized for other functional tests such as leg press, the back scratch and the arm reach. If individuals make more specific goals for themselves as opposed to solely looking for an increase in amount of weight lifted from pre to post program participation, their self-efficacy may improve. An example of a more specific goal could be the ability to carry groceries in from the car or reach for dishes on the kitchen shelf without losing their balance.

Overall, LIVE**STRONG®** is offering a variety of ways to help cancer survivors thrive. In the future, LIVE**STRONG®** should continue to support individuals in a group setting while also focusing on each individual setting and working towards well developed goals. Having individuals experience positive improvements on a personal level will improve self-efficacy and promote positive behavior change. Using social cognitive theory and its constructs may prove beneficial when designing future program sessions, and should be considered for future programming. Additionally the development of specific program objectives based on priority population needs will also drive programs to success. Future research will further increase the knowledge of the importance of cancer survivorship programs and address factors that may make these initiatives more successful.

Professionals in the public health field and specifically those working with LIVE**STRONG®** at the YMCA, can utilize the study results for insights into future directions for programming and evaluation. LIVE**STRONG®** is a nationwide program and the evaluation of this specific Midwest location can spark future investigation into

other LIVE**STRONG®** programs across the United States. Dissemination of this study protocol can help program managers and staff assess whether LIVE**STRONG®** is meeting its goals at program locations across the United States.

Additionally, results from this study can be utilized to gain support for the program. For example, being able to provide data for program outcomes can be tremendously impactful in grant proposals for future funding. Also, results can be shared to develop community support for the program. A report discussing specifically how program participants are improving physically and mentally as a result of LIVE**STRONG®** can show community members the importance of the program locally as well as regionally. Locally at the Midwest location, data from this study is currently contributing to a partnership among community organizations to create and bring health resources to community members.

Overall, professionals in the public health field, as well as individuals working with a cancer survivorship population need to continue to consider not just the physical needs of cancer survivors but mental and emotional needs as well. The presence of multifaceted and feasible programs such as LIVE**STRONG®** can positively contribute to a cancer survivor's health and overall quality of life. A wide array of factors needs to be considered when creating survivorship programs. This study can serve as a resource identifying how one specific program is associated with cancer survivor's mental and physical well being through the investigation of pre and post program participation. Results from this study can be used to drive future programming and support cancer survivors across the nation.

Summary

This study provided many insights into the LIVE**STRONG®** program at a Midwest YMCA facility. Information drawn from the data analysis within this study can be utilized to guide future program modifications as well as supply insights for LIVE**STRONG®** programs across the nation. The specific dependent variables within this study contributed to the determination of if LIVE**STRONG®** is meeting its goals. While the program goals are broad, recommendations have been made to allow for a more precise measurement of these outcomes. The study suggests that LIVE**STRONG®** at the specific Midwest location within this study is in fact meeting its program goals.

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APPENDIX A

LIVE**STRONG**® INTAKE FORM

Association: Branch:

LIVESTRONG® AT THE YMCA INTAKE FORM

PARTICIPANT INFORMATION

Name:		Date (DD/MM/YY): / /
Preferred phone number:	Email:	Preferred contact methods: ☐ Phone ☐ Email
Where were you treated?		
Physician name:		

1. **Date of birth (DD/MM/YY):** ___/___/___
2. **Gender:** ☐ Male ☐ Female
3. **Are you Hispanic, Latino/a, or Spanish origin?** [One or more categories may be selected]

   ☐ No, not of Hispanic, Latino/a, or Spanish origin
   ☐ Yes, Mexican, Mexican American, Chicano/a
   ☐ Yes, Puerto Rican
   ☐ Yes, Cuban
   ☐ Yes, Another Hispanic, Latino/a or Spanish origin
4. **What is your race?** [One or more categories may be selected]

   ☐ White
   ☐ Black or African American
   ☐ American Indian or Alaska Native
   ☐ Asian Indian
   ☐ Chinese
   ☐ Filipino
   ☐ Japanese
   ☐ Korean
   ☐ Vietnamese
   ☐ Other Asian
   ☐ Native Hawaiian
   ☐ Guamanian or Chamorro
   ☐ Samoan
   ☐ Other Pacific Islander
5. **How did you learn about the LIVESTRONG® at the YMCA cancer survivorship program?**

   ☐ Y staff member or volunteer
   ☐ A friend or family member or word of mouth
   ☐ A doctor or other health care professional
   ☐ A local or national cancer awareness or support organization or event
   ☐ A mailing or email communication
   ☐ A poster, or flyer or event at the Y
   ☐ A poster or flyer at a cancer or medical center
   ☐ The Y's website
   ☐ LIVESTRONG
   ☐ Media (TV, web, radio, print, etc.)
   ☐ Other (please specify): _____

HEALTH INFORMATION

6. Have you ever had any of the following health problems?

• Pulmonary (lung) problems	☐ Yes	☐ No
• Heart problems or surgery	☐ Yes	☐ No
• Diabetes	☐ Yes	☐ No
• Altered heart rate	☐ Yes	☐ No
• Dizziness or fainting (unrelated to cancer treatment)	☐ Yes	☐ No
• Chest, neck or arm pain	☐ Yes	☐ No
• Pain or cramping in legs while walking	☐ Yes	☐ No
• Short-term weakness on one side of the body	☐ Yes	☐ No
• Elevated blood pressure	☐ Yes	☐ No
• Low blood pressure	☐ Yes	☐ No
• High cholesterol	☐ Yes	☐ No
• Smoker or previous smoker	☐ Yes	☐ No
• Arthritis	☐ Yes	☐ No
• Other (please specify): _____		

6.a If you answered "YES" to any of the above, please describe briefly (255 character limit):

7. Type of Cancer:

☐ Bladder	☐ Leukemia	☐ Melanoma	☐ Other (please specify):
☐ Bone	☐ Liver	☐ Skin (Non Melanoma)	
☐ Brain	☐ Lung	☐ Stomach (Gastric)	
☐ Breast	☐ Lymphoma	☐ Testicular	
☐ Cervical	☐ Myeloma	☐ Thyroid	
☐ Colon and Rectal	☐ Oral	☐ Uterine	
☐ Endometrial	☐ Ovarian		
☐ Esophageal	☐ Pancreatic		
☐ Head and Neck	☐ Prostate		
☐ Kidney (Renal Cell)	☐ Rectal		

8. Cancer diagnosis date (MM/YY): ____/____

9. Surgery?	☐ Yes	☐ No	9.a. If yes, date of most recent surgery (MM/YY): ____/____
10. Chemotherapy?	☐ Yes	☐ No	10.a. If yes, date of last treatment (MM/YY): ____/____
11. Radiation?	☐ Yes	☐ No	11.a. If yes, date of last treatment (MM/YY): ____/____

12. Do you have an implanted port or Central Venous Access Catheter? ☐ Yes ☐ No

If yes, specify location (50 character limit):

13. Are you experiencing peripheral neuropathy (i.e. tingling/loss of sensation in your fingers and/or toes)? ☐ Yes ☐ No

If yes, specify location (50 character limit):

14. Has the cancer spread to any bones? ☐ Yes ☐ No

If yes, please describe where (50 character limit):

HEALTH INFORMATION CONTINUED...

15. Have you had any lymph nodes removed? ☐ Yes ☐ No

If YES:

15.a. Where have you had lymph node involvement?

☐ Head and Neck ☐ Right Upper Extremity
☐ Left Upper Extremity ☐ Right Lower Extremity
☐ Left Lower Extremity

15.b. Check all that are true:

☐ I have been DIAGNOSED with Lymphedema.
☐ I am currently experiencing STIFFNESS or LOSS OF RANGE OF MOTION in the area that the lymph nodes have been removed.
☐ I am currently experiencing PAIN or DISCOMFORT in the area that the lymph nodes have been removed.

16. Are there any other major illnesses, injury or issues (physical or psychological) we should be aware of? ☐ Yes ☐ No

16.a. If yes, please explain (255 character limit):

17. List current medications, including vitamins and over-the-counter (if not applicable, record 0):

18. Describe your health at the present time: ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

PHYSICAL ACTIVITY INFORMATION

19. Do you participate in exercise regularly? ☐ Yes ☐ No

If YES:

19.a Please describe the FREQUENCY of your exercise:

☐ Daily
☐ 2-6 times a week
☐ Once a week
☐ Less than once per week
☐ Monthly

19.b Please describe the INTENSITY of your exercise:

☐ Light
☐ Moderate
☐ Vigorous

19.c Please list the TYPES of exercise you participate in regularly (255 character limit):

PHYSICAL ACTIVITY INFORMATION CONTINUED...

20. Do you have any physical limitations that restrict your daily living activities or ability to exercise? ☐ Yes ☐ No

20.a If yes, please explain (255 character limit):

21. Are there any other limitations since your cancer diagnosis? ☐ Yes ☐ No

21.a If yes, please explain (255 character limit):

22. Are you working? ☐ Yes ☐ No

If YES:

22.a What is your level of activity at work?

- ☐ Sedentary
- ☐ Light
- ☐ Moderate
- ☐ Vigorous

If NO:

22.b Since when (MM/YY)? ____/____

23. Describe your past experience with resistance training and aerobic training (255 character limit):

24. What expectations do you have from this program (255 character limit):

25. Do you have any concerns about starting this exercise program (255 character limit):

APPENDIX B

PROMIS-29

Association: Branch:

LIVESTRONG® AT THE YMCA PROMIS-29 PROFILE

VERSION 1.0

Participant name	Date (MM/DD/YY): / /	Timepoint: ☐ Baseline ☐ Post

Please respond to each question or statement by marking one box per row.

	PHYSICAL FUNCTION Are you able to...	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
1	Do chores such as vacuuming or yard work?	☐	☐	☐	☐	☐
2	Go up and down stairs at a normal pace?	☐	☐	☐	☐	☐
3	Go for a walk of at least 15 minutes?	☐	☐	☐	☐	☐
4	Run errands and shop?	☐	☐	☐	☐	☐

	ANXIETY In the past 7 days...	Never	Rarely	Sometimes	Often	Always
5	I felt fearful	☐	☐	☐	☐	☐
6	I found it hard to focus on anything other than my anxiety	☐	☐	☐	☐	☐
7	My worries overwhelmed me	☐	☐	☐	☐	☐
8	I felt uneasy	☐	☐	☐	☐	☐

	DEPRESSION In the past 7 days...	Never	Rarely	Sometimes	Often	Always
9	I felt worthless	☐	☐	☐	☐	☐
10	I felt helpless	☐	☐	☐	☐	☐
11	I felt depressed	☐	☐	☐	☐	☐
12	I felt hopeless	☐	☐	☐	☐	☐

	FATIGUE In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
13	I felt fatigued	☐	☐	☐	☐	☐
14	I have trouble starting things because I am tired	☐	☐	☐	☐	☐
15	How run-down do you feel on average?	☐	☐	☐	☐	☐
16	How fatigued did you feel on average?	☐	☐	☐	☐	☐

SLEEP DISTURBANCE In the past 7 days...		Very poor	Poor	Fair	Good	Very good
17	My sleep quality was	☐	☐	☐	☐	☐
In the past 7 days...		**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
18	My sleep was refreshing	☐	☐	☐	☐	☐
19	I had a problem with my sleep	☐	☐	☐	☐	☐
20	I had difficulty falling asleep	☐	☐	☐	☐	☐

SATISFACTION WITH SOCIAL ROLE In the past 7 days...		Not at all	A little bit	Somewhat	Quite a bit	Very much
21	I am satisfied with how much work I can do (include work at home)	☐	☐	☐	☐	☐
22	I am satisfied with my ability to work (include work at home)	☐	☐	☐	☐	☐
23	I am satisfied with my ability to do regular personal and household responsibilities	☐	☐	☐	☐	☐
24	I am satisfied with my ability to perform my daily routines	☐	☐	☐	☐	☐

PAIN INTERFERENCE In the past 7 days...		Not at all	A little bit	Somewhat	Quite a bit	Very much
25	How much did pain interfere with your day to day activities?	☐	☐	☐	☐	☐
26	How much did pain interfere with work around the home?	☐	☐	☐	☐	☐
27	How much did pain interfere with your ability to participate in social activities?	☐	☐	☐	☐	☐
28	How much did pain interfere with your household chores?	☐	☐	☐	☐	☐

PAIN INTENSITY In the past 7 days...		No pain										Worst imaginable pain
29	How would you rate your pain on average?	0	1	2	3	4	5	6	7	8	9	10