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Predictors of Health Literacy Scores in the Adolescent Oncologic Population

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Walden University
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Abstract

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MS, Walden University, 2015

BS, The University of Kansas, 2013

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health Epidemiology

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November 2022

Abstract

Recent research showed a relationship between low health literacy in adult oncology patients, poor communication with providers, misconceptions about disease and treatment options, and the inability to adhere to treatment plans. Comparative literature addressing adolescent health literacy contained insufficient evidence of these relationships. The purpose of this exploratory cross-sectional quantitative study, based on the health literacy skills framework, was to assess the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or highest parent education level. Data were collected from 68 adolescents treated in the oncology department at an academic children's hospital using the Rapid Estimate of Adolescent Literacy in Medicine-Teen (REALM-Teen) assessment. Data were analyzed using simple and multiple linear regression as well as logistic regression. The scores for females were 4.4 points higher than their male counterparts, and for every 1-year increase in age, the REALM-Teen score increased by 2.7 points. Additionally, for every parent education level achievement increase, the REALM-Teen Score level location moved toward *Exceeds Health Literacy Level* by approximately 0.7 points. This study may raise awareness of levels of health literacy of the adolescent oncologic population. In addition, the findings of this study may identify areas for future research, including health literacy interventions to enhance health literacy levels in the adolescent oncologic population.

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Dedication

It is with genuine gratefulness and warmest regard that I dedicate this dissertation to several people who have meant and continue to mean the world to me. To my husband, Daniel, who has been a constant source of support and encouragement during the challenges of graduate school and life. There is no one else I would rather go through this life with. I am lucky to have you. I love you.

To my children, Skylar, Riley, Jordan, and Colton. The absolute light and joys of my life. The reason for my breaths and my heartbeat. Thank you for your understanding during times that I seemed distracted with this project. I love you all and my greatest hope is that you see that anything is possible with a little grit, determination, and persistence. Never give up on the things that make you smile.

To my dad, Treg Qualman, who has always loved me unconditionally and whose wonderful examples have taught me the value of hard work and that literally anything is possible if I am willing to go the distance.

Last but certainly not least, my grandma and grandpa, Evelyn and John Judson Hallman, Jr. To my grandma whose love knew no bounds and although she is no longer of this world, her memories continue to regulate my life, and to my grandpa who provided unwavering support, hours of advice, a listening ear, and an understanding heart.

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Chapter 1: Introduction to the Study

Social inequalities and health outcomes continue to be prevalent in society despite a plethora of research on this relationship. Health literacy was shown in recent research to be a factor in health outcome variability, thereby contributing to social inequalities (Clouston et al., 2017). Without proper health literacy, a patient cannot make an informed decision regarding their screening and treatment options (Okan et al., 2018). Recent research showed a relationship between low health literacy in adult oncology patients and poor communication with providers, misconceptions with regards to disease and treatment options, and inability to adhere to treatment plans (Okan et al., 2018). Comparative scientific literature addressing adolescent health literacy contained insufficient evidence of these relationships (Mackert et al., 2015; Okan et al., 2018). The current study was needed because health literacy in this population had not been well researched and represented a gap in the literature. Predictor variables may be discovered leading to a greater understanding of the development of health literacy within the adolescent population (Squiers et al., 2012; Velardo & Drummond, 2017). In this chapter, I present the background, problem statement, purpose, research questions, nature of the study, assumptions, and limitations for this research.

Background

The concept of health literacy has been around for decades, yet there are over two dozen different definitions of health literacy (McCormack et al., 2012). Some definitions are shared among different groups and individuals, and some are stand-alone. For example, the World Health Organization (WHO, 1998) along with a pioneer in the field

of health literacy, Nutbeam (1998) used the following definition of health literacy: “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” (p. 357). In contrast, the American Medical Association Ad Hoc Committee on Health Literacy (1999) stated that the definition of health literacy is “the constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment, such as the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials” (p. 553).

The variations in these definitions can be attributed to different factors including mode of data collection, prose, culture, validity, population, and functionality (McCormack et al., 2012). No matter what definition of health literacy is used in research, the goal remains the same: to improve health literacy. Researchers have worked toward this common goal employing the 3-tiered approach to measuring and improving health literacy: at the individual/person level, at the health information materials level, and at the health care system level (McCormack et al., 2012).

Health literacy has been acknowledged to be a notable public health issue by major federal and national organizations including but not limited to the American Medical Association, the Institute of Medicine, the United States Departments of Education and Health and Human Services, and the Agency for Healthcare Research and Quality (Betz et al., 2008). Health literacy has been shown in recent research to be a

factor in health outcome variability, thereby contributing to social inequalities (Beauchamp et al., 2015; Clouston et al., 2017).

Doctors and health care providers have been seen as those who possessed the information to facilitate healthy outcomes in patients, and patients have been expected to take their advice without question (Kimbrough, 2007). However, as society has evolved, more focus has been placed on a patient's autonomy and ability to take charge of their self-care and well-being. This authority has also been seen in the adolescent population as they prepare to transition to adulthood (Manganello, 2007; Taddeo et al., 2008). Nevertheless, there have been obstacles making it difficult for this autonomy to progress. One of these obstacles has been a patient's health literacy level. Health literacy levels have the capability to influence adolescents and are exceptionally critical for adolescents who have chronic conditions (Manganello, 2007).

Below-average levels of health literacy have been a challenge in health care and a problem in the United States for decades. The United States Department of Health and Human Services (DHHS, 2019) has listed health literacy as a key issue in the social determinants of health topic area for their Healthy People 2020 campaign. This phenomenon has been researched for nearly 3 decades. According to Stableford and Mettger (2007), there is a growing gap between being able to read in general and the ability to read written health information. I researched age, sex, number of months since cancer diagnosis, and highest parent education level in relation to adolescent health literacy scores to determine potential predictor variables leading to a greater

understanding of the development of health literacy within the adolescent population (see Squiers et al., 2012; Velardo & Drummond, 2017).

Problem Statement

Studies have shown that the health literacy of adolescents is a significant factor in the success rate of interventions for transition of health care into adulthood; health literacy influences the behaviors and attitudes toward a person's own health that are created during childhood and have a significant influence on health patterns as adults (Huang et al., 2014; Nash et al., 2018). Those who had inadequate health literacy as adolescents did not accumulate all the advantages associated with the interventions (Huang et al., 2014). With the transition from adolescence to adulthood, there is a shift in a person's health care. A need emerges for oncologic adolescents to develop autonomous self-care and to communicate effectively with their providers (Huang et al., 2014). The problem is the maldistribution of income contributes to poor health outcomes of oncologic adolescents because the adolescent health literacy of cancer patients is not well understood. Recent research showed a relationship between low health literacy in adult oncology patients, poor communication with providers, misconceptions with regard to disease and treatment options, and lack the ability to adhere to treatment plans (Okan et al., 2018). Comparative scientific literature about adolescent health literacy contained insufficient evidence (Okan et al., 2018). This was in part due to the nature of the adolescent oncologic population and the time commitment of previous tests including the Wide Range Achievement Test (WRAT4), which takes 30–45 minutes in children 8 and

up, and the Peabody Individual Achievement Test (PIAT), which takes 60–90 minutes to administer (Mathews-Lingen, 2018; Wilkinson & Robertson, n.d.).

Health literacy in this population has not been well researched and represented a gap in the literature. By researching age, sex, number of months since cancer diagnosis, and highest parent education level in relation to adolescent health literacy scores, I sought to identify predictor variables that may lead to a better understanding of the development of health literacy in this population (see Squiers et al., 2012). A validated questionnaire capable of assessing health literacy in adolescents, known as the Rapid Estimate for Adolescent Literacy in Medicine (REALM-Teen) form, was used in this study (see Davis et al., 2006).

Purpose of the Study

The purpose of this study was to assess the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or highest parent education level. These variables had been researched in previous studies and had been shown to be predictor variables in the adult population (Dharmapuri et al., 2015; Squiers et al., 2012). This study addressed the same variables in the adolescent population.

Research Questions

Three research questions (RQs) were molded based on adolescent health literacy and deriving determinants that affect these levels:

RQ1: Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients?

$H_0$1: There was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

$H_1$1: There was a significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

RQ2: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients?

$H_0$2: There was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

$H_1$2: There was a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

RQ3: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and parent education level for adolescent oncology patients?

$H_0$3: There was no relationship between health literacy scores and parent education level for adolescent oncology patients.

$H_1$3: There was a relationship between health literacy scores and parent education level for adolescent oncology patients.

Conceptual Framework

There are at least a dozen conceptual frameworks related to the concept of health literacy (McCormack et al., 2012). Each framework has a different focus. For example, Baker's (2006) framework identified mediators and moderators while emphasizing the role of prior knowledge. Manganello's (2007) framework focused on adolescents while adding media literacy skills related to health literacy. Passche-Orlow and Wolf's (2007) framework represented a causal model that focused on the pathways between outcomes and health literacy.

One group of developers of a health literacy conceptual framework combined ideas from the conceptual frameworks developed by Baker (2006), Passche-Orlow and Wolf (2007), and Manganello (2007) to create what is known as the health literacy skills (HLS) framework (Squiers et al., 2012). Each of those frameworks laid the foundation for the creation of a complete portrayal of the factors related to acquiring and utilizing health literacy skills (Squiers et al., 2012). The HLS framework seeks to decipher many complicated connections while alluding to the causal nature of health literacy making sure to be inclusive of the many different moderator and mediator variables (Squiers et al., 2012). This framework was selected for the current study based on its ability to depict the pathway from the evolution and moderators of skills as they pertain to health literacy, to utilization and resulting health-related outcomes.

Nature of the Study

I conducted an exploratory cross-sectional quantitative study using the REALM-Teen questionnaire. The focus of exploratory quantitative research is observational to

describe what is (University of Wisconsin, 2017). Because there was no intervention and the research included only data regarding the level of health literacy of adolescents treated in the oncology department at an academic children's hospital, cross-sectional quantitative analysis was the most applicable form of study. Spearman and Pearson correlations were conducted to determine the relationships among the variables, and multiple linear regression, simple regression, and ordinal regression were used to determine which predictor variables had the greatest effect on health literacy scores in this population. The dependent variable was health literacy score, and the independent variables were sex, age, number of months since cancer diagnosis, and highest parent education level.

Definition of Terms

Adolescent: "A young person who has begun puberty but has not yet become an adult. During adolescence a child experiences physical and hormonal changes that mark the transition into adulthood. Adolescents are generally between the ages of 10 and 19 years" (National Cancer Institute, n.d., p. 1).

Health literacy: "The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health" (Nutbeam, 1998, p. 357); "the constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment, such as the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials" (American Medical Association, 1999, p. 553); "the degree to which individuals have the

capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Selden et al., 2000, p. vi).

Oncology: "A branch of medicine that specializes in the diagnosis and treatment of cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs to treat cancer), radiation oncology (the use of radiation therapy to treat cancer), and surgical oncology (the use of surgery and other procedures to treat cancer)" (National Cancer Institute, n.d., p. 1).

Assumptions

The assumptions for this study were based on the conceptual framework, Health Literacy Skills (HLS), and the current literature. They included the following:

1. The responses recorded from the study participants were as accurate and honest as possible.
2. Health literacy is a multi-dimensional construct with multiple levels of influence including the individual trains outline in the conceptual framework model.
3. Study participants were sincerely interested in participating in the research and did not have any ulterior motives for their participation.
4. The inclusion criteria for this study were appropriate and ensured that the study participants had had similar medical experiences (oncology diagnoses).

Scope and Delimitations

The scope of this research was limited to the oncology department at an academic children's hospital located in Missouri. Participants who met the inclusion criteria were

invited to participate and were administered the REALM-Teen assessment. This assessment was used to measure the health literacy levels of the adolescents. Using these results and the demographics collected, I conducted descriptive statistics. The HLS framework was used to depict the pathway from the evolution and moderators of skills as they pertain to health literacy, to utilization and resulting health-related outcomes.

There were three delimitations that were significant to this study:

1. Only primarily English-speaking participants aged 10–19 years who had been diagnosed with cancer were included in this study because the REALM-Teen was validated only in English and for that age group.
2. Study participants were limited to those who visited the academic children's hospital in Missouri because this was the only location of the academic children's hospital with an oncology department.
3. The REALM-Teen was used to assess health literacy due to it, at the time, being the only validated health literacy assessment tool for adolescents geared toward being administered in the health care setting.

The HLS framework was chosen over Manganello's (2007) framework for adolescent health literacy to avoid potential bias because Manganello was also the creator and validator of the REALM-Teen assessment used in the current study. The Passche-Orlow and Wolf (2007) framework was avoided because it focused on health literacy and outcomes as opposed to the variables that contributed to low levels of health literacy, which were of interest in the current study.

Limitations

The limitations of this study included the following:

1. The findings were not generalizable to the overall population of adolescents with cancer because this study included a convenience sample of adolescent oncology patients from the hematology/oncology division of the academic children's hospital in Missouri.
2. The patient sample choice was limited to those willing to participate and those who were present on days that I was in clinic.
3. Patients for whom English was not their primary language were not included in the study because the REALM-Teen was not validated for any language other than English.

Significance

The results of this study may provide needed insight into the health literacy of the adolescent oncologic population. This area represented an under researched population worldwide (Manganello et al., 2017). Until recently, there had not been a validated method to test the health literacy in this population. Recent research showed that health literacy is an essential part of a person's health status. The positive social change implications of the current study are that key stakeholders could be informed as to what the health literacy level is of this population as well as whether the health literacy interventions that are currently in place are sufficient or need to be addressed. Stakeholders would then be able to tailor their health literacy interventions, leading to an increase in adolescent health literacy. This study has the potential to positively impact

health outcomes because adolescents are taking a more active role in the management of their personal health care by viewing and interacting with health care professionals, interventions, and health messages (see Gilljam et al., 2016). In recent years, a child's right to take an active role in their health care has been in the national and international spotlight (Gilljam et al., 2016).

The current study may raise awareness regarding the levels of health literacy of the adolescent oncologic population and may provide indications for future research and clinical care. This study may show that measuring the health literacy scores of adolescent oncologic patients is not only feasible but necessary to provide the proper educational focus based on the patient's health literacy score. Additionally, this study may identify the need for further research addressing possible barriers and facilitators to health literacy levels in the adolescent oncologic population. Furthermore, the results of this study may aid in the development of work with a focus on health literacy interventions geared toward improving the overall health outcomes in the population.

Summary

Health literacy remains an area of concern regarding public health and governing bodies. This study addressed factors that affect health literacy in the adolescent oncologic population to promote further interventions in this population. Through use of the REALM-Teen assessment, the required time commitment of obtaining the health literacy scores of this population were minimal and increased participation in this study. Chapter 2 presents information about the theoretical framework and literature search process and provides a review of the recent literature related to health literacy.

Chapter 2: Literature Review

Studies have shown that the health literacy of adolescents is a significant factor in the success rate of interventions for transition of health care into adulthood; health literacy influences the behaviors and attitudes toward a person' own health that are created during childhood and has a significant influence on health patterns as adults (Huang et al., 2014; Nash et al., 2018). Those who had inadequate health literacy as adolescents did not accumulate all the advantages associated with the interventions (Huang et al., 2014). There comes a time for oncologic adolescents to develop autonomous self-care and to communicate effectively with their providers (Huang et al., 2014). The problem is the maldistribution of income contributes to poor health outcome of oncologic adolescents because the adolescent health literacy of cancer patients is not well understood (Rikard et al., 2016). Recent research showed a relationship between low health literacy in adult oncology patients and poor communication with providers, misconceptions about disease and treatment options, and inability to adhere to treatment plans (Okan et al., 2018). Comparative scientific literature addressing adolescent health literacy contained insufficient evidence of these relationships (Mackert et al., 2015; Okan et al., 2018). This was in part due to the nature of the adolescent oncologic population and the time commitment of previous health literacy tests including WRAT4, which takes 30–45 minutes in children 8 and up, and the PIAT, which takes 60–90 minutes to administer (Mathews-Lingen, 2018; Wilkinson & Robertson, n.d.). Health literacy in this population has not been well researched and represented a gap in the literature. By researching age, sex, number of months since cancer diagnosis, and highest parent

education levels in relation to adolescent health literacy scores, I sought to identify predictor variables that may lead to a better understanding of the development of health literacy in this population (see Squiers et al., 2012; Velardo & Drummond, 2017).

The purpose of this study was to assess the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or highest parent education level. These variables had been researched in previous studies and had been shown to be predictor variables in the adult population (Berens et al., 2016; Dharmapuri et al., 2015; Heijmans et al., 2015; Kutner et al., 2006; Morrow et al., 2006; Robinson et al., 2011; Squiers et al., 2012). I assessed the same variables in the adolescent population.

In this chapter, I provide a description of my literature search strategy, the conceptual used to theorize the association between health literacy and health related outcomes, and a review of recent literature. The information discovered through the literature review was divided into sections including (a) health literacy and public policy, (b) health literacy definitions, (c) health literacy and chronic conditions, (d) variables affecting health literacy, (e) health literacy and adolescents, (f) previous research utilizing REALM-Teen, and (g) transitioning from adolescent to adult care. I conclude this chapter with a summary of the themes observed in the literature.

Literature Search Strategy

The initial literature search was conducted using PubMed. The search terms used included *health literacy*, *adolescent*, *adolescence*, *teen*, *REALM-Teen*, *REALM-TeenS*, and *transition to adult care*. The search was also limited to peer-reviewed articles with publish dates from 2008 to 2018 to ensure recent literature. This yielded 563 articles. After narrowing the search, I analyzed 143 full-text articles for extractable and pertinent data.

The next search involved the Cumulative Index to Nursing and Allied Health Literature. This search encompassed the same terms but was not limited by date published, only by peer-reviewed status. This search yielded 178 articles, many of which overlapped with those found in the PubMed search. However, this search provided numerous seminal articles.

Finally, the Walden University Thoreau search engine was used. The same search terms were used with the addition of *policy*, *oncology*, *oncologic*, *cancer*, and *Health Literacy Skills Framework*. Again, the publication date was not a limiting factor to account for potential seminal articles. Many articles overlapped, but an additional 44 articles were located.

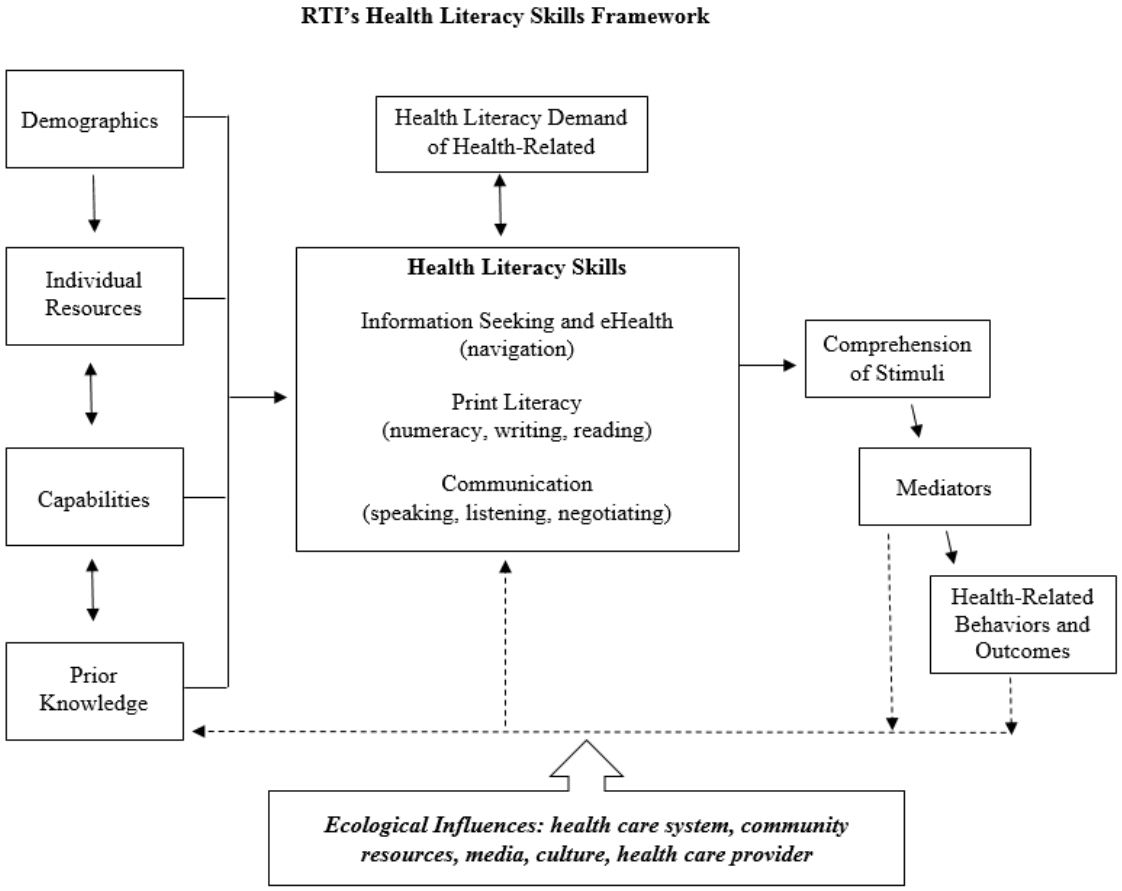
Conceptual Framework

The conceptual framework for this study was the HLS (see Squiers et al., 2012). The HLS was one of several frameworks that can be used in health literacy research. This framework was selected based on its ability to depict the entire pathway from the

evolution and moderators of skills as they pertain to health literacy, to utilization and resulting health-related outcomes (see Figure 1).

Figure 1

Health Literacy Skills Conceptual Framework



Note. Adapted from Squiers et al. (2012).

The HLS conceptual framework theorizes the associations between health literacy and health-related outcomes and demonstrates how health literacy operates at an individual level, while recognizing that an individual's external factors impact these associations (Squiers et al., 2012). The framework further shows that demographic

characteristics such as sex, age, education, and income, as well as prior knowledge (which includes illness and disease experiences) impacts the level that a person can develop, process, and utilize health literacy skills (Baker, 2006; Squiers et al., 2012). There are four main constituents of the HLS conceptual framework:

- elements that effect the evolution and application of health literacy skills,
- health-related stimuli,
- the health literacy skills that are necessary for the comprehension of the previously mentioned stimuli and performance of required tasks, and
- the mediators between health literacy and health outcomes (Squiers et al., 2012).

Lee et al. (2016) used the HLS framework to test the theory that health literacy among adults with type 2 diabetes relates to self-care tasks and self-efficacy. Although it was known that health literacy and health outcomes share an association, the nature of the association was not fully understood. Lee et al. attempted to fill the gap in knowledge by linking health literacy to self-efficacy and self-care tasks. The results confirmed that health literacy had a direct effect on self-care tasks ($\beta = .209$, $p < .001$) and self-efficacy ($\beta = .450$, $p < .001$), affirming the HLS framework.

Jin et al. (2018) examined the development of health literacy mediated by online health information seeking behaviors in the Korean American population and its effect on the decision to obtain colorectal cancer screening. Jin et al. used the HLS framework to determine possible pathways through which online health information-seeking behaviors impact health literacy leading to greater colorectal cancer screening rates. In this instance,

the HLS framework clarified the moderators that impact the maturation of health literacy as well as the mediators that influence the association between health literacy and health outcomes.

Literature Review

Social inequalities and adverse health outcomes continue to be prevalent in society despite a plethora of research on this relationship. Health literacy has been shown in recent research to be a factor in health outcome variability, thereby contributing to social inequalities (Beauchamp et al., 2015; Clouston et al., 2017). Health literacy is essential to obtaining, processing, and understanding information related to health and health care services (Okan et al., 2018). Without proper health literacy, a patient cannot make an informed decision regarding their screening and treatment options (Okan et al., 2018).

Health Literacy and Public Policy

Health literacy has been acknowledged to be a notable public health issue by major federal and national organizations including but not limited to the American Medical Association, the Institute of Medicine, the United States Departments of Education and Health and Human Services, and the Agency for Healthcare Research and Quality (Betz et al., 2008). Insufficient levels of health literacy cause a $230 billion a year burden on the public health system (Somers & Mahadevan, 2010). Even though health literacy was not a focus of the legislation passed for health care reform in 2010, many contended that the legislation could not be triumphant unless government efforts to address low health literacy in the public were amplified (Somers & Mahadevan, 2010).

Two congressional bills had the potential to amplify government efforts to address low health literacy in the public: the National Health Literacy Act of 2007 and the Plain Writing Act of 2010. The National Literacy Act of 2007 was introduced to Congress on December 6, 2007 (GovTrack.us, 2007). The main goal of this bill was "to ensure that all Americans have basic health literacy skills to function effectively as patients and health care consumers" (GovTrack.us, 2007, p. 1). In this bill, it was recognized that low health literacy is a problem for half of all adult Americans and that the issues with health literacy affect the cost, quality, and outcomes of health care (GovTrack.us, 2007). This bill further proposed that a health literacy implementation center be established to "enhance efforts to help eliminate the problem of low health literacy by improving measurements, research, development, and information dissemination" (GovTrack.us, 2007, p. 8). However, the National Health Literacy Act of 2007 never made it through Congress.

Several years later, the Plain Writing Act of 2010 emerged. This act originated in February of 2009. It was introduced to Congress at that time, and a little over a year later this bill was forwarded to the House and then to the Senate. The bill was signed into federal law by President Barack Obama on October 13, 2010 (GovTrack.us, 2019). Although this act did not mention the words "health literacy," they were implied. The act was the first of its kind to mandate that every document that a federal agency issues must be written in plain writing (GovTrack.us, 2019). The act further mandated plain writing training for federal employees while also creating a process for the monitoring of federal agencies' compliance with the act's requirements (GovTrack.us, 2019).

The term health literacy first appeared in a publication dating back to 1974 (Simonds, 1974). The article's focus was social policy about health education. Simonds (1974) deemed health literacy as health education that satisfies the nominal benchmarks for each school grade level. As the decades passed, government interest in health literacy gained momentum, and health literacy appeared as a goal in Healthy People 2010, a disease-prevention, and health-promotion agenda for the United States of America (DHHS, 2011). The goals were expanded further to state that an improvement in the health literacy of the population and increased percentages of people with proficient health literacy were being sought (DHHS, 2011). In a recent update to the initiative Healthy People 2020, new goals expanded previous iterations while adopting and promoting a complete social determinants perspective (DHHS, 2019; Koh et al., 2011). This initiative included the DHHS National Action Plan to Improve Health Literacy.

The National Action Plan to Improve Health Literacy visualized a reconstruction of the avenues and methods used to make and spread any kind of health information within the United States (DHHS, 2010). This plan further advocated for the assurance that all adolescents move into adulthood with the necessary health literacy efficiency that will allow them to have a life without unnecessary health disparities (DHHS, 2010). Limited health literacy affects all types of people regardless of age, income, race, or level of education (DHHS, 2010). Appealing to all types of persons is necessary.

The National Action Plan to Improve Health Literacy was provided to aid all entities, from individual people to large organizations, in the improvement of health literacy in their area (DHHS, 2010). This plan's foundation included two principles:

- All people equally have the right to health information that allows for them to make the best-informed decision.
- Delivery of health services should be provided in such a way that allows for understanding and benefiting quality of life, longevity, and health (DHHS, 2010).

This plan is comprised of seven goals that support the improvement of health literacy while providing different approaches to achieve it:

- Develop and disseminate health and safety information that is accurate, accessible, and actionable.
- Promote changes in the health care system that improve health information, communication, informed decision making, and access to health services.
- Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in childcare and education through the university level.
- Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.
- Build partnerships, develop guidance, and change policies.
- Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.
- Increase the dissemination and use of evidence-based health literacy practices and interventions (DHHS, 2010).

Although this is a step in the right direction, more needs to be done to alleviate the socioeconomic burden that accompanies a population with low health literacy.

Health Literacy Definitions

Over the years, knowledge of health literacy and its definition has evolved. Throughout the literature review, two definitions were consistent: Selden et al. (2000) defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. vi). The WHO (1998) defined health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (p. 10).

Despite the differences in the definition of health literacy, the underlying theme remains the same – the ability to use health information to achieve optimal health. To fully understand the meaning of health literacy, it is essential to understand the meaning of literacy itself.

Nutbeam (2000) suggested that there are three types of literacy: interactive/communicative literacy, functional/basic literacy, and critical literacy (2000). He stated that the current definitions of health literacy are lacking and do not fully explain the "meaning and purpose of literacy for people" (Nutbeam, 2000; p. 263). Nutbeam further ventured to classify health literacy based on what it allows a person to accomplish (2000). He defined the three types of literacy as follows:

- Functional or basic – “sufficient basic skills in reading and writing to be able to function effectively in everyday situations” (Nutbeam, 2000; p. 263)
- Interactive or communicative – “more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities” (Nutbeam, 2000; pp. 263-264)
- Critical – “more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and use this information to exert greater control over life events and situations” (Nutbeam, 2000; p. 264).

Nutbeam (2000) believed that by classifying literacy in this way, it could effectively show the progression of how literacy affects personal empowerment and autonomy. Furthermore, these classifications aid in showing how the progress between each level is reliant on cognitive development, among other factors (Nutbeam, 2000).

In addition to the definitions and classifications of health literacy, the dimensions of health literacy have also been studied over the past decade. Studies by the likes of Lenartz et al. (2014), and Martin and Chen (2014), Massey et al. (2012), Paakkari and Paakkari (2012), Rask et al. (2013), and Subramanim et al. (2015) have all deciphered what knowledge, concepts and skills comprise the dimensions of health literacy.

According to Massey et al. (2012), the dimensions of health literacy include:

- Navigating the healthcare system to include filling prescriptions and making appointments.
- The provider-patient relationship (trust, communication, and comfort levels);
- Preventative care (health screens and annual checkups);

- Rights and responsibilities (asking the proper questions and knowing one's rights); and
- Seeking information (information seeking behaviors and being able to interpret information).

Then, there is Martin and Chen (2014) and Rask et al. (2013) whose dimensions of health literacy focus on the basic abilities to read and write as the basic ability to communicate and evaluate information. Lenartz et al. (2014) and Paakkari and Paakkari (2012) took a different approach with the dimensions of health literacy and leaned more towards broad range competencies to include:

- Critical thinking.
- Theoretical knowledge.
- Being able to assume social responsibility.
- Practical knowledge; and
- Self-awareness.

As time has passed, the progression of the dimensions of health literacy have evolved to include factors such as attitude, motivation, self-efficacy, and intention as evidenced by Subramaniam et al. (2015). With this awareness of the dimensions of health literacy, now is the time to assess the associations correlated with health literacy levels.

Health Literacy and Chronic Conditions

Over the past several decades, there have been enormous gains with regards to chronic disease treatments. However, with those gains came increased medication and treatment complexities requiring adequate levels of health literacy to process and

understand. For a patient to be able to effectively manage their chronic condition, they need to be able to analyze, comprehend and ultimately utilize the information given to them (van der Heide et al., 2018). Many research studies have been conducted to determine the association between health literacy and health outcomes in patients with chronic conditions. It has been shown that patients with a low level of health literacy are at a higher risk for illness exacerbations, emergence of secondary conditions, and preventable hospitalizations (Betz et al, 2008; Federman et al., 2014; Marrie et al., 2014; McNaughton et al., 2014; Moser et al., 2015; Wright et al., 2018). Furthermore, after such hospitalizations, it has been demonstrated that those who have low levels of health literacy have an increase in healthcare use (McNaughton et al., 2013; Moser et al., 2015; Peterson et al., 2011; Wu et al., 2013).

In addition to increased hospitalization risks and increased healthcare use, those who have low health literacy also experience other hidden costs. These costs have been shown to include:

- being less productive at work.
- missing school.
- supplies.
- redirection of limited family resources.
- non-refundable transportation costs related to medical treatments.
- extra childcare costs.
- equipment; and
- extra burden on the family caregiver (Betz et al., 2008).

Studies have shown that health literacy is independently related to knowledge of chronic diseases (Gazmararian et al., 2003; Williams et al., 1998). For example, a study conducted by Gazmararian et al. (2003) demonstrated that people with congestive heart failure who also have inadequate levels of health literacy do not possess the information for or ability to complete the suggested self-care techniques provided to them by their physicians or caretakers. This has been shown to lead to an increased risk of heart failure exacerbation related hospitalizations (Gazmararian et al., 2003). Another example of the relationship between health literacy and knowledge of chronic conditions has been shown in patients with asthma who also possess insufficient levels of health literacy. In the population, these patients did not utilize their metered-dose inhaler correctly as often as their sufficiently health literate counterparts (Williams et al., 1998). Furthermore, it has been shown that patients with low health literacy who participated in standardized health education programs for management of chronic conditions such as asthma or diabetes, still possessed inadequate self-management skills and knowledge than those who had adequate health literacy and participated in the same programs (Gazmararian et al., 2003).

Another factor examined in studies was that of personal involvement in a patient's own medical decision making (Barton et al., 2014; Brabers et al., 2018; Goggins et al., 2014; McCaffery et al., 2013; Naik et al., 2011; Seo et al., 2012; Smith et al., 2014; Yin et al., 2012). Most of these studies have found that there was a positive correlation among patient involvement in medical decision making and health literacy (Barton et al., 2014; 2018; Goggins et al., 2014; McCaffery et al., 2013; Naik et al., 2011; Seo et al., 2012;

Smith et al., 2014; Yin et al., 2012). However, one study was unable to prove a correlation between a patient's involvement in their own medical decision making and their level of health literacy, positive or otherwise (Brabers et al., 2018).

Research studies have also assessed the overall relationship between health literacy and quality of life. There were mixed reviews among the studies. Some studies showed that low health literacy is associated with a lesser quality of life (Macabasco-O'Connell et al., 2011; Song et al., 2012; Wallace et al., 2008; Wang et al., 2013). However, one study conducted did not find a statistically significant association between a patient's level of health literacy and their overall quality of life (Smith & Haggerty, 2003).

Variables Affecting Health Literacy

In 2003, The National Center for Education Statistics (NCES) conducted the first ever National Assessment of Adult Literacy (NAAL) Health Literacy Component (HLC) (Kutner et al., 2006). The results were subsequently published in 2006. To date, this is the only published national assessment of health literacy. This assessment included over 19,000 persons aged 16 and older living in the United States (Kutner et al., 2006).

Age

The NAAL discovered that only 8% of those people 16-18 years old had proficient health literacy which was significantly lower than that of the older age groups (Kutner et al., 2006). Eleven percent of those who fell in the 19-24-year-old age group had a proficient level of health literacy, while 16% of the population in the 25-39-year-old age group had a proficient level of health literacy (Kutner et al., 2006). Similar results were found in studies conducted by Berens et al. (2016), Chang et al. (2015), Chisolm et al. (2014), and Ghaddar et al. (2012). However, four studies recently conducted did not find a significant relationship between age and health literacy (Hove et al., 2011; Paek and Hove, 2012; Page et al., 2010; Shone et al., 2011).

Sex

The assessment further discovered that a person's sex played was a factor in their level of health literacy. Overall, the average health literacy score for women was six points higher than those of men (Kutner et al., 2006). Furthermore, there was a higher percentage of men who had a below basic health literacy score than their women counterparts (Kutner et al., 2006). Of note, the difference between men and women who scored in the proficient health literacy level was not statistically significant (Kutner et al., 2006). Similar results have been shown in several other studies (Chang et al., 2016; Morrow et al., 2006; Rikard et al., 2016; Robinson et al., 2011; Wilkinson et al., 2016). However, studies conducted by Chang et al. (2015), Chisolm et al. (2014), Dharmapuri et al. (2015), and Ganesh (2017) failed to find a correlation between sex and health literacy. In a recent study involving adolescents conducted by Vardavas et al. (2009), it was found

that girls are more prone to look for health related information from their friends (26.9% vs. 11.0%), pamphlets (21.3% vs. 9.9%), or health care professionals (11.2% vs. 5.8%) than were their boy counterparts (2009).

Education Level

Education level was found to be positively correlated with a person's level of health literacy (Kimbrough, 2007; Kutner et al., 2006). Furthermore, the group who had not completed or attended high school had a higher percentage of below basic health literacy than those in all the other groups (Kutner et al., 2006). This was also found to be the case in a recent cross-sectional study conducted by Heijmans et al. (2015). Another study conducted by Ganesh (2017) also found a positive correlation between health literacy scores and education levels.

Recent studies have called for additional research exploring possible predictors of adolescent health literacy levels (Manganello, 2007; Velardo & Drummond, 2017). Given the contrast of sex and age in the schedule of developmental attributes corresponding to the health behaviors of adolescents, the influence of health literacy levels by these contrasts may be more relevant than what is shown in previous studies (Fleary et al., 2018).

Health Literacy and Adolescents

While it is recognized that health literacy levels have the capability to influence all adolescents, it is exceptionally critical for those adolescents who have chronic conditions (Manganello, 2007). Furthermore, research has shown that it is probable that those adolescents who have chronic conditions possess a larger level of authority when it

comes to managing their own interventions and care (Manganello, 2007; Taddeo et al., 2008). Thus, their need for effective levels of health literacy is greater as to avoid unnecessary health disparities.

Health literacy is deserving of additional consideration and research with regard to its significance in boosting the health of adolescents and thus the health of adults (Fleary et al., 2018). Different studies have conveyed that conduct which leads to health improvement correlates to subsequent health results (Lam et al., 2006). It is known that the basis for one's general health, their health behavior and their health literacy is formed during adolescence (Paakkari et al., 2018). Adolescence is considered an important life phase for many reasons, one of which being that this is the period when human beings learn autonomy (Ghanbari et al., 2016; Manganello, 2007). Studies with an adolescent health literacy focus are gaining in relevance due to the growing number of adolescents who actively obtain health information that infuses their activities and conduct (Chang, 2011; Steckelberg et al., 2009). Adolescents will rely on that autonomy to guide their decision making and health behaviors as they transition into adulthood. Research has shown that adult health disparities are directly related to health behaviors learned during adolescence (Inchley et al., 2016).

According to *The Nation's Report Card*, as of 2017 data, only 34% of all U. S. 8th graders are at or above reading proficiency on the National Assessment of Educational Progress (National Center for Education Statistics, 2017). Armed with this information, it is uncertain at what level adolescents are able to comprehend, manage and assess

information related to health (Manganello, 2016). This is not to say that adolescents lack interest, it just simply means that achieving this might prove to be an arduous task.

A study conducted by Li-Chun Chang (2011) found that adolescent health literacy was notably associated with self-reported health status. Those who had insufficient health literacy levels were less likely to consider themselves as having a good status of health as opposed to those who had an adequate level of health literacy (Chang, 2011). It is theorized that self-reported health status related to health literacy is likely since those with high levels of health literacy are more apt to purposely seek out information related to their health and to actively try and improve their health if they believe that their health is failing (Change, 2011). Additionally, Chang reported that those who had insufficient health literacy levels had lower scores for health improvement actions as opposed to those who had adequate levels of health literacy (Chang, 2011). A study conducted by Ghaddar et al. (2012) showed that adolescents who had high levels of electronic health literacy were more likely to search online for pertinent health promotion information. Another study conducted by Chisolm et al. (2014) found a negative correlation between health literacy levels and underage drinking. It was shown that adolescents who had lower levels of health literacy were at increased odds of underage alcohol consumption (Chisolm et al., 2014).

Previous Research Utilizing REALM-Teen

The Rapid Estimate of Adult Literacy in Medicine – Teen, otherwise known as the REALM-Teen, was developed and validated by Davis et al. (2006). Davis et al. (2006) realized that the adolescent population would soon be transitioning into adulthood

and with that transition would come the responsibility of managing one's own health care. Davis et al. (2006) further believed that it would be an ideal time to provide health literacy interventions to aid in that transition, but they needed to establish a baseline. Thus, REALM-Teen was born. The REALM-Teen utilizes a list of 66 health related words that the respondents must read with correct pronunciation (Manganello et al., 2016). A single point is lost for each word mispronounced. At the completion of the REALM-Teen, the respondent's score is tallied and a level of health literacy which corresponds with that score, is given (Manganello et al., 2016). Even though the REALM-Teen measures only word recognition, it has been proven to be a valid way to measure adolescent health literacy (Shone et al., 2010). A global review of academic publications focused on health literacy assessments showed that the REALM-Teen assessment is one of the most utilized tools for the measurement of health literacy (Machova & Brabcova, 2018). As of 2018, the REALM-Teen was the only validated instrument to test health literacy specifically in adolescents (Caldwell et al., 2018).

Since its validation, REALM-Teen has been utilized in many studies. One such study, conducted by Holstein et al. (2014) utilized the REALM-Teen assessment to describe the health literacy of adolescents in several different juvenile correctional facilities. The goal was to utilize the health literacy assessment tool to identify those who had low health literacy and in turn would be at risk for developing health-risk behaviors (Holstein et al., 2014). The study showed that one-third of the population was at a below grade reading level (Holstein et al., 2014). Additionally, the average age of the subjects was 17.4 years and the REALM-Teen revealed that the average REALM score was 60.2

which correlated with a reading grade level equal to between eighth and ninth grade (Holstein et al., 2014). The results of this study showed that there is a need for extensive health care provider involvement in this population (Holstein et al., 2014).

Another study, conducted by Shone et al., (2011), had similar results in the adolescent and young adult population. Shone et al.'s (2011) study was conducted with 266 adolescents and young adults in New York State. The purpose of this cross-sectional study was to examine health literacy levels and the understanding of acetaminophen in the target population considering the recent U. S. Food and Drug Administration's increasing concern of the level of misuse of the drug in the United States (Shone et al., 2011). The study concluded that about one-third of the target population had limited health literacy (Shone et al., 2011). Furthermore, this study showed that having a low level of health literacy was a risk factor for possible misuse of acetaminophen containing over-the-counter products (Shone et al., 2011).

Ganesh (2017) conducted a study in India utilizing the REALM-Teen health literacy assessment tool to test the health literacy levels of adolescents from Mangaluru, Dakshina Kannada District. This study not only used the REALM-Teen, but also the REALM- R (for adults). Both assessment tools were used on the same population. This population ranged in age from less than 25 years to greater than 45 years old (Ganesh, 2017). The population contained students, professionals, and businessmen from that district (Ganesh, 2017). The results of the study showed that there was a significant strong, positive correlation between the scores obtained from the REALM-Teen and the REALM-R assessments with a Pearson correlation coefficient of .692 (Ganesh, 2017).

Despite the age of the participants, the researchers received similar results from the test validated for adolescents and the test validated for adults.

An exploratory study of health literacy was carried out by Manganello et al. (2016) in the African American adolescent population. This study is similar one I am conducting as they are both exploring the health literacy of a target population in the hopes of bringing new information useful for creating pertinent interventions to further alleviate health disparities in the adolescent population (Manganello et al., 2016). Manganello et al. (2016) found that less than half of the target population had high health literacy levels. Furthermore, it was determined that those who had lower levels of health literacy relied more on their parents and caregivers than their high health literacy counterparts (Manganello et al., 2016). This highlights the possibility of an effect on the level of health literacy of a parent or caregiver on the level of health literacy of the dependent adolescent.

Transitioning From Adolescent to Adult Care

As the years have passed, childhood cancer survival rates have continued to rise and are currently over 80% leading to a growing number of adolescents who need to transition to adult care (Quillen et al., 2017). According to one study, 1 in 640 people is a survivor of pediatric cancer (Altekruse et al., 2010). These adults are now at a greater risk for the development of unfavorable health outcomes (Quillen et al., 2017). Research has shown that 75% of childhood cancer survivors have additional chronic health conditions decades after their initial cancer diagnosis and over a third of that population has more

than one health issue (Oeffinger et al., 2004). As the cancer survival rates increase, so does this rate of incidence.

To minimize the incidence of adverse health events in this population, it is essential that pediatric oncologic adolescents are given the proper training and knowledge to handle the follow-up care that is associated with their status. One study conducted by Nathan et al. (2008) revealed that less than one-third of adolescent and young adult survivors were provided with survivor-focused care, thus increasing their risk for further adverse health outcomes. The connection between adolescents with high levels of health literacy and adolescents with better health outcomes is starting to emerge (Caldwell et al., 2018). Furthermore, a study conducted by Caldwell et al. (2018) showed that health literacy is associated with the outcomes of those adolescents during their transition from pediatric to adult care. Additionally, there have been numerous studies showing survivors lack the appropriate information concerning their diagnosis, therapies received, and long-term complication risks (Kadan-Lottick et al., 2002; Landier et al., 2015; Oeffinger et al., 2009; Syed et al., 2016). These studies conclude that these adolescents and young adults do not have the necessary skills or knowledge to be able to be a proponent of their own healthcare as adults. It has further been concluded that adolescents with special health care needs are at risk for preventable unfavorable health outcomes (Betz et al., 2008).

As has been previously established, adolescence is a time when autonomy is developed. This autonomy aids adolescents in their future years with health care management and related decision making. Preferably, adolescents would be given instructional support throughout the transition process beginning while still under the

care of their pediatrician (Kenney et al., 2017). The essential elements of this support have been previously acknowledged and include providing adolescents with information regarding their disease, the therapies they have received, their long-term complication risks, giving instruction on how to self-manage their care prudently, and providing transfer coordination to include future follow-up contact (Freyer, 2010; Lugasi et al., 2011). This begins with a solid foundation built on adequate health literacy.

The American Academy of Pediatrics (AAP) recognized enhancing the transition to adult health care for adolescents with exceptional health care requirements as a top ten priority (Hughes & Maiden, 2018). After the release of this statement, more organizations began to back the AAP. In addition to the AAP's stance, the American Academy of Family Physicians and the American College of Physicians acknowledged the need to instruct, educate and prepare the adolescent population to allow for efficient management of their personal health care as they transition to adult care (Hughes & Maiden, 2018). The challenges of transitioning oncologic adolescents from pediatric care to adult care have been well documented. These challenges include, but are not limited to, transportation, accessibility to providers, and socioeconomic status (Quillen et al., 2017). When transitioning oncologic adolescents from pediatric care to adult care, the challenges are further compounded by insufficient health literacy levels (Quillen et al., 2017).

For health literacy to advance through the general population, there needs to be a focus on measurements that are age appropriate throughout different settings and age groups (World Health Organization [WHO], 2013). Adolescence is one of those age groups. Research has shown that there is a definitive and growing gap between autonomy

with regards to a person's health and the clear-cut skills that a person possesses (Gazmararian et al., 2005; WHO, 2013). Based on this research, developing health literacy within the adolescent population is not only advisable, but "could be regarded as a moral act" (Paakkari et al., 2018, p. 4).

Summary and Conclusions

Research related to adolescents and health literacy has been very limited (Ghanbari et al., 2016). Additionally, much of the research that has been conducted did not utilize instruments to assess health literacy that had previously been validated specifically for the adolescent population leading to cautionary interpretations of the findings (Perry, 2014). Despite the lack of research following health literacy levels from childhood to adulthood, it is known that having an insufficient level of health literacy as an adult is directly related to poorer health outcomes (Peralta et al., 2017). Thus, there is a push for early involvement that highlights disease prevention and health promotion in the adolescent population resulting in an overall healthier population (Peralta et al., 2017). Targeting adolescents with interventions specifically for the improvement of health literacy may assist in the promotion of healthier behaviors thus leading to a decrease in potential risks in the future (Bröder et al., 2017). These interventions cannot be successfully created and carried out without the knowledge of what the health literacy levels are in this population is to begin with. Thus, research of this nature is essential for aiding in future endeavors aimed at reducing negative health outcomes in the adolescent population.

Chapter 3: Research Method

The purpose of this study was to assess the health literacy of adolescents treated in the oncology department at a children's hospital in Missouri to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or highest parent education level. In this chapter, I provide information about the research design, population, sampling, data collection, operationalization of variables, and data analysis plan.

Research Design and Rationale

I used an exploratory cross-sectional quantitative design. The focus of exploratory quantitative research is observational and describes what is (University of Wisconsin, 2017). Because there was no intervention and the study focused on possible predictors of the level of health literacy of adolescents treated in an oncology department, a cross-sectional quantitative design was the most applicable form of study. In this study, there were five variables. The dependent variable was the collected health literacy scores based on the REALM-Teen tool. The independent variables were age, sex, number of months since diagnosis, and highest parent education level. There were no anticipated time or resource constraints.

Methodology

Population

The Division of Pediatric Hematology, Oncology and Blood and Marrow Transplant at a children's hospital in Missouri provides comprehensive care for nearly

2,000 children every year. The target population for this study were children who met the inclusion criteria: obtained informed consent, 10–19 years of age, cancer diagnosis, treated in the oncology clinic at a children's hospital in Missouri, and English speaking. The exclusion criteria were English as a second language and primary cancer diagnosis less than 6 months ago.

Sample Size

An a priori power analysis was conducted using G*Power 3.1.9.7 (see Faul et al., 2009) specific to each research question to determine how many participants would be needed. Based on these analyses, an overall minimum sample of 68 participants was required.

RQ1: Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients?

H_o1: There was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

$H_1 1$: There was a significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

The power analysis for RQ1 included the following criteria:

- dependent variable (DV): health literacy score (scale)
- independent variables (IVs): age (scale) or sex (dichotomous)
- test statistic: multiple linear regression
- alpha: 0.05
- power: 0.80

- effect size (f2): 0.15 (medium)
- number of predictors: 2
- Calculated Minimum Sample Size: 68
- *F* tests, linear multiple regression: fixed model, *R*2 deviation from zero

RQ 2: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients?

H_o2: There was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

$H_1$2: There was a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

The power analysis for RQ2 included the following criteria:

- DV: health literacy score (scale)
- IVs: number of months since cancer diagnosis (continuous)
- test statistic: Simple linear regression
- alpha: 0.05
- power: 0.80
- effect size (*f*2): 0.15 (medium)
- number of predictors: 1
- calculated minimum sample size: 1
- *F* tests, linear multiple regression: fixed model, *R*2 deviation from zero

RQ 3: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and highest parent education level for adolescent oncology patients?

H_o3: There was no relationship between health literacy scores and parent education level for adolescent oncology patients.

$H_1 3$: There was a relationship between health literacy scores and parent education level for adolescent oncology patients.

The power analysis for RQ3 included the following criteria:

- DV: health literacy score (transformed from scale to ordinal)
- IVs: highest parent education level (ordinal)
- test statistic: ordinal logistic regression
- alpha: 0.05
- power: 0.80
- odds ratio: 2.25
- number of predictors: 1
- calculated minimum sample size: 67
- Z tests, logistic regression

Procedures for Recruitment, Participation, and Data Collection

Potential participants were identified by their treating physicians and referred to me. The participant's private and identifiable information was not shared prior to receiving permission from the participant/parent to do so. The primary oncologist/advanced practice nurse initially approached potential participants. If a family

and participant were interested in the study, they were approached by me in the hematology/oncology clinic setting. The study was further explained, and assent/consent forms (Appendices A and B) were reviewed with the family at that time. The family was given copies of the consent or permission/assent form as well as my contact information if questions arose. Families were informed that the decision whether to participate in this study would not affect their current clinical care.

If families and participants expressed interest in participating in the study, signatures were obtained, and the questionnaire was given. The one-page tool (see Appendix C) contained 66 words that gradually became more difficult as the participant moved down the list. The participant was instructed to speak each word on the list beginning from the top; if they had trouble with saying a word and did not believe they could say it, they could say "skip" and continue reading down the list. If the participant paused, I reminded them to continue to pronounce whichever words they could that remained on the list. I also reminded them that this tool was administered free from time constraints. As the participant read off the words, I scored the responses on a separate form (see Appendix D) by placing a check mark next to each word that was pronounced correctly.

After completion of the REALM-Teen tool, participants were thanked for their participation and told that this concluded their participation in the study. Scores were then tallied separate from the time of administration, as advised in the REALM-Teen Administration Manual (see Appendix E). The average time of test administration and grading was 2–3 minutes (see Davis et al., 2006). This was the extent of the participant's

involvement in the study. I retained the participant's age, sex, primary diagnosis, months since diagnosis, grade in school, and parent education level on a secure Excel screening log for the purpose of data validation.

Instrumentation and Operationalization of Constructs

Instrumentation

The instrument used for this study was the REALM-Teen created and validated by Davis et al. (2006). With the REALM-Teen tool, researchers could assess adolescents' literacy in a health setting in an average of 3 minutes (Davis et al., 2006). Furthermore, this tool allowed for the adolescent population to be included in the expanding field of research focused on the impact and extent of health literacy levels on a person' overall health and subsequently their health care (Davis et al., 2006). With the current study being conducted in a health care setting and with the adolescent population, this tool was appropriate. The developer, Dr. Terry Davis, gave permission to use the REALM-Teen tool on July 11, 2017, and a copy of that is provided in Appendix F.

The REALM-Teen had a strong Cronbach's alpha value of .94 (Davis et al., 2006). Cronbach's alpha is a standard way to measure internal consistency and is used to measure the reliability of a scale. Additionally, during its validation, the REALM-Teen "demonstrated strong test-retest reliability ($r = 0.98$) and high criterion validity, as tested by correlation with the Wide Range Achievement Test-3 (WRAT-3) ($r = 0.83$) and Slosson Oral Reading Test-R (SORT-R) ($r = 0.93$)" (Davis et al., 2006). Both the WRAT-3 and the Slosson Oral Reading Test-R are standardized tests for reading that are prevalent in adolescent testing (Davis et al., 2006).

Operationalization

Five variables were evaluated in this study. Age, sex, number of months since cancer diagnosis, and parent education level were the independent variables, and health literacy score was the dependent variable. Each variable was measured/manipulated as follows:

- age: continuous variable collected in whole years
- sex: categorical dichotomous variable collected as biologically male or female
- number of months since diagnosis: continuous variable collected in whole number months (e.g., 9 months, 26 months)
- parent education level: categorical ordinal variable, choices included
    - no high school
    - some high school without graduation
    - high school graduate or general equivalency diploma
    - some college
    - college graduate
    - some graduate school
    - completed graduate school
- health literacy score: dependent variable measured on a continuous scale and interpreted as outlined in the REALM-Teen Administration Manual (see Appendix E)

Each participant's grade in school was also collected but used only for the purpose of scoring their level of health literacy as outlined in the REALM-Teen Administration

Manual (see Appendix E). Grade in school was a continuous variable collected as current grade in school and, if information was collected during the summer, grade the participant was going into, per the guidance in the REALM-TEEN Administration Manual (see Appendix E).

Data Analysis Plan

For this study, the IBM Statistical Package for the Social Sciences (SPSS) Version 27 was used. Prior to analysis, the data were cleaned. The process of cleaning the data included checking variable data to ensure that the values listed were possible and correct, detecting and eliminating possible duplicate cases, ensuring that there were no cases in the date that did not meet the inclusion criteria, looking for missing data, and making sure that the same value of string variables was always represented in the same manner (for example, “male” or “female” instead of “Male” or “Female”).

Three RQs guided this study. The questions were based on adolescent health literacy and deriving determinants that could affect these levels:

RQ1: Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients?

$H_0$1: There was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

$H_1$1: There was a significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

RQ2: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients?

$H_0$2: There was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

$H_1$2: There was a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

RQ3: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and parent education level for adolescent oncology patients?

$H_0$3: There was no relationship between health literacy scores and parent education level for adolescent oncology patients.

$H_1$3: There was a relationship between health literacy scores and parent education level for adolescent oncology patients.

Multiple linear regression was used to determine if age and sex were significant predictors of health literacy scores in the adolescent oncologic population (RQ1). The results from the multiple linear regression analysis were interpreted utilizing a 95% confidence interval. Because multiple linear regression was used, it was also important to ensure that the following eight assumptions were met to lessen bias and potential threats to the validity of the results:

- The dependent variable (health literacy score) had to be measured on a continuous scale.

- There had to be two or more independent categorical or continuous variables. For this study there were five independent variables.
- There had to be independence of observations which was checked utilizing the Durbin-Watson statistic. This would produce a value in between 0 and 4 with an acceptable range of 1.5 to 2.5.
- There would need to be a linear relationship between the dependent variable and each of the independent variables, and the dependent variable and the independent variables collectively. This was checked utilizing scatter plots in SPSS and visually inspecting these scatter plots to check for linearity.
- There would need to be homoscedasticity.
- There could not be multicollinearity between the independent variables.
- There could not be any significant outliers.
- The errors would need to be approximately normally distributed.

The first two assumptions were checked before analysis began and the last six assumptions were checked utilizing SPSS.

Simple linear regression was used to determine if number of months since cancer diagnosis was a significant predictor of health literacy scores in the adolescent oncologic population. The results from the simple linear regression analysis were interpreted utilizing a 95% confidence interval. Because simple linear regression was used, it was also important to ensure that the following six assumptions were met to lessen bias and potential threats to the validity of the results:

- The variables would be measured on a continuous scale.

- There would be independence of observations which was be checked utilizing the Durbin-Watson statistic. This would produce a value in between 0 and 4 with an acceptable range of 1.5 to 2.5.
- There would need to be a linear relationship between the dependent variable and each of the independent variables, and the dependent variable and the independent variables collectively. This was checked utilizing scatter plots in SPSS and visually inspecting these scatter plots to check for linearity.
- There would need to be homoscedasticity.
- There could not be any significant outliers.
- The errors would need to be approximately normally distributed.

The first assumption was checked before analysis began and the last five assumptions were checked utilizing SPSS.

Spearman or Pearson correlations was conducted to determine the relationships among the variables and simple linear regression was utilized to determine which predictor variables had the greatest effect on health literacy scores in this population. Spearman or Pearson correlations was used to measure the strength of the linear relationships between the variables (RQ2). Pearson correlation would be used to measure the direction and strength of the association between health literacy score and age and health literacy score and months since diagnosis. This was the chosen method provided that the following four assumptions were met:

- Both variables being utilized in the analysis had to be measured at the continuous level

- No significant outliers
- A linear relationship existed between the two variables
- The variables were normally distributed

The absence of significant outlier and the confirmation of a linear relationship would be confirmed using the visual of a scatterplot. To verify normal distribution, the Shapiro-Wilk test of normality was used. If the assumptions were not met for the variables, Spearman correlation was utilized.

Spearman correlation was best used when the variables were not measured on a continuous scale, no linear relationship existed between variables or when the variables did not have a normal distribution. Additionally, the only assumption that needed to be met is that of the variables being either ratio, interval, or ordinal.

Ordinal logistic regression was used to determine if highest parent education level was a significant predictor of health literacy scores in the adolescent oncologic population. The results from the ordinal logistic regression analysis were interpreted utilizing a 95% confidence interval. Because ordinal logistic regression was used, it was also important to ensure that the following four assumptions were met to lessen bias and potential threats to the validity of the results:

- The dependent variable would be measured at the ordinal level.
- One or more independent variables would be continuous, ordinal, or categorical.
- There cannot be multicollinearity.
- The odds are proportional.

The first two assumptions were checked before analysis began and the last two assumptions were checked utilizing SPSS.

Threats to Validity

The design of this study was such that its goal was to maximize external validity while minimizing internal validity. Internal validity threats that were accounted for in the study design include maturation and instrumentation. Maturation refers to changes within the participants during the study (Meltzoff, 2010). Each person's participation started the same day it ended. Each participant was consented, and the REALM-Teen assessment administered the same day. This ended the participant's involvement in the study. Given this short time frame, risk of maturation was not an issue with this study. Additionally, because I was the only one administering each REALM-Teen assessment and thus provided testing consistency, this minimized, if not eliminated, the possibility of instrumentation being a threat to validity.

This study was designed with the goal of minimizing sources of internal validity while maximizing external validity. However, threats to both internal and external validity were still present. History remains a threat to internal validity. Not knowing what experiences each participant has had in their life up until the day of the assessment introduced some threat into the results by simply not being able to account for all outside factors that may have had an undue effect on that participant's health literacy score. Furthermore, although the REALM-Teen assessment is validated for the healthcare setting, recognizing that a participant might be more comfortable completing the

assessment in a different atmosphere (i.e., their own home) and thus possibly leading to a higher health literacy score, posed a threat to the study's external validity.

Possible threats to statistical conclusion validity included low statistical power, statistical test assumption violations, and low reliability of measures. Each of these possible threats were addressed during the analysis. Some measures were put into place in the design of the study to account for these possibilities. For example, alternative options for analysis were discussed if assumptions were violated for the primary analysis method (Spearman and Pearson correlations). Additionally, the REALM-Teen assessment had been previously validated to ensure its reliability of measures (Davis et al., 2006).

Ethical Procedures

Because this study was conducted at an academic children's hospital in Missouri, it underwent full board review by the academic institution's Institutional Review Board. Once full approval was received, that information was sent to Walden University's Institutional Review Board for reciprocity IRB approval. No data was collected from participants without first obtaining full permission/assent/consent. The academic children's hospital's research policies on informed permission/assent/consent were utilized. Once participants expressed interest in this study to their treating physician/nurse practitioner, I approached the participant and legal guardian (if applicable) and further discussed the study and obtained informed consent. Consent was obtained from every subject aged 18 years or older. For those who were under 18 years of age, permission/assent was obtained. Assent was obtained from subjects of at least 7 years of

age, unless the subject had a limitation in understanding based on their condition (which was be noted in the permission assent form). Parental permission was obtained from one parent or Legally Authorized Representative (LAR) as was required by the consenting/assenting process for this study. The assent of a child was documented on the permission/assent form for the study.

Confidentiality of all participants participating in the trial and all their information was maintained. Each participant was identified by a unique identifier that was used on all data collection materials. All data collection materials and any identifying information were kept in a secure location with access limited to only me. Research data will be kept for five years after the last participant was enrolled. Participants were provided with study contact information for any questions or concerns that arose before, during, and after the study.

While confidentiality could not be guaranteed, protected health information (PHI) was protected to the greatest extent possible. There also might be some situations where laws require the release of protected health information. If PHI is shared with an organization that is not required to comply with federal privacy laws, health information is no longer considered protected and may be used and shared freely by that organization. PHI to be accessed and/or recorded for this research study: names/initials, diagnosis, and medical record number. Health Insurance Portability and Accountability Act (HIPAA) authorization was wrapped into the permission/assent/consent forms.

After the study was complete, the study binders were moved to a secure location with access limited to only me and, if needed, will be moved to Iron Mountain, 6301 Winchester Avenue, Kansas City, Missouri, 64133 for confidential/secure storage.

No conflict of interest existed in this study. While I work at the institution, I do not work in the clinic where the potential participants were seen, and I did not have any direct contact with the potential participants of my study.

Summary

This study utilized an exploratory, cross-sectional quantitative design to assess the health literacy of 68 adolescents treated in the oncology department at a children's hospital in Missouri to determine if there was a significant difference and relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or parent education level. Data was collected using the REALM-Teen tool and analyzed using Spearman and Pearson correlations, multiple linear regression, simple linear regression, and ordinal logistic regression. Chapter 4 provides the results of the data analysis.

Chapter 4: Results

The purpose of this study was to assess the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or parent education level. These variables had been researched in previous studies and had been demonstrated as predictor variables in the adult population (Dharmapuri et al., 2015; Squiers et al., 2012). I assessed the same variables in the adolescent population. In this chapter, I describe the data collection procedures and results of the statistical analysis.

Data Collection

Potential participants were identified by their treating physicians and referred to me. The participant's private and identifiable information was not shared prior to receiving permission from the participant/parent to do so. The primary oncologist/advanced practice nurse initially approached potential participants. If a family and participant were interested in the study, they were then approached by me in the hematology/oncology clinic setting. The study was further explained, and assent/consent forms (see Appendices A and B) were reviewed with the family at that time. The family was given copies of the consent or permission/assent form as well as contact information for me if questions arose. Families were informed that the decision whether to participate in this study would not affect their current clinical care.

If families and participants expressed interest in participating in the study, signatures were obtained, and then the questionnaire was given. The one-page tool (see

Appendix C) contained 66 words that gradually became more difficult as the participant moved down the list. The participant was instructed to speak each word on the list beginning from the top. If they had trouble with saying a word and did not believe they could say it, they could say "skip" and continue reading down the list. If the participant paused, I reminded them to continue to pronounce whichever words they could that were remaining on the list. I also reminded them that this tool was administered free from time constraints. As the participant read off the words, I scored the responses on a separate form (see Appendix D) by placing a check mark next to each word that was pronounced correctly.

After completion of the REALM-Teen tool, participants were thanked for their participation and told that this concluded their participation in the study. Scores were then tallied separate from the time of administration, as advised in the REALM-Teen Administration Manual (see Appendix E). The average time of test administration and grading was 2–3 minutes (see Davis et al., 2006).

This was the extent of the participant's involvement in the study. I retained the participant's age, sex, primary diagnosis, months since diagnosis, grade in school, and parent education level on a secure Excel screening log for the purpose of data validation. Of the 88 potential patients approached, two were ineligible due to no parent being present, one was sleeping, one was at end of life, one was autistic and unable to understand the directions, six were ineligible, nine declined to participate, and 68 agreed and successfully completed the study.

Results

Descriptive Statistics

Table 1 provides the frequency for the demographic variables in the study. There was an even representation between male and female participants (male *n* = 35, 51.5%; female: *n* = 33, 48.5%). Additionally, the age range of the participants was spread out with the smallest number of participants being 14 and 18 years (*n* = 4, 5.9%) and the largest number of participants being 15 and 16 years of age (*n* = 10, 14.7%). Regarding number of months since diagnosis, nearly 56% (*n* = 38) were participants who had been diagnosed with cancer less than 120 months ago while 44% (*n* = 30) had been diagnosed 120 months ago or more. Regarding parent education level, 72.1% (*n* = 49) of the participants had parents who had at minimum a college degree. Most participants met or exceeded their expected level of health literacy (*n* = 45, 66.2%).

Table 1

*Frequency Counts for Selected Variables (*N = *68)*

Variable	Category	*N*	Valid Percent
Sex	Male	35	51.5
	Female	33	48.5
Age [a]	10	5	7.4
	11	5	7.4
	12	8	11.8
	13	6	8.8
	14	4	5.9
	15	10	14.7
	16	10	14.7
	17	8	11.8
	18	4	5.9
	19	8	11.8
Number of months since diagnosis [b]	< 24	5	7.4
	24 – 47	8	11.8
	48 – 71	11	16.2
	72 – 95	7	10.3
	96 – 119	7	10.3
	120 and up	30	44.1
Parent education level	Some high school	0	0
	High school graduate	7	10.3
	Some college	12	17.6
	College graduate	30	44.1
	Some graduate school	4	5.9
	Graduate school graduate	15	22.1
REALM-Teen score grade range equivalent	3rd grade and below	7	10.3
	4th to 5th grade	2	2.9
	6th to 7th grade	26	38.2
	8th to 9th grade	10	14.7
	10th grade and above	23	33.8
REALM-Teen Score Interpretation	Exceeds	6	8.8
	Meets	39	57.4
	Below	23	33.8

[a] *M* = 14.78 years, *SD* = 2.753 years.
[b] *M* = 102.19 months, *SD* = 53.756 months.

Research Questions

RQ1: Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients?

$H_0$1: There was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

$H_1$1: There was a significant difference in health literacy scores in the adolescent oncologic population based on age or sex.

To approach *Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients*, a multiple linear regression analysis was conducted to evaluate the prediction of *REALM-Teen health literacy score* from *Age* and *Sex*. The results of the multiple linear regression analysis revealed *Age* to be a statistically significant predictor to the model ($p < .001$) and *Sex* to be a borderline-statistically significant predictor to the model ($p = .51$). Controlling for *Sex*, the regression coefficient [B = 2.714, 95% C.I. (1.911, 3.517) $p < .001$] associated with *Age* suggests that with each additional year of age, the *REALM-Teen health literacy score* increases by approximately 2.7 pts. Controlling for *Age*, the regression coefficient, B = 4.370, 95% C.I. (-0.021, 8.760) $p = 0.51$, associated with *Sex* suggests that females will score approximately 4.4 pts higher than males. The R^2 value of 0.446 associated with this regression model suggests that the *Age* and *Sex* account for 45% of the variation in *REALM-Teen health literacy score*, which means that 55% of the variation in *REALM-Teen health literacy score* cannot be explained by *Age* and *Sex* alone. The confidence interval associated with the regression analysis for *Age* does not

contain 0. The confidence interval associated with the regression analysis for *Sex* does contain 0 [95% C.I. (-0.021, 8.760)]. However, the 95% confidence interval lower limit is close to 0 which is at the borderline of significance. Therefore, the null hypothesis, *there was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex* can be rejected.

RQ2: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients?

$H_0$2: There was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

$H_1$2: There was a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients.

To approach *Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients*, a simple linear regression analysis was conducted to evaluate the prediction of *REALM-Teen health literacy score* from *Number of months since cancer diagnosis*. The results of the simple linear regression analysis revealed *Number of months since cancer diagnosis* not to be a statistically significant predictor to the model (p = .146). The R^2 value of 0.032 associated with this regression model suggests that the *Number of months since cancer diagnosis* accounts for approximately 3% of the variation in *REALM-Teen health literacy score*, which means that approximately 97% of the variation in *REALM-Teen health literacy score* cannot be

explained by *Number of months since cancer diagnosis* alone. Further, the confidence interval associated with the regression analysis does contain 0 [B = 0.040, 95% C.I. (-0.014, 0.093) p = .146], which means the null hypothesis, *there was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients*, cannot be rejected.

RQ3: Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and parent education level for adolescent oncology patients?

$H_0$3: There was no relationship between health literacy scores and parent education level for adolescent oncology patients.

$H_1$3: There was a relationship between health literacy scores and parent education level for adolescent oncology patients.

A logistic regression analysis to investigate *Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and parent education level for adolescent oncology patients?* was conducted. The dependent variable *REALM-Teen health literacy score* was transformed from a scale measure to ordinal measure and coded to *Below Health Literacy Level, Meets Health Literacy Level, and Exceeds Health Literacy Level*. The predictor variable, *Parent education level*, was tested a priori to verify there was no violation of the assumption of the linearity of the logit. The predictor variable, *Parent education level*, in the logistic regression analysis was found to contribute to the model. The threshold for *Health Literacy Levels* were 2.032 and 5.437. The estimate for *Parent education level* was Estimate = 0.678, SE = 0.224, Wald = 9.148,

p = .002, 95% CI (0.239, 1.117) meaning that for every parent education level achievement increase, the *Health Literacy Level* location moved toward *Exceeds Health Literacy Level* by approximately 0.7. The pseudo R-square, Nagelkerke = 0.175, suggested that approximately 17.5% of the variance is explained by the model. Therefore, the null hypothesis *There was no relationship between health literacy scores and parent education level for adolescent oncology patients*, can be rejected.

Summary

In summary, this study collected data from 68 adolescent patients at a children's hospital in Missouri and analyzed the relationship between health literacy scores and age, sex, number of months since diagnosis, and parent education level. For RQ1, *Using the REALM-Teen health literacy tool, was there a significant difference in health literacy scores based on age or sex of adolescent oncology patients,* the null hypothesis, *there was no significant difference in health literacy scores in the adolescent oncologic population based on age or sex* was rejected. For RQ2, *Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients,* the null hypothesis, *there was no relationship between health literacy scores and number of months since cancer diagnosis for adolescent oncology patients*, could not be rejected. Finally, for RQ3, *Using the REALM-Teen health literacy tool, was there a relationship between health literacy scores and parent education level for adolescent oncology patients,* the null hypothesis, *there was no relationship between health literacy scores and parent education level for adolescent oncology patients*, was rejected. In Chapter 5, these

findings will be weighed against the literature, implications and conclusions will be made, and recommendations will be proposed. Based on this research study, age, sex, and highest level of parent education influence an adolescent's health literacy score.

Chapter 5: Discussion

The purpose of this study was to assess the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri to determine whether there was a significant relationship between individual REALM-Teen health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or parent education level. These variables had been researched in previous studies and had been demonstrated as predictor variables in the adult population (Dharmapuri et al., 2015; Squiers et al., 2012). I assessed the same variables in the adolescent population. The results of this study showed that multiple linear regression analysis revealed *Age* to be a statistically significant predictor to the model ($p < .001$) and *Sex* to be a borderline-statistically significant predictor to the model ($p = .51$). and showed that *Parent education level* also had a statistically significant effect on the prediction of REALM-Teen scores. Overall, these results showed that *Age*, *Sex*, and *Parent education level* were sociodemographic factors that significantly predicted REALM-Teen scores in the adolescent oncologic population, while the number of months since the adolescent's cancer diagnosis was not a significant predictor of REALM-Teen scores. In this chapter, I discuss the interpretation of findings, limitations of the study, recommendations for future research, and implications for positive social change.

Interpretation of Findings

Prior to conducting this study, I anticipated that age, sex, number of months since diagnosis, and parent level of education would be predictive factors in an adolescent's

level of health literacy based on the correlative literature in adult populations (see Berens et al., 2016; Dharmapuri et al., 2015; Heijmans et al., 2015; Kutner et al., 2006; Morrow et al., 2006; Robinson et al., 2011; Squiers et al., 2012). The current study contributed to the understanding of the socioeconomic factors in the oncologic adolescent population that are predictive of REALM-Teen scores and translate into levels of health literacy. This study confirmed that age, sex, and parent education levels are predictor variables in the adolescent oncologic population similar to what had been reported in previous literature regarding the adult population (see Berens et al., 2016; Dharmapuri et al., 2015; Heijmans et al., 2015; Kutner et al., 2006; Morrow et al., 2006; Robinson et al., 2011; Squiers et al., 2012).

In this study, age and sex explained 45% of the variability of the REALM-Teen scores. Additionally, REALM-Teen scores for female patients were 4.4 points higher than their male counterparts and for every 1-year increase in age, the REALM-Teen score increases by 2.7 points. This increase represents 6.7% and 4.1%, respectively, of the total amount of points available on the assessment. With the difference between levels in the REALM-Teen scoring being as little as four points from one level to the next, these point differentiations can be significant. Similar results for age as a predictor of health literacy were found in studies conducted by Berens et al. (2016), F. C. Chang et al. (2015), Chisolm et al. (2014), and Ghaddar et al. (2012). Additionally, similar results for sex as a predictor of health literacy were found in studies conducted by F. C. Chang et al. (2016), Morrow et al. (2006), Rikard et al. (2016), Robinson et al. (2011), and Wilkinson et al. (2016).

However, the current results contradict four studies that did not find a significant relationship between age and health literacy (Hove et al., 2011; Paek & Hove, 2012; Page et al., 2010; Shone et al., 2011). Similarly, these results also contradict studies conducted by F. C. Chang et al. (2015), Chisolm et al. (2014), Dharmapuri et al. (2015), and Ganesh (2017) that did not find a correlation between sex and health literacy.

The current study also showed that parent education level had a statistically significant effect on the prediction of REALM-Teen health literacy levels. The threshold for *Health Literacy Levels* were 2.032 and 5.437. The estimate for *Parent education level* was Estimate = 0.678, SE = 0.224, Wald = 9.148, p = .002, 95% CI (0.239, 1.117) meaning that for every parent education level achievement increase, the *Health Literacy Level* location moved toward *Exceeds Health Literacy Level* by approximately 0.7. This added to the previous knowledge from a study conducted by Manganello et al. (2016) that highlighted the possibility of an effect of a parent or caregiver on the level of health literacy of the dependent adolescent. Despite supporting findings from previous literature regarding sex, age, and parent education level, the current study failed to support previous findings that number of months since diagnosis is a predicative factor for levels of health literacy (see Berens et al., 2016; Dharmapuri et al., 2015; Heijmans et al., 2015; Kutner et al., 2006; Morrow et al., 2006; Robinson et al., 2011; Squiers et al., 2012). This result shows that current health literacy interventions in this hospital have been unsuccessful given that the level of health literacy does not increase with the time since diagnosis.

Limitations of the Study

Despite the careful planning and preparation, this study had limitations. There were several delimitations based on the design of the study, the assessment tool chosen, and the resources available:

1. Only primarily English-speaking participants aged 10–19 years who had been diagnosed with cancer were included in this study because the REALM-Teen was only validated in English and for that age group.
2. Study participants were limited to those who visited the academic children's hospital in Missouri. This was done because this was the only location of the academic children's hospital with an oncology department.
3. The REALM-Teen was used to assess health literacy due to it, at the time, being the only validated health literacy assessment tool for adolescents geared toward being administered in the health care setting.

In addition to the known delimitations, the study included several limitations. The findings were not generalizable to the overall population of adolescents with cancer because I used a convenience sample of adolescent oncology patients from the hematology/oncology division of the academic children's hospital in Missouri. I had patient rights at only one children's hospital located in a large urban area. This limited the ability to represent participants from rural and suburban areas as there were several other hospital choices closer to those areas.

The patient sample was limited to those willing to participate and those who were present on days that I was in the clinic. I presented in the clinic on different days of the

week where I remained for the entirety of those days. I approached those patients who were present in the clinic during the days/times that I was there. Given that my recruitment took only 17 weeks, the sample was convenient since some patients visit every other month, quarterly, twice a year, or yearly and therefore did not have the same opportunity of being selected as participants. Finally, those participants for whom English was not their primary language were not included in the study because the REALM-Teen assessment was not validated for any language other than English.

Recommendations

Based on the known limitations of the current study, recommendations for next steps include (a) providing more resources to stimulate this population's interest in their own health, (b) broadening the scope of the quantitative study to include participants from different regions of the United States as well as populations from rural areas, and (c) using an assessment tool that is validated in different languages (i.e., Spanish, etc.) to be more diverse. Given these recommendations, it is believed that by providing more resources to stimulate this population's interest in their own health it could potentially lead to improvement in the perceptions of their personal health outcomes, thus potentially leading to actual improvement of their health outcomes. Furthermore, expanding the study would enhance the researcher's ability to evaluate other affected groups within the adolescent oncologic population and be able to generalize the results across that population. Additionally, narrowing the population by disease type would help close the gap on how types of cancer impact adolescent health literacy levels. Although the current study may aid in raising awareness of the levels of health literacy of the adolescent

oncologic population, further studies narrowed by types of cancer could help future health practitioners by providing indications for clinical care. Additionally, the current study indicated the need for further research addressing possible barriers and facilitators to health literacy levels in the adolescent oncologic population. The results of these studies may aid in the development of disease-specific health literacy interventions to enhance health literacy levels in the adolescent oncologic population.

Implications

The positive public health social change implications of this study include advancing scientific knowledge about the sociodemographic factors that affect health literacy levels of the adolescent oncologic population and informing key stakeholders as to what the health literacy level is of this population as well as whether the health literacy interventions that are currently in place are sufficient or need to be addressed. Stakeholders would then be able to tailor their health literacy interventions, leading to an increase in adolescent health literacy. This has the potential to positively impact health outcomes because adolescents would be taking a more active role in the management of their personal health care by viewing and interacting with health care professionals, interventions, and health messages. This would be significant because in recent years, a child's right to take an active role in their health care has been in the national and international spotlight. The study results may promote awareness of the relationship between age, sex, and parent level of education and health literacy levels in the adolescent oncologic population. These findings about the sociodemographic factors may

be used by public health professionals to aid in the development of health literacy interventions to enhance health literacy levels in the adolescent oncologic population.

For health literacy to advance through the general population, there needs to be a focus on measurements that are age appropriate throughout different settings and age groups (WHO, 2013). Adolescence is one of those age groups. Research has shown that there is a growing gap between autonomy regarding a person's health and the clear-cut skills that a person possesses (Gazmararian et al., 2005; WHO, 2013). Developing health literacy within the adolescent population is not only advisable, but "could be regarded as a moral act" (Paakkari et al., 2018, p. 4). Public health professionals may use results from the current study to inform public policy to promote and advocate for health literacy in the adolescent oncologic population. Targeting adolescents with interventions for the improvement of health literacy may assist in the promotion of healthier behaviors, leading to a decrease in potential risks in the future (Bröder et al., 2017). Current study findings could aid in the creation and implementation of population-specific interventions, thereby aiding in future endeavors aimed at reducing negative health outcomes in the adolescent population.

Conclusion

In this exploratory cross-sectional quantitative study, I assessed the health literacy of adolescents treated in the oncology department at an academic children's hospital in Missouri using the REALM-Teen assessment tool to determine whether there was a significant relationship between individual health literacy scores of this population based on age, sex, number of months since cancer diagnosis, or parent education level. These

results of this study could enhance understanding of the socioeconomic factors in the oncologic adolescent population that are predictive of REALM-Teen scores and translate into levels of health literacy. The results of this study may provide needed insight into the health literacy of the adolescent oncologic population and may promote awareness of the levels of health literacy of the adolescent oncologic population that could drive future research and clinical care. This study showed that measuring the health literacy scores of adolescent oncologic patients is not only feasible but necessary to provide the proper educational focus based on the patient's health literacy score, which may aid in the development of work with a focus on health literacy interventions geared toward improving the overall health outcomes in the population.

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Appendix A: Permission/Assent Form (for Participants Under 18 Years of Age)

PARENTAL PERMISSION AND CHILD ASSENT TO PARTICIPATE IN A RESEARCH STUDY AT CHILDREN'S MERCY HOSPITALS

Predictors of Health Literacy Scores in the Adolescent Oncologic Population

SUMMARY (Details of this information are in the sections below)

We are asking your child to be in this research study. Being in a research study is completely voluntary, and your choice will not affect your child's regular medical care. This research study is done to learn what factors have an influence on health literacy scores of this population. The following things are part of this study: REALM-Teen assessment and collection of demographic information. Being in this study will take 5-10 minutes. Study visits can happen at the same time as your child's regular clinic visits. Total study duration is 1 day. The biggest risks from being in this study are confidentiality risks. There may not be direct benefit to being in this study. Instead of being in this study, you can choose for your child not to be in this study.

WHO IS DOING THIS STUDY?

A study team led by Amber Jenkins, MSc, CCRC is doing this study. Other health care professionals may help them.

We are asking your child to be a part of this research study. Please read the information below and ask questions about anything that you do not understand before you make a choice.

WHY IS THIS STUDY BEING DONE?

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions. The purpose of this research study is to learn what factors have an influence on health literacy scores of this population.

WHO CAN BE IN THIS STUDY?

We are asking your child to be a part of this research study because your child is an adolescent being treated for cancer in the oncology clinic at Children's Mercy Hospital.

Up to 50 children and adults, ages 10 through 19, will be asked to be in this study at Children's Mercy Hospitals.

WHAT WILL HAPPEN TO MY CHILD IN THIS STUDY?

If you decide for your child to be in this study, the following things will happen:

- You will be given the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen) assessment. The assessment will take approximately 3-5 minutes to complete.
- We will collect the following information from you: demographic information, primary cancer diagnosis, number of months since diagnosis, grade in school, and parental education level. Information collected will be collected in various ways including reviewing your medical chart or through in person interview at the time of the REALM-Teen assessment.

When your child reaches adulthood (18 years of age), we will contact him or her to find out if he/she wants to give consent for continued participation in this study and/or use of their information.

If your child cannot be reached or chooses not to consent, the link between your child's identifiable information and sample will be destroyed. No identifiable information will be saved. The de-identified information will be kept in the oncology research office.

WHAT ARE THE RISKS OF THE STUDY?

As there will be no treatments or therapies given, there will be no clinical risk to your child.

However, there is a possibility that assessment scores, or data collected from the medical record, could be seen by someone not involved in the study. Those working within the study will be very careful to not let this happen.

There is a slight risk of loss of confidentiality. Your child's confidentiality will be protected to the greatest extent possible.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There may be no direct benefit to your child from being in this research study. By being in this study, your child may help researchers find areas that we, as medical personnel, can improve in how we educate our patients about health literacy.

WHAT ABOUT EXTRA COSTS?

There is no cost to you or your child for participating in this study. Basic expenses such as transportation and the personal time it will take to come to all of the study visits will be your responsibility. Your child's research visit may be combined with a routine care visit. Your insurance company will still be required to pay for all of your child's routine care that would have occurred if your child was not part of this research study.

WHAT ABOUT CONFIDENTIALITY?

Your child has rights regarding the privacy and confidentiality of his or her health information. When health information includes identifiers (like names, addresses, phone numbers and social security or individual taxpayer identification (ITIN) numbers) that link it directly to an individual, it is called protected health information (PHI). Federal laws require that PHI be kept secure and private. In certain situations, federal law also requires that you approve how your child's PHI is used or disclosed. A research study is one of those situations.

By signing this permission/assent form, you are permitting the following people to have access to your child's medical record and use your child's PHI for the research purposes described in this form. You are also permitting your child's PHI to be shared with everyone listed below:

- The research team, which includes persons involved in this study at Children's Mercy Hospitals;
- The Institutional Review Board at Children's Mercy Hospitals; The Institutional Review Board at Walden University;
- People from organizations that provide independent accreditation and oversight of hospitals and research;
- Federal agencies such as the Office for Human Research.

The research record is separate from your medical record. Information about you that is obtained during this study will be recorded in a research record. A research record will be created and kept in the oncology research office. That file may include documents that have your assessment scores and selected data from your medical record including name and date of birth. All research will be maintained in a confidential manner.

By signing this permission/assent form, you are allowing your child's health information to be recorded in the research record. You are also permitting your child's research record and medical record to be shared with everyone listed above.

Some people or groups who get your child's identifiable health information might not have to follow the same privacy rules that we follow. We will share your child's health information only when we must, will only share the information that is needed, and will ask anyone who receives it from us to protect your child's privacy. However, once your child's information is shared outside of CMH, we cannot promise that it will remain private.

You may choose not to sign this permission/assent form and not have your child be in the study. You may cancel your permission to use and share your child's PHI at any time by contacting the study personnel listed on this form. You may also contact Children's Mercy Hospitals Health Information Management (HIM) in writing. If you cancel your permission, your child may no longer participate in this study. Your child's PHI that has already been collected for the study may still be used; however, no new information will be collected except information related to adverse events or other safety issues.

If you do not cancel your permission, your child's PHI may continue to be recorded until the entire study is finished. This may take years. Any study information recorded in your child's medical record will be kept forever. Unless stated elsewhere in this form, you may not have access to your child's research record or research test results.

Results of this study may be made public. If made public, your child will not be identified in any publications or presentations.

WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?

Instead of being in this study, you or your child may choose for your child not to be in the study.

WHAT ARE MY CHILD'S RIGHTS AS A STUDY PARTICIPANT?

Being in a research study is voluntary. Your child does not have to be in this study to receive medical care. If you choose for your child not to be in this study or withdraw you child from this study, there will be no penalty or loss of benefits to which your child is otherwise entitled.

We will inform you of any new information that we find out during this study. This information may affect your decision to keep your child in the study. If you choose to withdraw your child from (quit) the study or if you are asked by your child's personal doctor to withdraw your child from the study, you must tell the study team as soon as possible.

You may withdraw your child from the study at any time without penalty or loss of benefits to which your child is otherwise entitled. If you withdraw your child from the study early for any reason, the information that already has been collected will be kept in the research study and included in the data analysis. No further information will be collected for the study.

WHO SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Amber Jenkins, MSc, CCRC is in charge of this research study. You may call Amber Jenkins at 816-302-6891 with questions at any time during the study.

You should call Amber Jenkins if you believe that you are sicker or have suffered injury of any kind as a result of being in this research study.

You may also call Children's Mercy Hospitals' Pediatric Institutional Review Board (IRB) at (816) 701-4358 with questions or complaints about this study. The IRB is a committee of physicians, statisticians, researchers, community advocates, and others that ensures that a research study is ethical and that the rights of study participants are protected.

SPONSOR AND INSTITUTIONAL RESPONSIBILITIES

This study involves data collection only. As detailed in the "What About Confidentiality?" section, your child's PHI will be kept safe to the greatest extent possible. Possible risks may be the unintentional use of your child's PHI. This could be by any of the parties listed in the "What About Confidentiality?" section above. If an unintentional use of PHI occurs by Children's Mercy Hospitals, there are no funds set aside to pay you. By signing this form, you, or your child, are not giving up any legal rights to seek damages for harm.

PERMISSION OF PARENT OR LEGALLY AUTHORIZED REPRESENTATIVE

The purposes, procedures, and risks of this research study have been explained to me. I have had a chance to read this form and ask questions about the study. Any questions I had have been answered to my satisfaction. I give permission for _____ to participate in this research study. A copy of this signed form will be given to me.

Signature of Parent/Legally Authorized Representative Date Relationship to Participant

ASSENT OF MINOR

I have been told that if I am in this study, I will complete the REALM-Teen Assessment. I have been told that I don't have to be in this study. I may quit the study at any time, and no one will be mad at me. I have had a chance to discuss the study and ask questions. My questions have been answered. I agree to be in the study and do what I am asked to do as long as I continue in the study.

Signature of Minor Date

STUDY PERSONNEL

I have explained the purposes, procedures, and risks involved in this study in detail to:

_____
Print name(s) of Parents/ Legally Authorized Representative, and

_____, who in my opinion IS / IS NOT capable of assenting to participate in this study.
Print child's name.

If child IS NOT capable of assenting, please state reason why:

__ Age of child:_____ (insert age)

__ Limitation in understanding based on child's condition

__ Other, please explain_____

Signature of Person Obtaining Permission/Assent Date Time

Print Name of Person Obtaining Permission/Assent _____

Appendix B: Consent Form (for Participants Over 18 Years Old)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY AT CHILDREN'S MERCY HOSPITALS

Predictors of Health Literacy Scores in the Adolescent Oncologic Population

SUMMARY (Details of this information are in the sections below)

We are asking you to be in this research study. Being in a research study is completely voluntary, and your choice will not affect your regular medical care. This research study is done to learn what factors have an influence on health literacy scores of this population. The following things are part of this study: REALM-Teen assessment and collection of demographic information. Being in this study will take 5-10 minutes. Study visits can happen at the same time as your regular clinic visits. Total study duration is 1 day. The biggest risks from being in this study are confidentiality risks. There may not be direct benefit to being in this study. Instead of being in this study, you can choose not to be in this study.

WHO IS DOING THIS STUDY?

A study team led by Amber Jenkins, MSc, CCRC is doing this study. Other health care professionals may help them.

We are asking you to be a part of this research study. Please read the information below and ask questions about anything that you do not understand before you make a choice.

WHY IS THIS STUDY BEING DONE?

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions. The purpose of this research study is to learn what factors have an influence on health literacy scores of this population.

WHO CAN BE IN THIS STUDY?

We are asking you to be a part of this research study because you are an adolescent being treated for cancer in the oncology clinic at Children's Mercy Hospital.

Up to 50 children and adults, ages 10 through 19, will be asked to be in this study at Children's Mercy Hospitals.

WHAT WILL HAPPEN TO ME IN THIS STUDY?

If you decide to participate in this study, the following things will happen:

- You will be given the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen) assessment. The assessment will take approximately 3-5 minutes to complete.
- We will collect the following information from you: demographic information, primary cancer diagnosis, number of months since diagnosis, grade in school, and parental education level. Information collected will be collected in various ways including reviewing your medical chart or through in person interview at the time of the REALM-Teen assessment.

WHAT ARE THE RISKS OF THE STUDY?

As there will be no treatments or therapies given, there will be no clinical risk to you.

However, there is a possibility that assessment scores, or data collected from the medical record, could be seen by someone not involved in the study. Those working within the study will be very careful to not let this happen.

There is a slight risk of loss of confidentiality. Your confidentiality will be protected to the greatest extent possible.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There may be no direct benefit to you from being in this research study. By being in this study, you may help researchers find areas that we, as medical personnel, can improve in how we educate our patients about health literacy.

WHAT ABOUT EXTRA COSTS?

There is no cost to you for participating in this study. Basic expenses such as transportation and the personal time it will take to come to all of the study visits will be your responsibility. Your research visit may be combined with a routine care visit. Your insurance company will still be required to pay for all of your routine care that would have occurred if you were not part of this research study.

WHAT ABOUT CONFIDENTIALITY?

You have rights regarding the privacy and confidentiality of your health information. When health information includes identifiers (like names, addresses, phone numbers and social security or individual taxpayer identification (ITIN) numbers) that link it directly to an individual, it is called protected health information (PHI). Federal laws require that PHI be kept secure and private. In certain situations, federal law also requires that you approve how your PHI is used or disclosed. A research study is one of those situations.

By signing this consent form, you are permitting the following people to have access to your medical record and use your PHI for the research purposes described in this form. You are also permitting your PHI to be shared with everyone listed below:

- The research team, which includes persons involved in this study at Children's Mercy Hospitals;
- The Institutional Review Board at Children's Mercy Hospitals; The Institutional Review Board at Walden University;
- People from organizations that provide independent accreditation and oversight of hospitals and research;
- Federal agencies such as the Office for Human Research.

The research record is separate from your medical record. Information about you that is obtained during this study will be recorded in a research record. A research record will be created and kept in the oncology research office. That file may include documents that have your assessment scores and selected data from your medical record including name and date of birth. All research will be maintained in a confidential manner.

By signing this consent form, you are allowing your health information to be recorded in the research record. You are also permitting your research record and medical record to be shared with everyone listed above.

Some people or groups who get your identifiable health information might not have to follow the same privacy rules that we follow. We will share your health information only when we must, will only share the information that is needed, and will ask anyone who receives it from us to protect your privacy. However, once your information is shared outside of CMH, we cannot promise that it will remain private.

You may choose not to sign this consent form and not be in the study. You may cancel your permission to use and share your PHI at any time by contacting the study personnel listed on this form. You may also contact Children's Mercy Hospitals Health Information Management (HIM) in writing. If you cancel your permission, you may no longer participate in this study. Your PHI that has already been collected for the study may still be used; however, no new information will be collected.

If you do not cancel your permission, your PHI may continue to be recorded until the entire study is finished. This may take years. Any study information recorded in your medical record will be kept forever. Unless stated elsewhere in this form, you may not have access to your research record or research test results.

Results of this study may be made public. If made public, you will not be identified in any publications or presentations.

WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?

Instead of being in this study, you may choose not to be in the study.

WHAT ARE MY RIGHTS AS A STUDY PARTICIPANT?

Being in a research study is voluntary. You do not have to be in this study to receive medical care. If you choose not to be in this study or withdraw from this study, there will be no penalty or loss of benefits to which you are otherwise entitled.

We will inform you of any new information that we find out during this study. This information may affect your decision to stay in the study. If you choose to withdraw from (quit) the study or if you are asked by your personal doctor to withdraw from the study, you must tell the study team as soon as possible.

You may withdraw yourself from the study at any time without penalty or loss of benefits to which you are otherwise entitled. If you withdraw yourself from the study early for any reason, the information that already has been collected will be kept in the research study and included in the data analysis. No further information will be collected for the study.

WHO SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Amber Jenkins, MSc, CCRC is in charge of this research study. You may call Amber Jenkins at 816-302-6891 with questions at any time during the study.

You should call Amber Jenkins if you believe that you are sicker or have suffered injury of any kind as a result of being in this research study.

You may also call Children's Mercy Hospitals' Pediatric Institutional Review Board (IRB) at (816) 701-4358 with questions or complaints about this study. The IRB is a committee of physicians, statisticians, researchers, community advocates, and others that ensures that a research study is ethical and that the rights of study participants are protected.

SPONSOR AND INSTITUTIONAL RESPONSIBILITIES

This study involves data collection only. As detailed in the "What About Confidentiality?" section, your PHI will be kept safe to the greatest extent possible. Possible risks may be the unintentional use of your PHI. This could be by any of the parties listed in the "What About Confidentiality?" section above. If an unintentional use of PHI occurs by Children's Mercy Hospitals, there are no funds set aside to pay you. By signing this form, you are not giving up any legal rights to seek damages for harm.

CONSENT OF SUBJECT

The purposes, procedures, and risks of this research study have been explained to me. I have had a chance to read this form and ask questions about the study. Any questions I had have been answered to my satisfaction. I consent to be in this research study. A copy of this signed form will be given to me.

Signature of Adult Date

STUDY PERSONNEL

I have explained the purposes, procedures, and risks involved in this study in detail to:

Print name(s) of Subject

Signature of Person Obtaining Consent	Date	Time

Print Name of Person Obtaining Consent _____

Appendix C: REALM Teen Data Collection Sheet

RAPID ESTIMATE OF ADOLESCENT LITERACY IN MEDICINE (REALM) Teen©

Terry Davis, PhD Joe Bocchini, MD Sandy Long, PhD Michael Wolf, PhD

Subject #_____ Sex_____ Age_____ Grade_____ Diagnosis_____

# of Months Since Diagnosis_____ Parental Education Level_____ Date_____

List 1		List 2		List 3	
eye	_____	fever	_____	nutrition	_____
pill	_____	pimple	_____	alcoholism	_____
fat	_____	virus	_____	antibiotic	_____
skin	_____	calories	_____	complications	_____
throat	_____	allergy	_____	delinquency	_____
blood	_____	marijuana	_____	penicillin	_____
weight	_____	pelvic	_____	puberty	_____
stress	_____	asthma	_____	menstrual	_____
death	_____	emergency	_____	pneumonia	_____
liquid	_____	infection	_____	constipation	_____
disease	_____	exercise	_____	diagnosis	_____
drug	_____	medicine	_____	nausea	_____
mouth	_____	violence	_____	acne	_____
ounce	_____	prevention	_____	anemia	_____
heart	_____	suicide	_____	hepatitis	_____
risks	_____	depression	_____	adolescent	_____
diet	_____	prescription	_____	bulimia	_____
teaspoon	_____	abnormal	_____	fatigue	_____
period	_____	injury	_____	anorexia	_____
cancer	_____	ointment	_____	tetanus	_____
stomach	_____	seizure	_____	bronchial	_____
headache	_____	diabetes	_____	obesity	_____

List 1 _____	List 2 _____	List 3 _____ Raw Score _____

Appendix D: REALM Teen Participant Word List

List 1	List 2	List 3
eye	fever	nutrition
pill	pimple	alcoholism
fat	virus	antibiotic
skin	calories	complications
throat	allergy	delinquency
blood	marijuana	penicillin
weight	pelvic	puberty
stress	asthma	menstrual
death	emergency	pneumonia
liquid	infection	constipation
disease	exercise	diagnosis
drug	medicine	nausea
mouth	violence	acne
ounce	prevention	anemia
heart	suicide	hepatitis
risks	depression	adolescent
diet	prescription	bulimia
teaspoon	abnormal	fatigue
period	injury	anorexia
cancer	ointment	tetanus
stomach	seizure	bronchial
headache	diabetes	obesity

Appendix E: REALM-Teen Administration Manual

Rapid
Estimate of
Adolescent
Literacy in
Medicine

(REALM-Teen)

Administration Manual

Terry Davis, PhD
Joseph Bocchini, MD
Robert Byrd, MD
Sandy Long, PhD
Michael Wolf, PhD

Table of Contents

Background

Low literacy is a prevalent social problem in the United States.[1,2] Almost half (43%) of American adults have basic or below-basic literacy levels according to the 2003 National Assessment of Adult Literacy, and 66 percent of high school students have similarly low levels on the National Assessment of Educational Progress.

Identifying low literacy in adolescents could be helpful to health professionals, as a screen for academic problems, a potential marker for health risk behaviors, and to know when to tailor health information. We know that low literacy is a risk factor for school failure and school drop out,[3, 4] both of which are associated with increased health risk behaviors in teens.[13 - 16]

Approximately one quarter of American adolescents are reading well below grade level.[4] These students do not have the reading skills to comprehend information found in their text books and are at risk for falling further behind and eventually dropping out of school. Currently, almost one third of ninth grade students (one half among minority students) do not finish high school.[17]

The authors have developed a brief literacy screening test for use with adolescents in health care settings. The test is modeled on the Rapid Estimate of Adult Literacy in Medicine (REALM),[20, 23, 24] the most commonly cited literacy test in adult health care settings. This test will allow health professionals to screen youth in grades 6-12 for below-grade reading.

Pertinent Definitions

Literacy in the United States is defined as "an individual's ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals and develop one's knowledge and potential."

Health Literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Word Recognition Tests are tests in which an individual reads aloud from a list of individual words. These tests measure an individual's ability to pronounce words in ascending order of difficulty. Though not designed to measure comprehension, word recognition tests are useful predictors of general reading ability in English. If an individual has difficulty pronouncing words in isolation, which is a beginning level reading skill, he or she is likely to have difficulty with comprehension (a higher order skill).

Examples: REALM-Teen, Slossan Oral Reading Test-Revised (SORT-R), Wide Range Achievement Test-Third Edition (WRAT-3) Reading subtest, Peabody Individual Achievement Test-Revised (PIAT-R) Reading Recognition Subtest.

Reading Comprehension Tests measure an individual's ability to derive meaning from printed words. Comprehension can focus on an individual's understanding of a word, phrase, sentence, longer passage or an individual's interpretation of the information. Most reading comprehension tests assess the individual's ability to understand text written at different levels of difficulty.

Examples: Comprehension Subtest, Cloze Technique, Test of Functional Health Literacy in Adults (TOFHLA), PIAT-R Comprehensive Subtest.

Description of the Test

The Rapid Estimate of Adolescent Literacy or REALM-Teen is a valid, reliable, easy-to-administer tool that will allow health professionals to screen youth in grades 6-12 for below-grade reading.

The REALM-Teen can be administered and scored in under three minutes with minimal training, and is strongly correlated with standardized literacy assessments such as the SORT-R and the WRAT-3 tests.

The REALM-Teen is a reading recognition instrument, modeled after the Rapid Estimate of Adult Literacy in Medicine (REALM), the most commonly used tool to screen adults for low literacy in health care settings. The REALM-Teen is a reading recognition instrument which measures an individual's ability to pronounce words in ascending order of difficulty. All test words are commonly used adolescent health terms.

This one-page instrument consisting of 66 health words arranged in increasing order of difficulty on three widely spaced columns on lime green paper. Adolescents taking the REALM-Teen are asked to say the words out loud beginning with the first word in the left-hand column.

All words on the REALM-Teen come from words used in Academy of Pediatrics patient education materials for adolescents.

Dictionary pronunciation is the scoring standard (A dictionary is the recognized guide for people seeking help in pronouncing unfamiliar words, regardless of their culture or the region of the country in which they reside). An adolescent's raw score is the total number of correctly pronounced words.

Test scores, expressed as grade-level estimates, can be compared to a patient's current grade level to determine reading skills below grade level. For instance, an adolescent patient enrolled in the 9th grade who scores a 54 on the REALM-Teen (6th-7th grade level) would be assessed as reading below grade level. In this manner, this tool can aid in alerting clinicians and researchers to possible reading and academic difficulties and may serve to identify teens at greater risk for engaging in negative health behaviors.

The REALM-Teen is a *word recognition* test-not a reading comprehension instrument. Adolescents are asked to de-code or pronounce words.

Design and Development

We recruited adolescents for one-time, in-person interviews from a pediatric private practice primary care clinic, five middle schools, three high schools, and two summer programs in Louisiana and in North

Carolina. A total of 1, 533 adolescents participated in structured interviews that included a general demographic survey.

Validity

Criterion validity was based on correlations between REALM-Teen raw scores and the raw scores of the most current versions of two standardized reading tests commonly administered to adolescents, the Slosson Oral Reading Test-Revised (SORT-R) [22] and the Wide Range Achievement Test-3 (WRAT-3).[21]

Table 1

Correlation of REALM with SORT and WRAT-3		
	SORT	WRAT-3
Correlation Coefficient	.93	.83
P Value	p<.0001	p<.0001

Reliability

Test-retest reliability was determined by calculating the Pearson r correlation between scores on the REALM-Teen at baseline and at one-week follow-up.

Table 2

Reliability
Test-Retest
(n=100)
.98

When to use the REALM-Teen

Before deciding to screen adolescents for below-grade level literacy, health professionals need to consider

- where patients will be tested.
- who will do the testing, and how they will be trained.
- how results will be used and documented. *Note: For some adolescents, particularly those with low literacy, test-taking may be an unpleasant experience in school; being given a literacy test in a health care setting, no matter how it is presented, can be a stressful.*

Previous studies in adult medicine found patients with low literacy are often ashamed and try to hide their problem. Clinicians and research assistants must be sensitive to these possibilities in screening for low literacy in adolescents.

REALM-Teen Administration

Testing Materials Needed:

- Laminated patient word list.
- Examiner record form.
- Clipboard.
- Pencil.

Personal Data Lines:

Patient Name/Subject #: Record the patient's name or assigned subject number.

Race: Record the patient's race.

Gender: Record the patient's gender.

Age: Record the patient's age.

Grade: Record current grade of the patient.

Date: Record the date of administration.

Site: Record the location.

Examiner: Record the examiner's name.

Administration and Scoring:

1. Give the patient the laminated copy of the REALM-Teen word list. Attach the examiner record form to the clipboard. Hold the clipboard at an angle such that the patient is not distracted by your scoring procedure.

In your own words, introduce the REALM-Teen to the patient:

In a research setting of for research purposes:

- *"We are trying to get an idea of what health words people your age are familiar with."*
- *"What I need you to do is say each of the words out loud to me starting here* [point to first word with pencil]*."*
- *"Say all the words you know. If you come to a word you don't know, you can sound it out or just skip it and go on."*
- If the patient stops, say, *"Look down this list,* [point] *are there any other words you recognize?"*

In a clinical setting:

- *"Sometimes in this office, we may use medical words that patients aren't familiar with."*
- *"We would like you to take a look at this list of words to help us get an idea of what medical words you are familiar with. This will help us know what kinds of patient education to give you."*
- *"Start with the first word,* [point to first word with pencil] *please say all of the words you know."*
- *"If you come to a word you do not know, you can sound it out or just skip it and go on."* If patient stops do as above.

Special Note: Do not use the words "read" and "test" when introduci
d administering the REALM-Teen. These words may make patients f
comfortable and unwilling to participate.

se <u>say</u> *these words for me."*

2. If the patient takes more than 5 seconds on a word, encourage the patient to move along saying, *"Let's try the next word."*

If the patient begins to miss every word of appears to be struggling or frustrated, tell the patient,

"Look down at the list, are there any other words on this list that you recognize?"

3. Count as an error any word that is not attempted or mispronounced (see "Special Considerations" for pronunciation/scoring guidelines).

4. Scoring options:

   a. Place a check mark (✓) in the box next to each word the patient pronounces correctly.
   OR
   b. Place an X in the box next to each word the patient does not attempt or mispronounces.

Scoring should be strict, but take into consideration any problems which could be related to dialect or articulation difficulties. Use the dictionary if in doubt. Count as correct any self-corrected word.

5. Count the number of correct words in each list to give you the "Raw Score". Match this score with its grade equivalent fond in Table 3.

Special Considerations for Administration and Scoring:

Examiner Sensitivity:

Many low literate patients will attempt to hide their deficiency. Ensure that you approach each patient with respect and compassion. You may need to provide encouragement and reassurance.

A positive, respectful attitude is essential for all examiners. (Remember, many people with low literacy feel ashamed.) Be sensitive.

Pronunciation:

Dictionary pronunciation is the scoring standard.

Count a word as correct if the word is pronounced correctly and no additions or deletions have been made to the beginning or ending of the word. For example: A patient who says "alcohol" would not receive credit for the word "alcoholism"; "eyes" would not receive credit for the word "eye"; "nervous" and "nerve" would not receive credit for "nerves". Words pronounced with a dialect or accent should be counted as correct provided there are no additions or deletions to the word. Particular attention should be paid for patients who use English as a second language.

Comprehension and Interpretation of Words:

Reading recognition does not imply comprehension or proper interpretation. The REALM-Teen is a reading-recognition test. If a patient indicates that he/she knows the meaning of the word but is unable to say it, no credit is given. Persons interested in assessing patient comprehension are referred to the PIAT Comprehensive Subtest.

Patients Who Speak Another Language:

The REALM-Teen is a reading-recognition test and is a reliable screening instrument to assess literacy in English. Reading-recognition is not useful in assessing literacy in other languages. For example, Spanish literacy is affected by the nature of the Spanish language. Spanish has regular phoneme-grapheme correspondence, meaning that one sound is usually represented by one letter and vice versa. Therefore, compared to English, it is relatively easy to sound out and pronounce words in Spanish if one can recognize letters, making it relatively easy for low-level readers to score high on word recognition tests. The REALM-Teen has not and cannot be translated into other languages for valid administration. Persons wishing to assess Spanish-speaking patients are referred to the Test of Functional Health Literacy in Adults-Spanish (TOFHLA-S). However, it has not been tested with adolescents.

Score Interpretation

Table 3

Raw Score	Grade Range Equivalent	Literacy Skills
0-37	3rd Grade and Below	These adolescents will have a 5 fold quarter likelihood of reading below grade level. They are reading below grade level and may be at risk of school failure.
38-44	4th to 5th Grade	
45-58	6th to 7th Grade	Will struggle with most patient education materials; may have skills to pass GED.
59-62	8th to 9th Grade	

63-66	10th Grade and Above	Will be able to read most patient education materials.

Ordering the REALM-Teen

Additional copies of the REALM-Teen and supplies can be obtained through the Health Education and Literacy office of the Louisiana State University Health Sciences Center-Shreveport. Contact: Terry Davis, PhD, Department of Pediatrics, P.O. Box 33932, Shreveport, LA 71130; (318) 675-5813; tdavis1@lsuhsc.edu.

Other Literacy Instruments Used in Health Care Settings

Word Recognition:

Slossan Oral Reading Test-Revised (SORT-R)
Slossan Educational Publications, Inc.
P.O. Box 280
East Aurora, NY 14052
1-800-828-4800; Fax: 1-800-655-3840

Wide Range Achievement-Third Edition (WRAT-3)
Jastak Associates, Inc.
P.O. Box 3410
Wilmington, DE 19804
1-800-221-9728

Peabody Individual Achievement Test-Revised (PIAT-R)
American Guidance Service, Inc.
P.O. Box 99
Circle Pines, MN 55014
612-786-4343

Health Comprehension (English and Spanish):

Test of Functional Health Literacy in Adults (TOFHLA) and Spanish-TOFHLA (S-TOFHLA)
Peppercorn Books and Press
PO Box 693
Snow Camp, NC 27349
877-574-1634

Instrument for Diagnosis of Reading (Instrumento Para Diagnosticar Lecturas)

Kendall Hunt Publications
Dubuque, I

Appendix F: Communication With Terry Davis, PhD

Jenkins, Amber,

From: Davis, Terry <tdavis1@lsuhsc.edu>
Sent: Tuesday, July 11, 2017 3:58 PM
To: Jenkins, Amber,
Cc: jmanganello@albany.edu
Subject: RE: REALM-Teen Test Interest
Attachments: REALM Teen Development and Validation_Peds_2006.pdf; REALM Teen - Word List.pdf; submitted manuscript file 122016.pdf

Follow Up Flag: Follow up
Flag Status: Flagged

*** This message was sent to you from an External Source. Please do not open untrusted links or attachments. ***

Amber
I will be happy to send you the REALM Teen
You might also want to use the REALM Short form (see attached)

Terry

Terry C. Davis, PhD
Professor, Departments of Medicine and Pediatrics
Louisiana State University Health Sciences Center
1501 Kings Highway
Shreveport, LA 71130
Phone: 318-675-8694
Fax: 318-675-4319
E-mail: tdavis1@lsuhsc.edu

From: Jenkins, Amber, [mailto:anjenkins@cmh.edu]
Sent: Tuesday, July 11, 2017 3:47 PM
To: Davis, Terry <tdavis1@lsuhsc.edu>
Cc: Jenkins, Amber, <anjenkins@cmh.edu>
Subject: REALM-Teen Test Interest

EXTERNAL EMAIL: EVALUATE
Good afternoon, Dr. Davis. My name is Amber Jenkins and I am currently a PhD student studying Public Health with an emphasis on Epidemiology. I am interested in utilizing the REALM-Teen test in relation to my dissertation (health literacy and the pediatric AML population). I found the administration manual online and obtained your information from that manual. Would you be able to send me an electronic copy of the REALM-Teen test so that I may review it and, if appropriate, utilize it to gather data for use in my dissertation? Is there a charge for utilization of this test? If so, what is the estimated charge?

Your time and efforts are greatly appreciated and I look forward to hearing from you. Thank you.

AJ